

# Implementing shared decision making in the UK

*A report for the  
Health Foundation*

---

Angela Coulter, PhD

---

Produced as a scoping paper for the Health Foundation in 2009.

# Contents

---

Acknowledgements	6
Introduction	7
Shared decision making	7
Decision aids	8
The Health Foundation's plans	9
Aims of the scoping study	9
Methods	9
Report structure	9
UK researchers/practitioners in SDM	11
Information prescriptions	11
Informed decision making for osteoarthritis of the knee	11
Informed Health Choice	12
Medicines Partnership at the National Prescribing Centre	13
National Refractory Angina Treatment Centre	13
NHS Choices	14
Risk Communication and Decision Making programme	14
Urology Informed Decision Making project	15
International initiatives to implement SDM	17
Australia: Sydney Health Decision Group	18
Canada: Ottawa Health Research Institute	18
Germany: Patient as partner in medical decision-making	19
International Patient Decision Aids collaboration	20
The Netherlands: Dutch decision aids implementation programme	20
Sweden: Swedish Rheumatology Registers, Karolinska Institute	21
USA: Center for Informed Choice, Dartmouth Institute for Health Policy and Clinical Practice; Center for Shared Decision Making, Dartmouth–Hitchcock Medical Center	21
USA: Foundation for Informed Medical Decision Making; Health Dialog	22
USA: Healthwise and the Center for Information Therapy	23

---

# Contents

<b>Implementation changes</b>	25
Culture and attitudes	25
Resources and time pressures	27
Systems and incentives	29
Scope and focus	31
Choice of topic and practice setting	32
Project planning	33
Development and use of decision aids	35
Persuading people to get engaged	38
<b>References</b>	40
<b>Appendix 1: Interviews with experts in SDM</b>	44
<b>Appendix 2: UK-based research groups</b>	47
<b>Appendix 3: Cochrane register of decision aids</b>	48
<b>Appendix 4: Participants in 12 March 2009 Health Foundation roundtable</b>	50

---

# Acknowledgements

*I owe a considerable debt of gratitude to everyone who generously gave their time to answer my questions, either by email or on the phone. Many went to great lengths to provide helpful information, confirming my previous conviction that those interested in shared decision making are an extraordinarily nice bunch of people.*

---

# 1 Introduction

## Shared decision making

Shared decision making (SDM) is a process in which patients are encouraged to participate in selecting appropriate treatments or management options.

Not being properly told about their illness and the options for treatment is the most common cause of patient dissatisfaction.<sup>1,2</sup> Most patients nowadays want more information and a greater say in decisions about how they will be treated.

In SDM, patients are involved as active partners with the clinician in clarifying acceptable medical options and choosing a preferred course of clinical care.<sup>3</sup>

Choosing an appropriate treatment with full patient involvement can be a complex process.<sup>4</sup> It involves a number of steps:

- recognise and clarify the problem
- identify potential solutions
- discuss options and uncertainties
- provide information about potential benefits, harms and uncertainties of each option
- check understanding and reactions
- agree a course of action
- implement the chosen treatment
- arrange follow-up
- evaluate the outcome.

SDM is appropriate in any situation when there is more than one reasonable course of action and no one option is self-evidently best for everyone. This situation is very common since there are often many different ways to treat a health problem, each of which may lead to a different set of outcomes. These are known as ‘preference-sensitive’ decisions.<sup>5</sup> In these cases the patient’s attitude to the likely benefits and risks should be a key factor in the decision. The principles of SDM ought to be observed whenever clinicians have to obtain informed consent or communicate risks.

SDM relies on two sources of expertise:

- the health professional is an expert on the effectiveness, probable benefits and potential harms of treatment options
- the patient is an expert on themselves, their social circumstances, attitudes to illness and risk, values and preferences.

Both parties must be willing to share information and accept responsibility for joint decision making. The clinician must provide patients with information about the diagnosis and treatment options and the patient must tell the clinician about their preferences.

The idea of SDM attracts broad support from patients,<sup>6</sup> professionals,<sup>7</sup> and policy makers,<sup>8</sup> yet it is infrequently implemented in clinical practice in the UK.<sup>9-11</sup> Clinicians have been slow to respond to the evidence that a majority of patients want to be involved in decisions about their care.<sup>6,12,13</sup>

## Decision aids

Patient decision aids have been developed to support SDM. These take a variety of forms including web applications, videos/DVDs, computer programmes, leaflets and structured counselling. Most share the following three characteristics:

- providing facts about the condition, options, outcomes and probabilities
- clarifying patients' evaluations of the outcomes that matter most to them
- guiding patients through a process of deliberation so that a choice can be made that matches their informed preferences.<sup>5</sup>

Decision aids can be used in a wide variety of clinical situations. The Ottawa Health Decision Centre lists three main types of health decision for which they may be appropriate:

- preference-sensitive decision making that requires careful weighing of benefits and harms across treatment or screening options (eg vasectomy, prostate cancer screening, place of care at end of life)
- symptom management and triage to the most appropriate level of care, including self-care (eg sore throat, diarrhoea, minor head injury)
- chronic condition management decisions to determine the course of action that best fits the patient's informed values (eg diabetes, asthma, hypertension).

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.<sup>14-25</sup>

Decision aids help to increase patient involvement in decision making and increase patients' confidence in the process. Some studies suggest 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.<sup>14-17,19-21</sup>

Use of decision aids has an impact on screening uptake, increasing it in some cases and reducing uptake (appropriately) in the case of prostate cancer screening.<sup>16-18,21-25</sup>

Decision aids have mixed effects on choice of treatment. There is no evidence that they increase demand for expensive treatments. On the contrary, trials that have measured economic outcomes have shown that decision aids can be either cost-effective, because they lead patients to choose less expensive treatments, or cost-neutral.<sup>20</sup> Several trials have shown that decision aids can lead to a significant reduction in rates of elective surgery with no adverse effect on patient satisfaction or health outcomes.<sup>5</sup>

Studies have found improved adherence to treatment recommendations when patients are encouraged to play an active role in consultations and decision making, but as yet there is little evidence of long-term effects on health status, possibly because few studies have included sufficiently long follow-up periods.<sup>15,20,26-28</sup>

## The Health Foundation's plans

This publication was commissioned to help the Health Foundation develop a demonstration project to advance the implementation of SDM including the use of evidence-based patient decision aids in clinical settings in the NHS. They want to identify, test and perfect an approach that will support a clinical service to move from a position where they are not using SDM approaches or tools to a position where they are reliably and routinely using them in everyday clinical care.

This paper reports the findings from the scoping study and subsequent discussions at a roundtable meeting that took place in London on 12 March 2009.

## Aims of the scoping study

- To determine who are the leading researchers/practitioners in the field of SDM.
- To suggest options for the scope and scale of the project.
- To outline practical considerations for implementing SDM in the NHS.

## Methods

Contact was made with 17 UK-based SDM experts and 16 overseas experts (see appendix 1). Responses were received from 27 of those approached (82%) and interviews were conducted by telephone and email.

Published papers on issues related to the implementation of SDM were reviewed and summarised.

The Cochrane register of decision aids was reviewed to identify suitable topics and tools that could potentially be used for the project.

## Report structure

This report starts by describing some prominent examples of SDM implementation projects in the UK and abroad. It then describes the main implementation challenges and goes on to outline various practical considerations that should be taken into account when designing an implementation programme.

Magic is the new shared decision making programme, supported by the Health Foundation, run by a team led by the Cardiff University, Cardiff and Vale University Health Board, University of Newcastle, and Newcastle upon Tyne Hospitals Foundation Trust.

An overview of their work can be found at [www.health.org.uk/shareddecisionmaking](http://www.health.org.uk/shareddecisionmaking)

## 2

# UK researchers/practitioners in SDM

*Several groups are working on practical implementation projects to introduce decision aids and/or SDM more generally into clinical settings in the UK.*

### Information prescriptions

[www.informationprescription.info/resource/index.html](http://www.informationprescription.info/resource/index.html)

See also the information prescription service [www.nhs.uk/ipg](http://www.nhs.uk/ipg)

Key contact:  
**Ian Maidment**, national coordinator

The Department of Health (DH) has developed and promoted this new scheme. From 2008, everyone who has a long-term condition or social care need is supposed to be offered an 'information prescription' (IP), in consultation with a health or social care professional.

It is intended that IPs will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence. This includes information about conditions and treatments, care services, benefits and support groups. IPs also contain links or signposts to sources of information about local health, social care and other services – usually phone numbers, websites etc. They are not specifically designed to support decision aids, but there seems no reason why they could not be adapted for this purpose at some future stage.

### Informed decision making for osteoarthritis of the knee

[www.informeddecisionmaking.org.uk/home.asp](http://www.informeddecisionmaking.org.uk/home.asp)

Key contacts:  
**Dr Steve Laitner**, chair of the steering group;  
**Suzie Normanton**, project manager

The aim of this project, which is currently planned to run from November 2007 to April 2009, is to develop a personalised decision aid to support patients with symptomatic arthritis of the knee as they consider their treatment options, including knee replacement surgery.

The project is funded by the NHS Institute for Innovation and Improvement. The project leaders are supported by a steering group and a wider reference group of clinical experts and patient representatives.

An adaptation of a decision aid produced by the Foundation for Informed Medical Decision Making (FIMDM) is being developed for use in the project. It is hoped to place this on a website, probably NHS Choices ([www.nhs.uk](http://www.nhs.uk)). It will include general information about the condition and a component to help predict individualised risks and benefits from knee replacement surgery.

To achieve this it will draw on data from the osteoarthritis (OA) joint registry and from the routine PROMs (patient-reported outcome measures) studies now required by the DH. The developers intend the aid to be used by patients, with appropriate support from specialist nurses, therapists or health coaches.

The plan of action is as follows:

- Select measures for use in predicting the benefits and risks of knee replacement surgery incorporating co-morbidities, symptom severity, age and other measures to assess the operative and post-operative benefits and risks from knee replacement surgery.
- Create a statistical model to predict individual health gain and risk based upon a patient's baseline variables.
- Use data derived from routine collection of PROMs to improve the predictive power of the decision aid.
- Define the generic process required to develop, pilot and refine a decision aid.
- Implement the decision support in three to four pilot sites and organise an evaluation to gather evidence to refine the final knee arthritis decision aid.

## Informed Health Choice

[www.informedhealthchoice.com](http://www.informedhealthchoice.com)

Key contacts:

**Prof Glyn Elwyn** and **Prof Adrian Edwards**,  
School of Medicine, Cardiff University

The Informed Health Choice group has built on their academic research to develop and evaluate decision support technologies (decision aids) on a not-for-profit basis. A decision aid on screening for prostate cancer (ProsDex) is available on their website and others are under development including one on breast screening (BresDex), one on amniocentesis (AmnioDex) and one on quitting smoking (QuitEx).

## Medicines Partnership at the National Prescribing Centre

[www.npc.co.uk/med\\_partnership/index.htm](http://www.npc.co.uk/med_partnership/index.htm)

Key contact:

**Prof Alison Blenkinsopp**, University of Keele

Originally established by the DH in 2002, the Medicines Partnership is now hosted by the National Prescribing Centre (NPC) and located with NPC Plus at Keele University. It promotes the concept of concordance, or shared decision making, as an approach to help patients get the most from their medicines. Within NPC Plus the programme will focus on developing and delivering training and support to healthcare professionals to assist them to engage in shared decision making with patients about medicines.

Since 2007 the NPC has developed a number of decision aids. Currently more than 25 decision aids on medicines are available for download at [www.npci.org.uk/lift/lift.php](http://www.npci.org.uk/lift/lift.php)

## National Refractory Angina Treatment Centre

[www.angina.org](http://www.angina.org)

Key contact:

**Prof Mike Chester**, director

The National Refractory Angina Treatment Centre at the Royal Liverpool and Broad Green University Hospital NHS Trust in Liverpool aims to ensure that patients are fully involved in decisions about the care, treatment and self-management of angina.

Upon referral, patients are given an initial consultation lasting 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 attend four two-hour group cognitive behavioural therapy 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.

## NHS Choices

[www.nhs.uk](http://www.nhs.uk)

Key contacts:

**Clare Thompson**, director of innovation, strategy and engagement,  
**Helen Rowntree; Robert Cleary; Paul Nuki**

The NHS Choices website has now incorporated all the material that used to be held on NHS Direct Online, including the Health A-Z giving information on about 750 conditions and treatments. While the information is useful, it is not specifically designed to inform patients' decisions and does not comply with the basic requirements of decision aids.

However, the site does include the DH's prompt sheet for patients, *Questions to ask*, which suggests a series of questions that patients may want to ask the doctor about their condition, diagnostic tests and treatment options. It also includes a set of information prescriptions designed to support personalised care planning for people with long-term conditions.

Responsibility for NHS Choices has recently been handed over from Dr Foster Intelligence, the original developers, to Capita. Capita are committed to an extensive review of the content of the site and are interested in including decision aids as part of the content.

## Risk Communication and Decision Making programme

[www.ncl.ac.uk/ihs/research/risk](http://www.ncl.ac.uk/ihs/research/risk)

Key contact:

**Prof Richard Thomson**, Institute of Health and Society, Newcastle University

This Newcastle-based programme includes innovative work in developing and evaluating shared decision making and risk communication, initially in stroke prevention and atrial fibrillation, but now extending more widely (eg pain relief and labour, Caesarean section, falls prevention in older people, vaccination). Work is under way on the population and public health implications of shared decision making.

The programme, which has also developed and evaluated decision aids, includes collaboration with clinicians in the School of Clinical Medical Sciences and in obstetrics and fetal medicine.

## Urology Informed Decision Making project

[www.informeddecisionmaking.org.uk/urology-project.asp](http://www.informeddecisionmaking.org.uk/urology-project.asp)

Key contacts:

**Dr Mary Archer**, chair of the steering group;  
**Jo Finn**, project manager

The Urology Informed Decision Making project set out to help patients diagnosed with either early stage localised prostate cancer or benign prostatic hyperplasia to reach 'good quality' decisions about their treatment in partnership with healthcare professionals.

The decision support programme comprises a package of materials for each group of patients. The packages include a DVD, a booklet and a personal decision form. Training is available for specialist urology nurses who work with patients to guide them through the process, helping them use the information to reach a decision on which treatment would suit them best.

The project comprises three phases. Phase 1, which ran from 2003 to 2005, involved the urology departments of five NHS acute trusts in England and was monitored and evaluated by researchers at Picker Institute Europe. The programme was originally hosted by the Action on Urology team (part of the NHS Modernisation Agency), who worked with a steering group chaired by Mary Archer, chair of Addenbrooke's NHS Trust, and including consultant urologists, nurse specialists, patient representatives, and members of the DH, the FIMDM in Boston USA, the Ottawa Health Research Institute, Canada, and the Picker Institute. Nurse training was provided by Annette O'Connor from the Ottawa Health Research Institute. Decision aid videos or DVDs were provided by FIMDM.

The evaluation found that clinicians valued being able to give good quality, audio-visual information, and patients found it useful and informative. Patients' knowledge about their condition and the implications of differing treatments improved after the decision aid was introduced. It was felt that the introduction of decision support could achieve significant benefits to patients and the NHS, but the decision aids would be more effective if they were anglicised.

Phase 2 of the project (2006–2009) was concerned with developing a decision support package for the UK by producing anglicised versions of FIMDM's DVDs and booklets and redesigning the personal decision forms. Phase 3 involves rolling these out nationally across the NHS. Two videos have been commissioned, using filmed interviews with patients and accompanying booklets and personal decision forms have been prepared. Future plans include putting the materials on the web, translating them into other languages, and making them interactive and more personalised so that patients can generate information specific to their situation.

---

### 3

## International initiatives to implement SDM

*There is a sizeable international community of researchers working on SDM. Many are involved in the International Patient Decision Aids (IPDAS) collaboration and they meet at international conferences, including the Society for Medical Decision Making and the biannual International Shared Decision Making conference. Some have been involved in initiatives to implement SDM in regular clinical practice. The following examples are the most prominent of these implementation initiatives.*

## Australia: Sydney Health Decision Group

[www.health.usyd.edu.au/shdg/about/aims.php](http://www.health.usyd.edu.au/shdg/about/aims.php)

Key contacts:

**Prof Phyllis Butow, Prof Martin Tattersall, Associate Prof Alex Barratt, Dr Kirsten McCaffery, Dr Lyndal Trevena**

The aim of the Sydney Health Decision Group is to facilitate evidence-based decision making at the level of the consumer, clinician and policymaker. They have a particular focus on the development of tools and methods to support health decisions in the fields of cancer screening and treatment.

The group has developed decision aids on cancer screening, women's health and child health.

To date, one decision aid has been implemented nationally: the National Health and Medical Research Council commissioned the Sydney group to produce a decision aid for women considering hormone replacement therapy. Copies were distributed to general practitioners across Australia and can be downloaded from the internet:

[www.nhmrc.gov.au/publications/synopses/wh35syn.htm](http://www.nhmrc.gov.au/publications/synopses/wh35syn.htm)

## Canada: Ottawa Health Research Institute

[www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid)

Key contacts:

**Prof Annette O'Connor**, Tier 1 Canada research chair in health care consumer decision support;  
**Dr Dawn Stacey**, assistant professor at the School of Nursing, University of Ottawa

The Ottawa Health Decision Centre (OHDeC) was established in November 1995 as part of the Clinical Epidemiology Unit of the Ottawa Health Research Institute at the Ottawa Hospital and the faculties of Medicine and Health Sciences at the University of Ottawa.

Annette O'Connor is a world leader in the development and evaluation of patient decision aids. Her contributions include: a conceptual framework for managing decisional conflict; over 30 patient decision aids; a widely used evaluation measure of decisional conflict; the first systematic review of trials of patient decision aids, and several knowledge translation interventions for implementing patient decision support.

Internationally, she leads the International Cochrane Collaboration team that summarises trials of patient decision aids (more than 60 trials have been conducted) and that updates a global inventory of evaluated patient decision aids (there are over 500 listed on the register – see appendix 3).

Annette O'Connor also co-leads (with Glyn Elwyn) a 14-country international consensus process on standards for developing and evaluating patient decision aids (IPDAS).

The OHDeC team has produced a number of training modules, accessible on their website at <http://decisionaid.ohri.ca/index.html>, on how to develop and implement decision aids.

## Germany: Patient as partner in medical decision making

[www.patient-als-partner.de](http://www.patient-als-partner.de)

Key contacts:

**Prof Martin Härter**, director of the Institute and Polyclinic for Psychological Medicine at the University of Hamburg;  
**Dr Andreas Loh**, lecturer at the Department of Psychiatry and Psychotherapy, University Medical Centre, Freiburg

Policy makers in Germany see patient participation in treatment decision making as a priority and the German Ministry of Health has funded a national research consortium with SDM projects in various disease areas. SDM is now part of the medical curriculum in nearly half of all medical schools. Nationwide training initiatives are under way led by medical school staff at the Universities of Freiburg, Hamburg, Heidelberg and Jena.

Decision aids are being developed at the Universities of Hamburg and Witten-Herdecke, by the German Agency for Quality in Medicine and by individual health insurance companies. A university for patients was founded in Hanover in 2006 ([www.patientenuniversitaet.de](http://www.patientenuniversitaet.de)). The university's goal is to offer health education and empowerment to citizens and patients.

## International Patient Decision Aids (IPDAS) collaboration

[www.ipdas.ohri.ca](http://www.ipdas.ohri.ca)

Key contacts:

**Prof Annette O'Connor; Prof Glyn Elwyn**

The collaboration is a group of researchers, practitioners and stakeholders from around the world. The goal of the IPDAS collaboration is to establish an internationally approved set of criteria to determine the quality of patient decision aids.

There are over 500 patient decision aids available or being developed by many different individuals and groups around the world. However, people have difficulty knowing whether or not a decision aid is a source of reliable health information that can help in decision making.

The IPDAS standards represent the efforts of more than 100 participants from 14 countries around the world. The results of the voting process and new standards for developing and evaluating patient decision aids are now available. Two published papers outline how the standards were developed and tested.<sup>29,30</sup>

## The Netherlands: Dutch decision aids implementation programme

[www.kiesbeter.nl/algemeen/default.aspx](http://www.kiesbeter.nl/algemeen/default.aspx)

Patient participation in medical decision-making was formally defined in *Wet op de Geneeskundige Behandelingsovereenkomst* (WGBO), a Dutch law initiated in 1995. This was supplemented by national guidelines issued by the Dutch College of General Practitioners and a network of research projects in the Universities of Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam and Utrecht.

The Netherlands Organisation for Health Research and Development has initiated the Dutch Decision Aids Implementation Programme. Decision aids have been developed on prostate cancer screening, post-menopausal symptoms, cardiovascular risk management, non-metastatic breast cancer, and depression and more are under development. These are available on the Dutch government's patient portal.

## Sweden: Swedish Rheumatology Registers, Karolinska Institute

[http://ki.se/content/1/c6/06/38/02/HIC%20project%20DS\\_2%20Predictive%20models.pdf](http://ki.se/content/1/c6/06/38/02/HIC%20project%20DS_2%20Predictive%20models.pdf)

Key contact:

**Prof Staffan Lindblad**, Associate Professor, Karolinska Institute, Stockholm

A web-based rheumatology quality register (Rheuma-register) generates a comprehensive patient overview which visualizes an individual patient's disease course with the treatments prescribed and the resulting effects on the disease activity. Patients and health providers use this overview as a decision support at more than 500 clinical visits monthly all over Sweden.

The evidence-based treatment guidelines of the Swedish Society for Rheumatology are included. The knowledge management system is now being further developed to enable patients to understand and evaluate their condition and the likely effects of treatment and to help them manage the logistics of their care. The project goal is for care to be equally shared between patients and professionals based on evolutionary knowledge management and continuous adaptive learning.

## USA: Center for Informed Choice, Dartmouth Institute for Health Policy and Clinical Practice; Center for Shared Decision Making, Dartmouth-Hitchcock Medical Center

[www.dartmouth.edu/~cecs/siipc](http://www.dartmouth.edu/~cecs/siipc)

[www.dhmc.org/shared\\_decision\\_making.cfm](http://www.dhmc.org/shared_decision_making.cfm)

Key contacts:

**Prof Dale Collins**, director;  
**Hilary Llewellyn-Thomas**, co-director;  
**Kate Clay**, program director

The Dartmouth Institute's Center for Informed Choice (CIC) exists to improve the decision-making capabilities of patients and to foster informed, preference-based patient choice (decision quality). It investigates fundamental and applied research questions in key aspects of the shared decision making process; creates pioneering educational programs about the theories, measurement methods, and research designs involved in studying patients' health care decision making; designs and tests innovative clinical practice models that incorporate shared decision making as an integral part of care; investigates the role played by patients' preferences in the conduct and interpretation of clinical trials in surgery.

The Center for Shared Decision Making is a hospital-based clinical implementation centre employing counsellors who can help patients make an informed decision about any healthcare treatment choice. Their support services include one-to-one counselling sessions, a library of decision aids, and a healthcare decision guide worksheet. The centre aims to be a prototype of a dedicated decision support service for emulation by other healthcare organisations around the world.

## USA: Foundation for Informed Medical Decision Making; Health Dialog

[www.informedmedicaldecisions.org](http://www.informedmedicaldecisions.org)  
[www.healthdialog.com/hd](http://www.healthdialog.com/hd)

Key contacts:

**Dr Jack Fowler**, president of FIMDM;  
**Dr Al Mulley**, chief of the General Medicine Division of Massachusetts General Hospital and associate professor of medicine and health policy at Harvard University;  
**Dr Mike Barry**, chief, General Internal Medicine Unit, Massachusetts General Hospital

FIMDM is a non-profit organisation based in Boston, USA dedicated to ensuring that patients understand their choices and have the information they need to make sound decisions affecting their health and wellbeing. FIMDM has close links with Health Dialog, a company that was formed to promote SDM commercially by providing health coaching, decision aids and predictive modelling. Health Dialog has recently been acquired by BUPA.

FIMDM aims to improve the quality of medical decision making by combining two distinct and important bodies of research:

1. systematic reviews of the science and evidence to gather the most current unbiased information on a given clinical condition
2. focus groups to gather patient perspectives and preferences about these clinical conditions.

They then pull this information together to develop professional SDM programmes (decision aids – DVDs, videos, booklets, etc). These are produced in collaboration with Health Dialog, a commercial company set up to market the products of FIMDM's research. All FIMDM's decision aids:

- present the latest clinical evidence about the risks and benefits of treatment options in ways patients can understand
- explain why there is sometimes a lack of evidence to support one option over another
- include interviews with patients who have undergone treatments and experienced good and bad outcomes, illustrating the variety of patient perspectives and concerns
- focus on helping patients engage in high-quality decision making with their doctors
- support patients in carrying out their choices with confidence and competence.

The decision aids offer a balanced presentation of each option, from both clinical and patient experience perspectives. The goal is never to encourage any one treatment approach over the others, but rather to explain fairly and clearly the pros and cons of each option – and let patients, working with their doctors, decide which is best for them.

FIMDM also funds research into SDM and works with clinical groups to implement it in routine clinical practice. Examples include:

- Dartmouth–Hitchcock Medical Center
- Massachusetts General Hospital John D Stoeckle Center for Primary Care Innovation
- University of California San Diego, Division of Family Medicine
- University of North Carolina, General Internal Medicine
- Division of General Internal Medicine and Health Services Research
- White River Junction Veterans Administration
- Allegheny General Hospital Breast Care Center
- University of California at San Francisco Breast Care Center

## USA: Healthwise and the Center for Information Therapy

[www.healthwise.org](http://www.healthwise.org)  
[www.ixcenter.org](http://www.ixcenter.org)

Key contacts:

**Don Kemper**, chairman and CEO of Healthwise;  
**Dr Joshua Seidman**, president of the Center for Information Therapy

Healthwise is a not-for-profit company that provides paper-based and online patient information. Their goals are:

- to help people do as much for themselves as they can
- to help people ask for the healthcare they need
- to help people say 'no' to the care they do not need.

The reach of Healthwise content extends from Alaska to South Africa. Nearly 120 million times a year people use Healthwise information to make better health decisions. More than 31 million Healthwise self-care guides have been distributed, which is the equivalent to one in every 10 American homes. And nine of the top 10 managed care organisations and hundreds of hospitals and employers use Healthwise information. They are also the largest provider of patient decision aids in the world.

Healthwise founded the now independent Washington-based Center for Information Therapy (IxCenter) to advance the practice and science of information therapy. Launched in 2001, the IxCenter acts as a catalyst for healthcare delivery innovation by diffusing Ix strategies through research, education and collaboration.

# 4

## Implementation challenges

Most of the relevant studies of implementation of SDM have focused on attempts to encourage the uptake and use of patient decision aids.<sup>5,7,31-38</sup> These have drawn attention to various barriers and facilitators that can inhibit or enhance the likelihood of wider implementation of SDM. The following factors have been highlighted in the literature and were reinforced by the experts consulted for this scoping study:

- culture and attitudes
- resources and time-pressures
- systems and incentives.

In addition, there are a number of practical considerations to think about when planning an implementation programme. These include:

- scope and focus of the project
- practice settings and clinical topics
- project planning
- development and use of decision aids
- working with partners
- persuading people to get engaged.

### Culture and attitudes

Shared decision making will never be widely practised unless doctors, nurses and other clinicians embrace the idea. Like any proposed change in healthcare delivery, professionals need to be convinced that the advantages to patients outweigh the perceived disadvantages of adapting their traditional routines.

A systematic review of 38 studies of health professionals' perceptions of the barriers and facilitators to implementing SDM found that time constraints were the most frequently reported problem (in 22 studies), followed by a perception that it was not appropriate for their patients (18 studies) or their clinical specialty (16 studies).<sup>35</sup> The three most often reported facilitators were provider motivation (23 studies), positive impact on the clinical process (16 studies) and on patient outcomes (16 studies).

For example, Charles and colleagues surveyed all surgeons and oncologists in Ontario treating women with early stage breast cancer to assess their attitudes to SDM.<sup>32</sup> Most respondents were enthusiastic about SDM and a majority said they tried to practise it, but many cited barriers in addition to the ubiquitous problem of lack of time. In particular, some doctors felt that their patients would not understand the information or were not emotionally ready or willing to participate in treatment decisions.

A British study investigated the views of consultant orthopaedic surgeons on the potential feasibility and acceptability of decision aids for hip and knee replacement surgery.<sup>7</sup> Most were very positive about the idea but none had any experience of using one. They said they would be likely to use it if it:

- improved patients' understanding
- helped communication
- helped patients clarify what is important to them.

They would be unlikely to use it if it:

- increased the workload in outpatients
- was not kept up-to-date
- if patients disliked it.

Most said their preferred dissemination model would be a decision aid that patients could be given at the first consultation to take home to work with, returning for a second consultation ready to decide on the best treatment for them.

SDM involves a reorientation from traditional paternalistic models of practice towards new forms of thinking about patient-practitioner relations. This is not easy for practitioners who are wedded to a practitioner-centred model of decision making.<sup>33,36</sup>

Obtaining physician buy-in may be the greatest challenge for SDM programmes. Even if the design of the implementation programme allows for much of the work to be done by non-doctors, eg nurses, doctors need to endorse the project and their encouragement of individual patients to use the decision aids is essential for success. Physician buy-in seems largely dependent on them having a 'felt problem' and the belief that there is a non-disruptive solution to that problem.

Persuading these people to rethink their approach will require a non-doctrinaire strategy, both to delineate the problem and to develop solutions. There is still a debate about how to define SDM, what it consists of, and how to promote it in practice. Some doctors may respond more favourably to the concept if they can see how it could help them with tasks that they acknowledge to be difficult, for example obtaining informed consent, or communicating risk in a comprehensible way. Rather than trying to impose a single model of SDM, a flexible approach to implementation is advised.<sup>39</sup>

Formal training can help to overcome resistance. Many experts suggested that this should be seen as an essential component of SDM implementation programmes. This involves teaching professionals to respect patients' autonomy, a skill that can be taught but must not be taken for granted. The Ottawa Health Research Institute has successfully implemented training courses with different groups of clinicians.<sup>4,40-44</sup> These include autotutorial and skill-building workshops in decision support and the use of decision aids, structured decision support protocols and performance feedback with real or simulated patients.<sup>45</sup>

FIMDM is currently trying to present SDM in the more general context of continuous quality improvement. This requires thought leadership, access to established communication channels, knowledge of process integration, and a commitment to service redesign. Additional essential components include training and skills acquisition for clinicians using both modelling and feedback techniques.

## Resources and time pressures

Time pressures are frequently cited as a reason for not engaging patients in SDM.<sup>46</sup> For example, an early study to determine the feasibility of implementing decision aids in three hospitals in Michigan, USA, found that recruitment of patients by doctors was disappointingly low, despite the fact that they had been initially enthusiastic.<sup>31</sup> While they liked the decision aids, the clinicians rarely made time for them in practice. Time pressures got in the way of best intentions. The authors concluded that relying on enthusiastic clinicians to refer their patients to decision aids may not be a reliable way of ensuring that patients can access them. They suggested three alternatives:

- incorporating decision aids into the informed consent process
- making it a requirement in hospital quality assurance schemes to provide them
- introducing a financial incentive for clinicians to make decision aids available to their patients.

In 2003 FIMDM offered free copies of their decision aids on early stage breast cancer to two community cancer resource centres, six community hospital cancer centres and seven academic cancer centres. Cancer centre staff were then invited to participate in a study to learn more about the feasibility of using the decision aids with patients.<sup>34</sup> The sites that used the aids opted either to arrange for them to be viewed in the clinic or to lend them out to patients for viewing at home.

The study highlighted the importance of enthusiastic leadership from senior clinicians and the need to integrate them into regular routines and patient pathways in the clinics. If the videos were to be viewed in the clinic it was essential to set aside space and time for this. Implementing a loan system involved establishing a process for getting the decision aids to the patients and ensuring they were returned.

A follow-up study by the same group emphasised the important role of nurses, social workers or patient educators who played a crucial role in ensuring that patients received the decision aids and were able to use them.<sup>37</sup> Implementation depended on agreement from the doctors in charge of the cases, but it was much more likely to be successful if these other clinical staff understood the concept of SDM and were enthusiastic about using decision aids to help patients play an active role.

Those involved in the British Urology Informed Decision Making project, which involved providing a decision aid and using a structured form to check patients' understanding and treatment preferences, quickly realised that implementing SDM involved a certain amount of additional administration.<sup>38</sup> Fitting it into existing clinical pathways was not always straightforward, especially if it involved organising an additional appointment. Most sites ended up mailing the decision aids and personal decision forms to the patients, in some cases without checking that patients had used them and fully understood the options they faced. Administrative tasks included printing them on hospital headed paper, photocopying forms, receiving and storing the videos or DVDs, logging videos out to patients and recording their return.

Use of the decision aids may have reduced the time that doctors had to spend providing basic information, but it led to more work for the nurses and/or administrative staff. However, most staff, including the nurses, were positive about the programme and the training they received, saying it enhanced their ability to inform and engage patients. Patients who received the decision aids were very positive, finding them both interesting and useful.

Some doctors prefer to control the distribution of decision aids to ensure they are viewed only by those for whom they were intended. For example, it may be desirable to ensure that information designed for women with early stage breast cancer is not viewed by patients with metastatic disease. In these situations DVDs or leaflets may be preferred.

At Dartmouth, appointment secretaries organise the scheduling of decision aids. After diagnosis and prior to the first appointment with the specialist, patients are invited to view the aids in the clinic or they are mailed to them for viewing at home. They also complete a computerised health screen which gathers data about their situation, knowledge and preferences, for forwarding to the physician. The surgeons and oncologists, some of whom were initially sceptical, now welcome the fact that the patient comes to the subsequent consultation armed with all the basic information and ready to discuss treatment options.

Manual systems depend on someone being available to take charge of developing and maintaining an effective loan system. And it is more difficult to ensure that hand-held decision aids are removed from circulation when they go out-of-date. Instead of relying on individual staff members to take on the additional workload of handing out decision aids, it may be more efficient to incorporate them into IT systems that could cue the aids at the appropriate time, linked to electronic patient records.

Another option is to make the aids available on websites for viewing or downloading by patients. In these cases updating is relatively easy because it can be done on the web. Healthwise have developed patient information systems that are integrated into electronic clinical pathways.

Some US healthcare organisations, for example the Mayo Clinic, have included decision aids on their websites (see [www.mayoclinic.com/health/TreatmentDecisionIndex/TreatmentDecisionIndex](http://www.mayoclinic.com/health/TreatmentDecisionIndex/TreatmentDecisionIndex)). The British informed decision making projects in urology and knee replacement are hoping that their decision aids can be hosted on the NHS Choices website, but there is not yet a system for linking these to electronic patient records in the UK.

While making the decision aids freely available to all on a publicly accessible website may be a good idea, it is unlikely to be sufficient to ensure that they are used effectively. Professionals will need to signpost their patients to them and must adapt their practice styles to incorporate active support for patients wanting to participate in decision making.

## Systems and Incentives

Overcoming the many barriers to change necessitates paying attention to incentives for professionals, patients and managers to make the required adaptations to the clinical context in which they are working. The Normalization Process Model (NPM), which focuses attention on how complex interventions become routinely embedded in practice, may be helpful here.<sup>47</sup>

This provides a structure for understanding the relationships between a complex intervention and the context in which it is implemented, paying attention to the process of implementation, the required skill-set, integration into existing routines and patterns of interpersonal behaviour. It draws attention to ways of working towards SDM, avoiding a narrow focus on the technology of decision aids. As well as considering the interaction between patient and professional, the model points to the need to take account of professional and organisational norms that are typically oriented to expert-led decision making instead of preference-sensitive decision making by patients.

Using the NPM to analyse the steps involved in embedding SDM across the system of care, Elwyn and colleagues have suggested that this would involve realigning incentives so that professionals are required to involve patients in decision making.<sup>47</sup> In this brave new world clinicians would be monitored for their ability to accomplish this task.

Training would be provided in SDM and the use of decision aids and patient engagement would be incorporated into clinical guidelines, using patient feedback to check progress. Health professionals and managers would require the use of decision aids to achieve performance targets. Relevant metrics might include the percentage of patients who report having had the opportunity to make informed decisions. Such metrics could be incorporated into accreditation and reimbursement strategies.

External factors and legal requirements, such as the requirement to demonstrate true informed consent (see for example the 2007 legislative changes in Washington State<sup>48</sup>), could also provide a strong incentive to make the shift from traditional paternalistic practice. Those concerned with risk management could benefit from insights derived from research into SDM and risk communication. Clinicians are always vulnerable to legal challenge and being able to demonstrate that effective methods have been used to communicate risk may prove to be a useful defence in court cases.<sup>49-51</sup>

Another possibility would be to establish virtual preference laboratories where patients could view decision aids on a website, receive decision support by telephone and answer a few key questions to check their knowledge, values and preferences.<sup>52</sup> An automated report could be sent to the clinician informing them of the patient's preferences and concerns (see <http://makingadifference.bmj.com>). The clinician could then focus on issues of concern to the patient, such as fears of the side-effects of surgery. Time in the outpatient clinic would be used more efficiently and the care provided would be more patient-centred.<sup>53</sup>

In England virtual laboratories could possibly be established alongside Integrated Clinical Assessment and Treatment Services (ICATS), set up as part of the 18-week wait initiative. Or there could be national decision support laboratories, perhaps sponsored by specialist groups. They could be linked to evidence resource centres, such as the newly established NHS Evidence, who could ensure that the content of decision aids remained up-to-date and in accordance with the best evidence.<sup>54</sup>

## Scope and focus

It is important to be clear at the outset about the scope of an SDM implementation project. This could be quite narrow, for example restricted to a single clinical decision in several sites, or much broader – implementing SDM across a whole organisation spanning all relevant clinical specialties and decision points.

Those interviewees who were most interested in research and evaluation felt it would be best to restrict the number of variables by having a tight focus on a homogeneous set of clinical decisions. Others suggested that if the ultimate objective is to demonstrate broad-based feasibility, acceptability, effectiveness and sustainability, this could be most convincingly demonstrated using several different types of demonstration sites and diagnostic groups.

Ideally one might want to engage whole organisations in understanding and implementing the SDM process, in which case some sort of 'whole system' approach across a single NHS trust would be worth considering. This could involve engaging senior support including, for example, the trust chief executive, medical director, executive and non-executive board members as well as specialty teams. Given the need for active clinician engagement this might prove difficult to achieve, at least initially, but if successful it would do much to raise the profile of SDM.

Another suggestion was to implement SDM in a single specialty across a whole strategic health authority (SHA). One or two centres could be selected to trial the intervention, reporting back to their colleagues across the SHA and to the relevant professional bodies.

Most implementation projects to date have focused on a single condition or a narrow range. There may be a problem about generalising from these to other conditions and settings. A key decision for the Health Foundation is whether the project should take a broad approach to the implementation of SDM, allowing flexible interpretation by clinical teams, or whether it should insist on the incorporation of specific elements, eg the use of decision aids. If the Foundation wishes to fund a truly innovative programme that looks at the feasibility of applying the principles of SDM across the NHS, it may be advisable to site it in diverse settings and focus on a selected range of different clinical topics.

If learning is to be maximised it may be considered a good idea to limit the scope of the project so that each site is proceeding on broadly comparable lines, but this could require a considerable effort of coordination to ensure that everyone sticks to the plan. It could be difficult to compare the diverse experiences of the clinical teams that are 'doing their own thing'.

Several experts emphasised the need to start from the desire to inform and involve patients in clinical decisions, rather than from a specific decision aid. Some form of decision support will be essential, so decision aids are likely to be required, but they are simply a component of SDM, not an end in themselves.

Long experience at the Center for Shared Decision Making at Dartmouth has taught experts the importance of building on the broader idea of decision support as a systematic clinical intervention. Over-emphasising decision aids while neglecting the concept of decision support as a clinical skill creates unnecessary obstacles. For example it can lead to:

- confusion about how decision aids differ from classic patient education materials
- clinician resistance if decision aids are seen as low quality, inaccurate, and/or supplanting (rather than fostering) patient–clinician communication
- clinicians’ assumptions that they are hamstrung and ‘can’t provide decision support’ for a particular group of patients if a condition-specific decision aid is not yet available for that group
- patients’ feelings of abandonment if decision aids are seen as ‘doses’ of information that are force-fed at inappropriate times, without concomitant patient–clinician dialogue.

## Choice of topic and practice setting

SDM is applicable when there is more than one reasonable option and/or a measure of uncertainty about treatment/management outcomes. These situations arise frequently in all health settings including:

- acute care (primary, secondary, tertiary)
- chronic care
- palliative care
- preventive care.

The list of conditions for which decision aids have been developed (appendix 3) illustrates the wide range of clinical topics where SDM may be useful.

Interviewees gave mixed responses to the question about whether it was better to focus implementation of SDM in primary care or secondary care. Several people argued that implementation is much easier in secondary care – especially in elective surgery – but it might have greater long-term impact in primary care. Some suggested that more generic decision aids may be useful in primary care, especially if these are targeted at patients with low health literacy.

The Ottawa Health Research Institute has developed a generic decision aid designed to help with any major decision. This might prove to be useful in primary care.

It will be important to ensure that implementation of SDM does not lead to an increase in health inequalities, so consideration should be given to the needs of people with low health literacy.

## Project planning

Hilary Llewellyn-Thomas from the Dartmouth Institute stressed the need for careful, detailed assessment and planning at multiple levels (organisational, professional, patient) before launching into implementation. This takes time to do well, but it can foster understanding and buy-in on the part of all stakeholders. Ignoring it can result in confusion about objectives and processes, leading to disintegration of the project. This early assessment and planning should be undertaken by clinical leaders in practice settings who:

- understand the philosophy, theory and methods of decision support
- are committed to the long-range effort this will require.

Assessment involves seeking out multiple viewpoints about the decision points of particular interest. Stakeholders need to consider the following questions: Is this crossroad decision difficult? What makes it difficult? What helps with this difficult decision? What hinders? Could this proposed service help? Why or why not? How should it be redesigned to be most helpful? What kind of evidence would convince you that this decision support service was actually helping?

The planning process should also involve detailed mapping of current practice pathways, pinpointing the decision crossroads. Projects could focus on sections of pathways where practitioners agree that problems currently occur in relation to team communication, lapses in patient-centred care, and lapses in patient safety, or lack of coordination/continuity of care. Participants could consider ways in which the decision support service could help resolve identified pathway problems. For example, they might identify the ‘bird seed’ that would immediately attract practitioners to working with the proposed service, eg time savings, rapid ‘feed-forwarding’ of patients’ health status reports, rapid identification of patients’ misunderstanding of information, unrealistic expectations, or unclear values, and so on.

The next step is to plan how to bring together the redesigned service and the current clinical pathway so they fit together as seamlessly as possible with minimal disruption of work flow. If possible this should be integrated with other electronically-supported initiatives (eg an electronic patient records system).

Consideration should be given to how to help clinicians, managers and patients gain genuine awareness of:

- the concept of preference-sensitive care
- the importance of informed (as opposed to naïve) preferences for participating/not participating in making elective choices
- the consequences of failure to ensure match between patients' informed therapeutic preferences and what they actually receive = undermining of patient autonomy/patient-centred care/patient safety/distributive justice
- the idea that the decision support service is intended to help those patients who wish to be involved in making elective choices, and thereby reduce likelihood of mismatches between patients' informed therapeutic preferences and what they actually receive
- the ways in which a good decision support service can be theory-based, evidence-based, and monitored for excellence.

The plan should involve a systematic strategy for integrating SDM into a particular clinical setting and the underlying rationale for that strategy.

The plan should include the following components:

- a plan for identifying and engaging eligible patients
- a means of ensuring the decision aids are of highest quality
- endorsement of decision aids by clinicians
- a plan for distributing the decision aids
- a means for identifying and removing out-of-date decision aids
- a method for collecting evaluative data from clinicians and patients on their experience of SDM
- a brief summary card for clinicians giving the key informational points on the decision aids that their patients are viewing to help them readily review the information with patients after viewing the decision aid

- a brief worksheet for patients to use at the end of the decision support session to help the patient identify:
  - a) aspects of information still misunderstood or confusing
  - b) which way they are preferentially leaning and why
  - c) if any social pressure issues
  - d) if lacking material resources required to enact preferred option – and then – to reveal a, b, c, and d in post-decision support discussions with the clinician
- a system for collecting, analysing and providing clinicians with two kinds of feedback information:
  - a) individualised information – tracking individual patients' progress through decision making as part of their regular care
  - b) aggregated information – in the form of periodic reports about decision-making patterns observed in the overall patient population.

## Development and use of decision aids

Most SDM implementation schemes to date have incorporated the following elements:

1. evidence collection, review and consensus-building
2. development of decision aids for patients (paper-based, video/DVD/audio, computer-based, web-based)
3. training for professionals
4. practical implementation in clinical care pathways
5. explicit process for values clarification and/or knowledge testing
6. monitoring and evaluation.

One problem, evident in the Urology Informed Decision Making project, is that steps 1 and 2 can take an inordinate amount of time. The advantage of encouraging groups of clinicians to develop their own decision aids from scratch is that they should then feel confident about the content. However, there is a marked tendency to underestimate the amount of work involved in developing good quality decision aids and the difficulties of achieving consensus on the content.

Most experts interviewed for this scoping study stressed the point that developing good quality decision aids is a professional task. Most recommended the use of existing decision aids, either ‘off the shelf’ or adapted as necessary. Appendix 3 lists those currently recorded on the Cochrane register. This list is not necessarily comprehensive but it illustrates the wide range of aids already available. It should be possible to capitalise on the hard work that went into developing these decision aids, either by adopting them wholesale, or by producing adapted versions tailored to the UK context. This may involve adaptation to the local clinical context, checking use of terminology, re-filming patient interviews and voice-overs, and other aspects of cultural translation.

If it is decided to use or adapt existing decision aids, it will be very important to reach agreement about intellectual property and license fees early on in the process. Even some British universities now expect to charge license fees for products such as decision aids. Failure to reach early agreement with the original developers of the decision aid and booklet that were adapted for use in the project caused problems in the urology project. At the time of writing those involved in the OA knee project are in discussion with Health Dialog/FIMDM about a contractual arrangement that may provide a model for use in other settings.

Placing decision aids on publicly available websites would seem to fit best with the current policy emphasis on making patient information available on NHS Choices, but it will be important to ensure that the materials remain accessible to all patients, including those without access to the internet. Placing decision aids on websites may limit the choice of aids if commercial providers are unwilling to allow their products to be used in this way. If this is not feasible, it should be possible to organise distribution and loan systems for decision aids on DVDs or paper-based aids. If possible, these should be the responsibility of administrative staff, adequately trained and rewarded for the task.

There is a great deal of interest in the provision of personalised information that can give patients a good idea of the risk and outcome probabilities that apply to people with their specific characteristics in terms of age group, symptom severity and so on. The early decision aids developed by FIMDM used sophisticated data models to produce personalised information and interactive tools, but these proved difficult to implement and later versions have used simpler models.

Some people felt that the early versions were overengineered, requiring sophisticated and unreliable technology (video disks) that proved troublesome when used in busy clinics. However, new web-based technologies make it more feasible to use detailed decision analytic models and there is now a renewed interest in developing more complex tools to help patients with significant co-morbidities or those facing multiple treatment options or decision steps.

Some current projects (for example the Swedish Rheumatology Registers and the informed decision making for OA of the knee project) are attempting to develop more personalised tools by incorporating data from disease registers and PROMs studies to supplement information from clinical trials and systematic reviews. Research undertaken during the development of the FIMDM programmes used this method to ensure the decision aids were as comprehensive as possible.<sup>55</sup> If decision aids are placed on websites it should be possible to ask users to give their consent to being approached at a later stage with a request to complete an electronic outcomes questionnaire. The resulting data could be used to update the decision aid.

Some experts argued that the best can be the enemy of the good when it comes to designing decision aids. A good quality information leaflet and a values clarification exercise may be sufficient, especially if it is coupled with the chance to talk through the decision with a knowledgeable but neutral person. Evidence from a large randomised trial of decision support in gynaecology confirms the importance of talking through the key elements of the decision – what FIMDM call ‘closing the loop’.<sup>56</sup>

Elwyn and colleagues used web log analysis to look at how patients used their ProsDex decision aid. On average they spent only 18–20 minutes viewing it and the video clips were rarely viewed. However, those who spent more time viewing the aid were better informed than those who rushed through it, underscoring the need to convey to patients the desirability of devoting sufficient time to absorb the information.

To some extent the complexity or otherwise of a decision aid will be dictated by the nature of the condition and treatment options. It is not always necessary to provide patients with precise probabilities or to go to extreme lengths to tailor the information for specific subgroups. However, there is evidence that interactivity enhances the learning process, so decision aids that engage patients actively are likely to be more effective than those requiring only a passive response.

## Persuading people to get engaged

Promoting the theoretical concept of SDM is not very difficult, but generating sufficient interest to get people to agree to incorporate it into their daily routines may be more so. And, of course, it crucially depends on who you are trying to persuade.

The following arguments have been found to attract the interest of specific groups:

- **Doctors** respond positively if they think it will benefit their patients without causing them extra time and trouble. The benefits to patients include increased understanding of their condition and the treatment options, more realistic expectations of benefits and harms, clearer preferences, better match between their favoured option and what is actually received, more individualised care, improved communication, and improved adherence to medical advice and therapy.

It is important to find out which problems clinicians find difficult and time consuming and design a strategy that will make their lives easier. On the whole, surgeons do not want to operate on unwilling patients. Reduced risk of litigation may be another benefit for doctors. Depending on who is responsible for counselling patients, it may reduce the time the doctor has to spend providing basic information. Doctors involved in decision aid trials have said that they free up time to find out what is most important to the patient, enabling them to have better informed, more effective discussions.

- **Nurses** appreciate recognition of their important role in informing and supporting patients, but it is essential to involve them in planning the implementation programme from

the beginning. Not surprisingly they can react badly if decisions that will affect their workload and style of working are taken without their active involvement. Nurses sometimes find it difficult to accept the notion of patient autonomy, clinical equipoise and handling scientific uncertainty, so training is likely to be essential.

- **Managers** are interested in the potential for effective demand management and cost savings. There is evidence that SDM can reduce unwarranted variations in preference-sensitive care and that well-designed decision aids reduce demand for more cost-intensive options. They may also improve adherence to the chosen therapy. Estimates from a number of trials of decision aids in elective surgery suggest they can lead to reductions in surgical rates of the order of 25%, but this may not be applicable to all settings.
- **Professional bodies** such as the General Medical Council (GMC) and medical royal colleges should value SDM because it concurs with ethical practice guidelines, such as the GMC's *Good Medical Practice* and encourages the implementation of evidence-based medicine.
- **Politicians** should be interested in SDM as an important component of a strategy to promote patient choice, tackle health literacy and encourage a more realistic assessment of strengths and limitations of medical care.
- **Patients** who have participated in SDM projects are usually overwhelmingly positive about it. They appreciate receiving detailed and reliable information, their views being sought and listened to, and having a say in what happens to them.

# References

- 1 Coulter A, Cleary PD. Patients' experiences with hospital care in five countries. *Health Aff (Millwood)* 2001; 20(3):244-252.
- 2 Grol R, Wensing M, Mainz J, Jung HP, Ferreira P, Hearnshaw H et al. Patients in Europe evaluate general practice care: an international comparison. *Br J Gen Pract* 2000;50:882-887.
- 3 Sheridan SL, Harris RP, Woolf SH. Shared decision making about screening and chemoprevention: A suggested approach from the U.S. Preventive Services Task Force. *Am J Prev Med* 2004;26(1):56-66.
- 4 Elwyn G, Charles C. Shared decision making: the principles and the competencies. In: Edwards A, Elwyn G, eds. *Evidence-based patient choice*. Oxford: Oxford University Press, 2009;118-143.
- 5 O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR et al. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff (Millwood)* 2007;26(3):716-725.
- 6 Coulter A, Jenkinson C. *European patients' views on the responsiveness of health systems and healthcare providers*. *Eur J Public Health* 2005;15(4):355-360.
- 7 Adam JA, Khaw FM, Thomson RG, Gregg PJ, Llewellyn-Thomas HA. *Patient decision aids in joint replacement surgery: a literature review and an opinion survey of consultant orthopaedic surgeons*. *Ann R Coll Surg Engl* 2008;90(3):198-207.
- 8 Department of Health. *The NHS Constitution 2009*. London: Department of Health, 2009.
- 9 Stevenson FA, Cox K, Britten N, Dundar Y. *A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance*. *Health Expect* 2004;7(3):235-245.
- 10 Richards N, Coulter A. *Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-07*. Oxford: Picker Institute Europe, 2007.
- 11 Coulter A. *Engaging patients in their healthcare: how is the UK doing relative to other countries?* Oxford: Picker Institute Europe, 2006.
- 12 Davey HM, Barratt AL, Davey E, Butow PN, Redman S, Houssami N et al. *Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results*. *Health Expect* 2002;5(4):330-340.
- 13 Coulter A, Magee H. *The European patient of the future*. Maidenhead: Open University Press, 2003.
- 14 Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Robinson MB et al. *Informed decision making: an annotated bibliography and systematic review*. *Health Technol Assess* 1999;3(1).
- 15 Molenaar S, Sprangers MA, Postma S, Rutgers EJ, Noorlander J, Hendriks J et al. *Feasibility and effects of decision aids*. *Med Decis Making* 2000;20(1):112-127.
- 16 Edwards A, Hood K, Matthews E, Russell D, Russell I, Barker J et al. *The effectiveness of one-to-one risk communication interventions in health care: a systematic review*. *Med Decis Making* 2000;20(3):290-297.
- 17 Estabrooks C, Goel V, Thiel E, Pinfold P, Sawka C, Williams I. *Decision aids: are they worth it?* *J Health Services Res and Policy* 2001;6(3):170-182.
- 18 Jepson RG, Forbes CA, Sowden AJ, Lewis RA. *Increasing informed uptake and nonuptake of screening: evidence from a systematic review*. *Health Expect* 2001;4:116-126.
- 19 Whelan TJ, O'Brien MA, Villasis-Keever M, Robinson P, Skye A, Gafni A et al. *Impact of cancer-related decision aids: an evidence report*. Hamilton, Ontario: McMaster University Evidence-based Practice Center, 2001.
- 20 O'Connor AM, Stacey D, Rovner D, Holmes-Rovner M, Tetroe J, Llewellyn-Thomas H et al. *Decision aids for patients facing health treatment or screening decisions (Cochrane Review)*. Oxford: Update Software, 2002.
- 21 Whelan TM, O'Brien MA, Villasis-Keever M, Robinson P, Skye A, Gafni A et al. *Impact of cancer-related decision aids*. Rockville, MD: Agency for Healthcare Research and Quality, 2002.
- 22 Briss P, Rimer B, Reilly B, Coates RC, Lee NC, Mullen P et al. *Promoting informed decisions about cancer screening in communities and healthcare systems*. *Am J Prev Med* 2004;26(1):67-80.
- 23 Evans R, Edwards A, Brett J, Bradburn M, Watson E, Austoker J et al. *Reduction in uptake of PSA tests following decision aids: systematic review of current aids and their evaluations*. *Patient Educ Couns* 2005;58(1):13-26.
- 24 Edwards A, Unigwe S, Elwyn G, Hood K. *Personalised risk communication for informed decision making about entering screening programs*. *Cochrane Database Syst Rev* 2003;(1):CD001865.
- 25 Volk R, Hawley S, Kneuper S, Holden E, Stroud L, Cooper C et al. *Trials of decision aids for prostate cancer screening: a systematic review*. *Am J Prev Med* 2007;33(5):428-434.
- 26 Currell R, Urquhart C. *Nursing record systems: effects on nursing practice and health care outcomes*. *Cochrane Database Syst Rev* 2003;CD002099(3).
- 27 Brown HC, Smith HJ. *Giving women their own case notes to carry during pregnancy*. *Cochrane Database Syst Rev* 2004;CD002856(2).
- 28 Pitkethly M, MacGillivray S, Ryan R. *Recordings or summaries of consultations for people with cancer*. *Cochrane Database Syst Rev* 2007. Available from: URL:DOI:10.1002/14651858
- 29 Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A et al. *Developing a quality criteria framework for patient decision aids: online international Delphi consensus process*. *BMJ* 2006;333(7565):417.
- 30 Elwyn G, O'Connor AM, Bennett C, Newcombe RG, Politi M, Durand MA et al. *Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi)*. *PLoS ONE* 2009;4(3):e4705.
- 31 Holmes-Rovner M, Valade D, Orłowski C, Draus C, Nabozny-Valerio B, Keiser S. *Implementing shared decision-making in routine practice: barriers and opportunities*. *Health Expect* 2000;3(3):182-191.
- 32 Charles C, Gafni A, Whelan T. *Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach*. *Health Expect* 2004;7(4):338-348.
- 33 Thomson R, Murtagh M, Khaw FM. *Tensions in public health policy: patient engagement, evidence-based public health and health inequalities*. *Qual Saf Health Care* 2005;14(6):398-400.
- 34 Silvia KA, Sepucha KR. *Decision aids in routine practice: lessons from the breast cancer initiative*. *Health Expect* 2006;9(3):255-264.
- 35 Legare F, Ratté S, Gravel K, Graham ID. *Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions*. *Patient Educ Couns* 2008;73(3):526-535.
- 36 Watson DB, Thomson RG, Murtagh MJ. *Professional centred shared decision making: patient decision aids in practice in primary care*. *BMC Health Serv Res* 2008;8:5.
- 37 Silvia KA, Ozanne EM, Sepucha KR. *Implementing breast cancer decision aids in community sites: barriers and resources*. *Health Expect* 2008;11(1):46-53.
- 38 Wirrman E, Askham J. *Implementing patient decision aids in urology*. Oxford: Picker Institute Europe, 2006.
- 39 Entwistle VA, Carter SM, Trevena L, Flitcroft K, Irwig L, McCaffery K et al. *Communicating about screening*. *BMJ* 2008;337:a1591.
- 40 Stacey D, Graham ID, O'Connor AM, Pomey MP. *Barriers and facilitators influencing call center nurses' decision support for callers facing values-sensitive decisions: a mixed methods study*. *Worldviews Evid Based Nurs* 2005;2(4):184-195.
- 41 Stacey D, Chambers SK, Jacobsen MJ, Dunn J. *Overcoming barriers to cancer-helpline professionals providing decision support for callers: an implementation study*. *Oncol Nurs Forum* 2008;35(6):961-969.
- 42 Elwyn G, Edwards A, Kinnersley P, Grol R. *Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices*. *Br J Gen Pract* 2000;50:892-899.
- 43 Elwyn G, Edwards A, Hood K, Robling M, Atwell C, Russell I et al. *Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice*. *Fam Pract* 2004;21(4):337-346.
- 44 Stacey D, Murray MA, Legare F, Sandy D, Menard P, O'Connor A. *Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy*. *Worldviews Evid Based Nurs* 2008;5(1):25-35.

- 45 O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR et al. *Toward the 'tipping point': decision aids and informed patient choice*. Health Aff (Millwood) 2007;26(3):716–725.
- 46 Stevenson FA, Barry CA, Britten N, Barber N, Bradley C. *Doctor-patient communication about drugs: the evidence for shared decision making*. Soc Sci Med 2000;50:829–840.
- 47 Elwyn G, Legare F, Weijden T, Edwards A, May C. *Arduous implementation: Does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice*. Implement Sci 2008;3:57.
- 48 King JS, Moulton B. *Rethinking informed consent: the case for shared medical decisionmaking*. Am Law Med 2006;32:429–501.
- 49 Thomson R, Edwards A, Grey J. *Risk communication in the clinical consultation*. Clin Med 2005;5(5):465–469.
- 50 Trevena LJ, Davey HM, Barratt A, Butow P, Caldwell P. *A systematic review on communicating with patients about evidence*. J Eval Clin Pract 2006;12(1):13–23.
- 51 Edwards A, Elwyn G, Mulley A. *Explaining risks: turning numerical data into meaningful pictures*. BMJ 2002;324(7341):827–830.
- 52 O'Connor AM. *Using decision aids to help patients navigate the 'grey zone' of medical decision-making*. CMAJ 2007;176(11):1597–1598.
- 53 Stacey D, Hawker G, Dervin G, Tomek I, Cochran N, Tugwell P et al. *Management of chronic pain: improving shared decision making in osteoarthritis*. BMJ 2008;336(7650):954–955.
- 54 Holmes-Rovner M, Llewellyn-Thomas H, Entwistle V, Coulter A, O'Connor A, Rovner DR. *Patient choice modules for summaries of clinical effectiveness: a proposal*. BMJ 2001;322(7287):664–667.
- 55 Barry MJ, Fowler FJ, Jr., Bin L, Pitts JC, III, Harris CJ, Mulley AG, Jr. *The natural history of patients with benign prostatic hyperplasia as diagnosed by North American urologists*. J Urol 1997;157(1):10–14.
- 56 Kennedy AD, Sculpher MJ, Coulter A, Dwyer N, Rees M, Abrams KR et al. *Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial*. JAMA 2002;288(21):2701–2708.
- 57 Sepucha K, Fowler FJ, Mulley AG. *Policy support for patient-centred care: the need for measurable improvements in decision quality*. Health Affairs 2004;VAR 54–VAR.62.

# Appendix 1: Interviews with experts in SDM

## UK-based experts consulted

Name	Position and expertise	Interview completed
Dr Mary Archer	Chair of Addenbrookes NHS trust; chair of the Informed Decision Making in Urology steering group	✓
Dr Hilary Bekker	Senior lecturer in behavioural sciences, Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds	✓
Prof Mike Chester	Director of the UK NHS National Refractory Angina Centre; professor of rehabilitation and preventive health, Liverpool Hope University	x
Dr Aileen Clarke	Associate clinical professor in public health and health services research, Health Sciences Research Institute, University of Warwick	✓
Prof Bernard Crump	Chief executive of the NHS Institute for Innovation and Improvement	✓
Prof Adrian Edwards	Professor of primary care and public health, School of Medicine, Cardiff University	x
Prof Glyn Elwyn	Research director, Department of Primary Care and Public Health, School of Medicine, Cardiff University	✓
Prof Vikki Entwistle	Associate director, Social Dimensions of Health Institute; reader within the alliance for self care research, University of Dundee	✓
Jo Finn	Project manager, Informed Decision Making in Urology project	✓
Dr Steve Laitner	General practitioner; consultant in public health medicine; associate medical director, East of England SHA; clinical advisor to 18-Week National Implementation Team, Department of Health	✓
Sir Muir Gray	Chief knowledge officer of the NHS; consultant in public health	✓
Sam Hudson	Lead associate, NHS Institute for Innovation and Improvement	✓
Dr Alan Montgomery	Director, Bristol Randomised Trials Collaboration; senior lecturer, Department of Primary Health Care, University of Bristol	x
Dr Elizabeth Murray	Director, Primary Care E-Health Unit, Department of Primary Care and Population Health, University College London	✓
Dr Jo Protheroe	RCUK clinical research fellow, National Centre for Primary Care Research and Development, University of Manchester	✓

Name	Position and expertise	Interview completed
Dr Dr Fiona Stevenson	Lecturer in medical sociology, Department of Primary Care and Population Health, University College London	✓
Prof Richard Thomson	Chair of epidemiology and public health, Institute of Health and Society, Medical School, Newcastle University	✓

## Overseas experts consulted

Name	Position and expertise	Interview completed
Prof Alex Barratt	Associate professor in epidemiology, School of Public Health, University of Sydney	✓
Dr Mike Barry	Chief, General Internal Medicine Unit, Massachusetts General Hospital; professor of medicine, Harvard Medical School	✓
Prof Cathy Charles	Department of Clinical Epidemiology and Biostatistics, McMaster University and Centre for Health Economics and Policy Analysis	x
Prof Dale Collins	Professor of surgery, Dartmouth Medical School; director, Centre for Informed Choice, The Dartmouth Institute for Health Policy and Clinical Practice	✓
Prof Annette O'Connor	Senior scientist, clinical epidemiology, Ottawa Health Research Institute; Tier 1 Canada research chair in health care consumer decision support; professor, School of Nursing, Faculty of Health Sciences, University of Ottawa; professor, Epidemiology and Community Medicine, Faculty of Medicine, University of Ottawa	✓
Dr Jack Fowler	President of the Foundation for Informed Medical Decision Making	✓
Prof Amiram Gafni	Department of Clinical Epidemiology and Biostatistics, McMaster University and Centre for Health Economics and Policy Analysis	✓
Prof Bill Godolphin	Department of Pathology and Laboratory Medicine, University of British Columbia	✓
Prof Martin Härter	Director, Institute and Polyclinic for Psychological Medicine, University of Hamburg	
Prof Margaret Holmes-Rovner	Professor of Health Services Research, Center for Ethics and Humanities in the Life Sciences, Michigan State University	

## Appendix 2: UK-based research groups

There are a number of university-based research groups in the UK with a special interest in SDM.

### Overseas experts consulted

Name	Position and expertise	Interview completed
Prof France Légaré	Canada research chair in implementation of shared decision making in primary care, Université Laval	✓
Prof Staffan Lindblad	Associate professor, Karolinska Institute, Stockholm	✓
Prof Hilary Lewellyn-Thomas	Professor, Department of Community and Family Medicine; co-Director, The Center for Informed Choice, The Dartmouth Institute for Health Policy and Clinical Practice; founding research director, DHMC Center for Shared Decision Making	✓
Dr Al Mulley	Chief of the General Medicine Division of Massachusetts General Hospital; associate professor of medicine and health policy, Harvard University	✓
Dr Karen Sepucha	Senior scientist with the Health Decision Research Unit, Massachusetts General Hospital; instructor in Medicine at Harvard Medical School	✓
Dr Richard Wexler	Foundation for Informed Medical Decision Making	✓

### UK academics with an interest in SDM

University	Lead researcher
Cancer Research UK Primary Care Education Research Group, Cancer Epidemiology Unit, University of Oxford	<b>Dr Joan Austoker</b> Reader in public health and primary care (epidemiologist)
Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds	<b>Dr Hilary Bekker</b> Senior lecturer in behavioural sciences (psychologist)
School of Pharmacy, University of Keele	<b>Prof Alison Blenkinsopp</b> Professor of the practice of pharmacy (pharmacist)
Health Sciences Research Institute, University of Warwick	<b>Dr Aileen Clarke</b> Associate clinical professor in public health and health services research (public health physician)
School of Medicine, Cardiff University	<b>Prof Adrian Edwards</b> Personal chair, primary care and public health (GP)
School of Medicine, Cardiff University	<b>Prof Glyn Elwyn</b> Research director, primary care and public health (GP)
Social Dimensions of Health Institute (SDHI), University of Dundee	<b>Prof Vikki Entwistle</b> Associate director, SDHI; reader within the alliance for self care research (social scientist)
Department of Primary Health Care, University of Bristol	<b>Dr Alan Montgomery</b> Director, Bristol Randomised Trials Collaboration; senior lecturer (epidemiologist)
Department of Primary Care and Population Health, University College London	<b>Dr Elizabeth Murray</b> Director, Primary Care E-Health Unit (GP)
National Primary Care Research and Development Centre, Division of Primary Care, University of Manchester	<b>Dr Jo Protheroe</b> RCUK clinical research fellow (GP)
Department of Primary Care and Population Health, University College London	<b>Dr Fiona Stevenson</b> Lecturer in medical sociology, Primary Care E-Health Unit (medical sociologist)
Institute of Health and Society, Medical School, Newcastle University	<b>Prof Richard Thomson</b> Chair of epidemiology and public health (public health physician)

# Appendix 3: Cochrane register of decision aids

<http://decisionaid.ohri.ca/AZlist.html>

The Cochrane register lists decision aids that meet certain criteria. To be included in the A-Z inventory decision aids must:

- satisfy the Cochrane definition of a patient decision aid: ‘Patient decision aids are interventions designed to help people make specific, deliberative choices by providing information about the options and outcomes that are relevant to a patient’s health status and by clarifying personal values. They are intended as adjuncts to counselling’

- have a development process that includes expert review
- have an update policy
- support statements with scientific evidence and
- disclose funding sources and/or conflict of interest.

The table below lists the principal developers of decision aids and the names and numbers of tools they have developed.

## Decision aid developers

Developer	Country	Name	Number
1. Healthwise	USA	Decision points	137
2. FIMDM/Health Dialog	USA	Shared decision making programs	26
3. Mayo Clinic	USA	Treatment decisions	16
4. Midwives Information and Resource Service	UK	Informed choice	7
5. University of Sydney	Australia	Decision aids	6
6. National Cancer Institute	USA	–	5
7. Ottawa Health Decision Center	Canada	Patient decision aids	3
8. Agency for Healthcare Research and Quality	USA	Consumer summary guide	2
9. Centers for Disease Control and Prevention	USA	Decision guide	2
10. Cardiff University	UK	Decision explorer	1

Decision aids listed in the register cover the following clinical topics (numbers in parenthesis indicate developers:

- acne (1)
- allergy (1)
- alternative medicine (1)
- Alzheimer’s disease (1)
- ankle injuries and disorders (1)
- arrhythmia (1)
- back pain (1,3)
- birth control (1, 3)
- blood transfusion and donation (1)
- breast and ovarian cancer screening (1, 6)
- breast cancer treatment (1, 2, 3, 5)
- bronchitis (1)
- carpal tunnel syndrome (1, 3)
- cervical cancer (1)
- child health (1, 3)
- childbirth (1, 3, 4)
- cholesterol (1)
- colorectal cancer (1, 2, 3, 5)
- connective tissue disorders (1)
- chronic obstructive pulmonary disease (7)
- coronary artery disease (1, 2)
- depression (1, 2, 3, 8)
- diabetes (1)
- elbow injuries and disorders (1)
- end-of-life issues (1, 7)
- erectile dysfunction (1)
- eye problems (1)
- gallbladder diseases (1)
- gastroesophageal reflux disease (1)
- hair disease and hair loss (1)
- headache (1, 3)
- hearing disorders (1)
- heart valve diseases (1)
- heel injuries and disorders (1)
- haemophilia (1)
- haemorrhoids (1)
- hepatitis (1)
- hernia (1)
- herniated disk (1, 2, 3)
- high blood pressure (1)
- HIV infection (1)
- hysterectomy (1, 2)
- infertility (1)
- irritable bowel syndrome (1)
- kidney failure (1)
- kidney stones (1)
- knee injuries and disorders (1, 2, 3)
- menopause (1, 2)
- multiple sclerosis (1)
- nail diseases (1)
- obesity (1, 2)
- obsessive compulsive disorder (1)
- OA (1, 2, 8)
- osteoporosis (1, 7)
- ovarian cancer (1)
- panic disorder (1)
- pelvic support problems (1)
- peripheral vascular disease (1)
- pregnancy (1, 4)
- premenstrual syndrome (1)
- prenatal testing (1)
- prostate cancer (1, 2, 3, 6, 9, 10)
- prostate diseases (1, 2, 3)
- shoulder injuries and disorders (1)
- sleep apnoea (1)
- sleep disorders (1)
- smoking cessation (1)
- spinal diseases (1, 2)
- stroke (1)
- temporomandibular joint dysfunction (1)
- testicular cancer (1)
- thyroid cancer (6)
- thyroid diseases (1)
- toe injuries and disorders (1)
- tooth disorders (1)
- ulcerative colitis (1)
- urinary incontinence (1)
- uterine diseases (1, 2)
- uterine fibroids (1, 2, 3)
- vaginal diseases (1)
- varicose veins (1)
- warts and plantar warts (1).

## Appendix 4: Participants in 12 March 2009 Health Foundation roundtable

Name	Title	Organisation
Dr Mary Archer	Chair of the Urology Informed Decision Making project	Chairman of the Addenbrooke's NHS Trust Board of Directors
Jean Balfour	Consultant	Bailey Balfour Consulting Ltd
Jo Bibby	Director of Improvement Programmes	The Health Foundation
Penny Brooks Cordon	Director of Standards and Engagement	Sheffield Primary Care Trust (PCT)
Mike Cheshire	Clinical vice-president	Royal College of Physicians
Aileen Clarke	Associate clinical professor in public health and health services research	Health Services Research Institute, Warwick Medical School
Kate Clay	RN program director	Center for Shared Decision Making, Dartmouth-Hitchcock Medical Centre
Jenny Cockin	Marketing and communications officer	The Health Foundation
Angela Coulter	Independent analyst/consultant	
Sheila Dilks	Director of patient care and professions	Kirklees Patient Care Trust
Glyn Elwyn	Researcher	Department of Primary Care and Public Health, Cardiff University
Vicki Entwistle	Professor of values in health care	Social Dimensions of Health Institute, University of Dundee
Shani Evans	Co-creating Health patient representative	
Paula Franklin	Head of healthcare leadership development	BUPA
Sam Hudson	Lead associate	Practice Partner Network and Patient and Public Involvement, NHS Institute for Innovation and Improvement (NIII)

Name	Title	Organisation
Janette Garden	Urology project nurse	Urology Informed Decision-Making Project
David Gozzard	Medical director	North Wales Trust
Natalie Grazin	Assistant director	The Health Foundation
Charles Kelly	Oncologist	Newcastle upon Tyne Hospitals NHS Foundation Trust
Steve Laitner	Clinical lead NIII Shared Decision Making Project, GP and public health consultant	West Hertfordshire PCT
Claire Lees	Programme officer	The Health Foundation
Michael Lockett	Patient representative	Patient representative on the Urology Informed Decision Making project
Al Mulley	Chief of the general medicine division; director of the Medical Practices Evaluation Center	Massachusetts General Hospital, Harvard Medical School
Bob Norfolk	Patient representative	
Suzie Normanton	Project manager, informed decision making for osteoarthritis of the knee	freelance consultant SDN Consultancy
Gary Parkes	GP	The Lime Surgery, Hertfordshire
Mark Platt	Director, policy and public affairs	National Voices
Tina Strack	Programme manager	The Health Foundation
Victoria Thomas	Programme manager, patient and public involvement, Clinical and Public Health Directorate	NICE Evidence
Richard Thomson	Professor of epidemiology and public health	Institute of Health and Society, Medical School
Steve Wild	Clinical director; consultant obstetrician; gynaecologist	North Tees and Hartlepool NHS Foundation Trust

*The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK.*

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable.

We believe that in order to achieve this, health services need to continually improve the way they work.

The Health Foundation  
90 Long Acre  
London WC2E 9RA  
T 020 7257 8000  
F 020 7257 8001  
E [info@health.org.uk](mailto:info@health.org.uk)

Registered charity number 286967  
Registered company number 1714937

[www.health.org.uk](http://www.health.org.uk)