



# **ANALYSIS**

# Implementing shared decision making in the NHS: lessons from the MAGIC programme

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Shared decision making requires a shift in attitudes at all levels but can become part of routine practice with the right support, say **Natalie Joseph-Williams and colleagues** 

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Adoption of shared decision making into routine practice has been remarkably slow, despite 40 years of research and considerable policy support. In 2010, the Health Foundation in the UK commissioned the MAGIC (Making Good Decisions in Collaboration) programme to design, test, and identify the best ways to embed shared decision making into routine primary and secondary care using quality improvement methods (box 1). In 1910

The learning from MAGIC derives from a variety of sources, including facilitated shared learning events, clinic and consultation observations, interviews with clinicians and patients, patient and public involvement panels, focus groups, and questionnaires. We assessed progress using "plan do study act" data collection tools, <sup>11</sup> monthly project team meetings (including researchers, clinical teams, healthcare organisations, and patient representatives), and an independent evaluation report of phase 1. <sup>10</sup> Here, we draw on our learning from the three year programme and subsequent experience to summarise the key challenges of implementing shared decision making and to offer some practical solutions (table  $1 \Downarrow$ ).

### Challenge 1: "We do it already"

Changing attitudes is a key challenge for any change programme. Both structural change, in terms of healthcare pathways and delivery, and culture and attitudinal change among clinicians and patients are required for shared decision making and patient choice to become routine. Many clinicians feel that they already involve patients in decisions about their care, so

often do not see how shared decision making differs from their usual practice. A minority of clinicians view their role as "decision maker" to act in the best interests of their patients. Clinicians' long held commitment to doing what they perceive to be the best for their patients is a key barrier to attitudinal change. This is well intended, but fails to recognise that patients' values, opinions, or preferences are important and might differ from their own.

An essential step in implementing shared decision making is to increase understanding of what it entails.  $^{11\,13}$  Clinical teams need support to review current practice, to build a shared understanding of how shared decision making differs from their current practice, and to decide how they want to make decisions with patients. We found interactive skills training workshops based on a shared decision making model (fig  $1 \!\!\downarrow)$   $^{12}$  helped build coherence, improving skills, and promoting positive attitudes.  $^{14}$ 

Workshop feedback indicated that role play based training, which emphasised practical skills, worked better than theory heavy presentations. We increasingly included exercises that challenged embedded attitudes and promoted discussion around them. The teams were generally already good at recognising options and discussing them with patients, but there was potential to improve their communication of risk and the task of exploring what matters to patients. The training helped clinicians understand how shared decision making differed from their current ways of working. Some clinicians reported

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### Box 1: Summary of MAGIC programme

Phase 1 (August 2010–February 2012): Designing and testing the best ways to implement shared decision making in routine clinical settings

#### Site

Cardiff University (lead), Cardiff and Vale University Health Board

Newcastle University (lead), Newcastle upon Tyne Hospitals NHS Foundation Trust, Northumbria Healthcare NHS Foundation Trust

### Clinical areas

- · General practices (four each in Cardiff and Newcastle)
- Breast cancer (surgical options for early stage breast cancer)
- · Chronic kidney disease (treatment for end stage renal failure), Cardiff
- · Head and neck cancer (treatment options for head and neck cancer), Cardiff
- · Paediatric ears, nose and throat (surgery for recurrent tonsillitis), Cardiff
- · Maternity (options relating to mode of delivery after caesarean, place of birth, and screening for Down's syndrome), Newcastle
- · Urology (treatment options for prostate cancer), Newcastle

Phase 2 (February 2012–October 2013): Demonstrate that shared decision making can become part of routine clinical care (wider dissemination, implementation and sustainability) and build practical and transferable knowledge about the conditions for success

#### Cardiff

- Work with up to 10 clinical teams across the Cardiff and Vale University Health Board to involve more patients in shared decision making (spread from phase 1)
- Teams had access to support and interventions/approaches developed during phase 1: shared decision making skills, decision support tools, patient participation, quality improvement support

#### Vewcastle

- Provide tools, materials, and resources to enable clinical implementation teams from phase 1 to continue their plans for sustainable change
- Engage with four new clinical teams (two each from primary and secondary care)
- · Engage with third sector organisations, providing versions of skills training workshops to service users and advocates
- · Further develop tools, materials, and processes to facilitate spread of shared decision making and to demonstrate sustainable change

changing their view from, "We do this already" to, "We could do this better."

# Challenge 2: "We don't have the right tools"

Many clinicians believe that a decision aid will itself enable shared decision making and that decisions cannot be shared without a tool to give their patients. A key learning point from the MAGIC programme was that "skills trump tools, and attitudes trump skills." Developing attitudes and understanding is essential, but then clinicians need to consider their communication skills to engage patients in decision making, drawing on evidence based tools when appropriate. There will never be decision support tools for every decision; nor will every patient find them acceptable or helpful. The skills to have different types of conversations with patients are paramount, with or without an available tool.

In the skills training workshops, role play was particularly effective for showing that tools may support the process but do not replace communication skills. Patient information sources designed for use outside the consultation, such as websites, are costly and time consuming to develop and keep updated. Developing brief decision support tools helped overcome this challenge. <sup>15-19</sup> Clinicians willingly designed brief evidence based tools to use inside the consultation, such as Option Grids in the Cardiff sites <sup>15</sup> and brief decision aids in the Newcastle sites. <sup>19</sup> These provide short (one to three pages) summaries of the treatment choices, the likely outcomes, and the factors that patients might consider when making their decision, including risk and benefit data.

Experience from MAGIC suggests that in-consultation tools are often better at facilitating discussion between patient and clinician than those used outside the consultation. Some patients used the tools to guide their questions for the clinician and it

prompted them to discuss what mattered to them—the nub of shared decision making. However, the risk is that clinicians use brief decision aids to enhance information transfer and talk at patients, rather than improving how they work with patients.

# Challenge 3: "Patients don't want shared decision making"

Clinicians often report that their patients do not want to be involved in making healthcare decisions. This might be the case for some patients, and some patients want different levels of involvement, so the shared decision making process should respect the patient's preference. This preference should itself be informed, rather than based on a clinician's presumption about what the patient wants. Many patients feel unable rather than unwilling to share in decision making.<sup>20-22</sup> Some patients think they will annoy clinicians by trying to be more involved,<sup>23</sup> and their desire to be a "good" patient over-rides their desire for sharing decisions. Often this comes from longstanding experience and expectations of a paternalistic approach and seems to be more common in older people.<sup>24</sup> This can be mistaken for lack of interest in engaging in decision making. Clinicians' misconceptions about what patients want must be addressed. It is neither possible nor desirable to make every patient be more involved, but more can be done to make patients feel included and respected, and clinicians can often make more

Patient activation and preparation can increase the likelihood of mutually useful conversations between patients and clinicians. Patient activation campaigns focus on changing patients' attitudes about involvement in healthcare decisions, explaining what shared decision making involves, why it might help, and provide interventions such as question prompt lists. Interventions

effort to understand what is important to the patient. However,

patients may also need support and preparation to take part in

a different type of consultation.

such as the Ask 3 Questions campaign can help patients know what to expect and give "permission" and encouragement to be involved. 26-28

Successful implementation also needs wider patient and public involvement. In the MAGIC programme we included patients with the relevant conditions in designing local interventions as well as having a wider user panel to guide the broader implementation process. The lay panel was crucial in identifying areas for improvements in the implementation work, identifying users' needs, and aiding intervention development and testing.

### Challenge 4: "How can we measure it?"

Clinicians and managers implementing shared decision making want to know what difference it makes to their patients and to clinical practice. In the MAGIC programme we found it difficult to identify or develop suitable patient reported measures to capture experience of shared decision making. Patient reported measures are hampered by social desirability bias (wanting to give high satisfaction ratings), and patients may also not fully understand and identify shared decision making if they have not experienced it previously.<sup>29</sup> However, the three item CollaboRATE measure (used in over 40 studies worldwide) shows promise in overcoming these problems.<sup>30</sup>

Tensions exist between the need for validated and reliable measures for research and measuring for quality improvement. Focusing on quality improvement helped embed shared decision making more readily with some clinical teams. When measures directly informed practice and improved patient care we witnessed greater motivation to improve and to sustain the improvement (eg, the decision quality measure in breast cancer, table 1 U). Linking with local quality improvement expertise and resources, where available, was valuable. For example, the 1000 Lives Plus national improvement service for NHS Wales had supported development of quality improvement skills across the Cardiff site, which was used to implement shared decision making. 32

# Challenge 5: "We have too many other demands and priorities"

Changing attitudes and behaviours takes effort at all organisational levels. Clinical teams face many competing demands and priorities, some of which are compulsory, some even incentivised (whether financially or by targets). For example, the Quality and Outcomes Framework rewards general practitioners for behaviours that are evidence based but not necessarily about what matters most to patients. Tensions are also increasing between shared decision making and clinical threshold guidelines or referral management schemes, which are widely applied within commissioning in England. Similarly, for cancer treatment time targets, the current emphasis is on time to treatment but patients may prioritise time to make the decision.

Visible organisational buy-in and support are essential. During the MAGIC programme, key organisational leaders showed clinicians that shared decision making was an important organisational priority to drive improvement (table 11) and clinical leadership was critical to implementation. This led to greater engagement because clinicians then saw shared decision making as something the organisation does, rather than as another initiative being imposed on them and competing with other demands. Teams sometimes needed support from the organisation to adapt clinical pathways to support effective shared decision making. Shared decision making is not the sole

responsibility of doctors; it should be supported by all members of the clinical team. Responsibility can be distributed—for example, a breast care surgeon can explain the choices, but the specialist nurse can elicit the patient's preferences in more detail. It is important to share learning about what works both within and between teams to avoid "reinventing the wheel."

### Recommendations for implementation

We have summarised the key challenges we faced during a programme to implement shared decision making in organisations across primary and secondary care, but many other factors also affect implementation (fig  $2 \parallel$ ). More detailed discussion of the barriers and solutions is available elsewhere. Similar findings have been reported in the US.  $^{34-36}$ 

In the real world, finance, resources, and time are all scarce. Although shared decision making is mentioned in key policy documents, such as the NHS Constitution 2015,<sup>2</sup> it has no incentives and is not promoted systematically at national, regional, or organisational levels. We still need to foster cultural change among clinicians and patients, and this is a momentous challenge. A receptive culture will truly exist only if clinicians view shared decision making as usual practice and as a fundamental component of safe, effective, and compassionate healthcare for patients. It needs to be embedded in the medical and nursing curriculums and interprofessional training programmes. Similarly, much health policy and professional practice has led to feelings of powerlessness and passivity for many patients. Increasing patient agency, activation, and health literacy are equally important.<sup>37</sup>

Although these actions may help embed shared decision making, they do not standardise the process: every discussion varies, depending on the patient, clinician, their preferences, and the type of decision being made. Shared decision making may not necessarily result in, or depend on, complete agreement between a clinician and a patient. Instead, it is about bringing both types of expertise together, and weighing up the available options in light of both of these perspectives; it makes it more likely that the final decision is informed by what the clinician knows (medical evidence, clinical experience) and by what the patient knows (what matters to them, the outcomes they are prepared to accept).

We need to change attitudes to reflect this, so that patients are not seen as "non-compliant" if they have a different opinion and clinicians are not seen as overly paternalistic if they are listening to the patient's preferences and considering this in a recommended treatment plan. Furthermore, we should emphasise that shared decision making is not confined to one patient and one clinician, during one consultation. The process is distributed across healthcare teams, and between patients and their families, all of whom will influence the process, especially for patients with long term conditions.<sup>38</sup>

Implementing shared decision making is challenging but possible. No one intervention will succeed in isolation. It requires interventions to support organisations, clinicians, and patients: a bundle of interventions working together holistically across all healthcare settings.

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### Key messages

Shared decision making is about more than tools: skills trump tools, but attitudes trump skills

Successful implementation relies on a combination of interventions supporting the organisation, clinicians, and patients

Organisational support and local ownership are vital for engagement

contributors, including Andrew Rix (independent chair of the Delivery Board of Health and Care research Wales, responsible for promoting public involvement in health and social care in Wales), the organisational representatives, clinical teams, and patients for their contribution to the learning.

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## **Table**

rable i recommend	led solutions to challenges to implementing shared decision	
ntervention/approach	What it involved	What it helped with
Interactive skills workshops	Team based sessions lasting 2-3 hours based on shared decision model for clinical practice. <sup>12</sup> Focus on practical skills using clinical scenarios and role play with actors or other participants.	Challenging clinicians' attitudes and differentiating shared decision making from current practice
		Developing shared understanding of the approach to decision making.
	When feasible, used the team's existing training or meeting structures and processes (eg, continuing professional development) as more likely to engage senior clinicians with this approach	Improving microskills for shared decision making
		Overcoming the belief that shared decision making is only about tools
	Examples of the skills workshops are available from http://personcentredcare.health.org.uk/resources/shared-decision-making-skills-training-workshops	Demonstrating the importance of understanding patients' values
Development of brief tools	Facilitating teams to identify key decision points suitable for shared decision making and mapping care pathways to agree on point of	Making reliable information available at the time of the consultatio for both patient and clinician
	delivery  Developing brief evidence based in-consultation tools (1- 3 pages), that are locally relevant and fit with care pathway, including patients in design and user testing. See: http://optiongrid.org and <a href="http://patient.info/decision-aids">http://patient.info/decision-aids</a> )	<ul> <li>Facilitating discussion between clinician and patient that is more than information transfer by changing the dynamics of the consultation</li> </ul>
		Getting clinicians to support and engage with shared decision makin
Patient activation and preparation	Dedicated panel of patient and public representatives (general or clinical team specific) to guide development and testing of interventions, and guide implementation plans	User panel identifies user needs rather than perceived needs
		Changing clinicians' perceptions that patients do not want to share decision making.
	Preparing patients to participate in shared decision making by raising awareness of the approach, explaining what it involves, and providing tools/skills to help with engagement (eg, Ask 3 Questions campaign) through posters and videos in waiting areas and on websites; flyers; and information sent ahead of consultations with appointment letter	Increasing patient awareness and promoting positive attitudes among patients about shared decision making
		Preparing patients ahead of time to become more engaged in decision making
Measurement	Clinically useful measures that have a direct effect on practice—eg. decision quality measure for breast cancer, which measures patients' knowledge and preferences. Breast care team uses the tool to identify knowledge gaps, demonstrate improvements in knowledge, and elicit patients' preferences for further discussion	Engaging organisations and clinical teams
	Link to healthcare improvement programmes, when possible (expertise and resources)  Use existing routine data collection systems, when available	Demonstrates improvement or change associated with shared decision making
		Reminds clinical teams that shared decision making is a priority for them and the organisation
Organisation buy-in/senior level support	Visible support—eg, through walkarounds (clinic visits) by executive board members; internal board reports identifying shared decision making as an organisational priority; grand rounds presented by senior clinicians; dedicated executive board member working with implementation team; "board check list"	Getting clinicians to support and engage with shared decision makin
		Belief that it is an organisational priority and a valued activity
		Patients' perceptions that the healthcare organisations and clinicians want them to become more involved
	Framing interventions /approaches as healthcare organisations initiatives (internally promoted)	
Collaborative and facilitated approach	Dedicated clinical lead	Clinical leads help to drive the work forward in each clinical team
	Regular contact	Understanding clinical teams' priorities/demands and making sure
	Clinical team mapping care pathways and identifying areas for improvement. Also assessing fit with current pathways and other objectives or priorities	shared decision meeting fits in with these  Getting clinicians to support and engage with shared decision makin
	Regular shared learning opportunities (eg, clinical lead meetings, learning sets), including top-up learning sessions where clinicians could bring real world challenges	Motivation to engage with and sustain implementation

<sup>\*</sup>A wide range of the MAGIC resources/interventions listed in this table can be found on the Health Foundation's Person Centred Care Resource Centre: http://personcentredcare.health.org.uk/ All of the MAGIC materials included on this website are available open access.

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# **Figures**

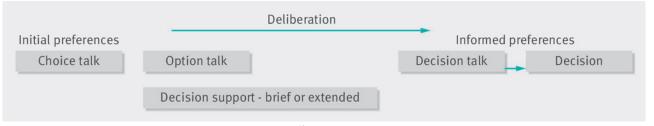


Fig 1 Shared decision making model for clinical practice<sup>12</sup>

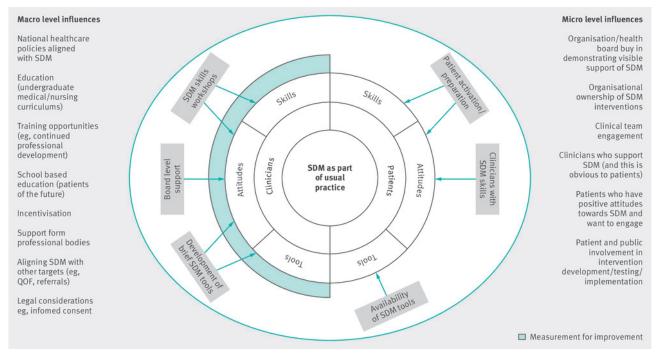


Fig 2 Summary of key factors influencing implementation of shared decision making (SDM). (QOF=Quality and Outcomes Framework)