

Implementing shared decision making

Clinical teams' experiences of implementing shared decision making as part of the MAGIC programme



Acknowledgements

This learning report is based on seven improvement stories produced by the Office for Public Management (OPM), as part of its independent evaluation of the Health Foundation's MAGIC (Making good decisions in collaboration) improvement programme.

We would like to thank all those participating in MAGIC, and in particular those who were interviewed for these stories (27 in-depth interviews with clinicians and 21 short interviews with patients).

OPM's full evaluation of the MAGIC programme is available at:
www.health.org.uk/publications/the-magic-programme-evaluation/

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Preface

The Health Foundation's MAGIC (Making good decisions in collaboration) improvement programme aims to support clinical teams in primary and secondary care to embed shared decision making (SDM) with patients in their everyday practice. The programme is also developing and testing practical solutions that support patients to make informed and considered decisions about their own care and treatment.

The programme started in August 2010. Initially due to finish in January 2012, it has now been extended until October 2013.

A consortium of experts from Newcastle University and Cardiff University is working with healthcare professionals, in various clinical settings, from Newcastle upon Tyne NHS Foundation Trust, Northumbria Healthcare NHS Foundation Trust and Cardiff and Vale University Health Board.

In each clinical setting, participants are working to:

- change professional attitudes and practice and the culture of the health service, and to inspire staff to work closely with patients
- demonstrate the benefits of shared decision making to health professionals and patients
- help teams and patients build the skills they need to do more and better shared decision making consultations
- show how clinical teams can use a standard, simple but robust approach to develop their own simple decision aids for use during consultations
- explore how shared decision making can fit into the existing health system, overcoming time and resource limitations.

This learning report is based seven improvement stories developed by the Office for Public Management (OPM) as part of their evaluation of the first phase of the programme. This evaluation aimed to assess the extent to which the programme has been successful in embedding SDM within clinical settings, and how it has done so. The stories draw on a series of interviews with clinicians and patients carried out by the evaluation team. They demonstrate the experiences of seven of the teams participating in the MAGIC programme. For details about the full evaluation, and the programme as a whole, visit www.health.org.uk/magic


The stories present the experiences of both primary care and hospital-based teams.

Primary care teams

- Collingwood Surgery, a GP practice in North Shields
- The Practice of Health, a GP practice in Barry, Glamorgan
- Central Surgery, a GP practice in South Shields

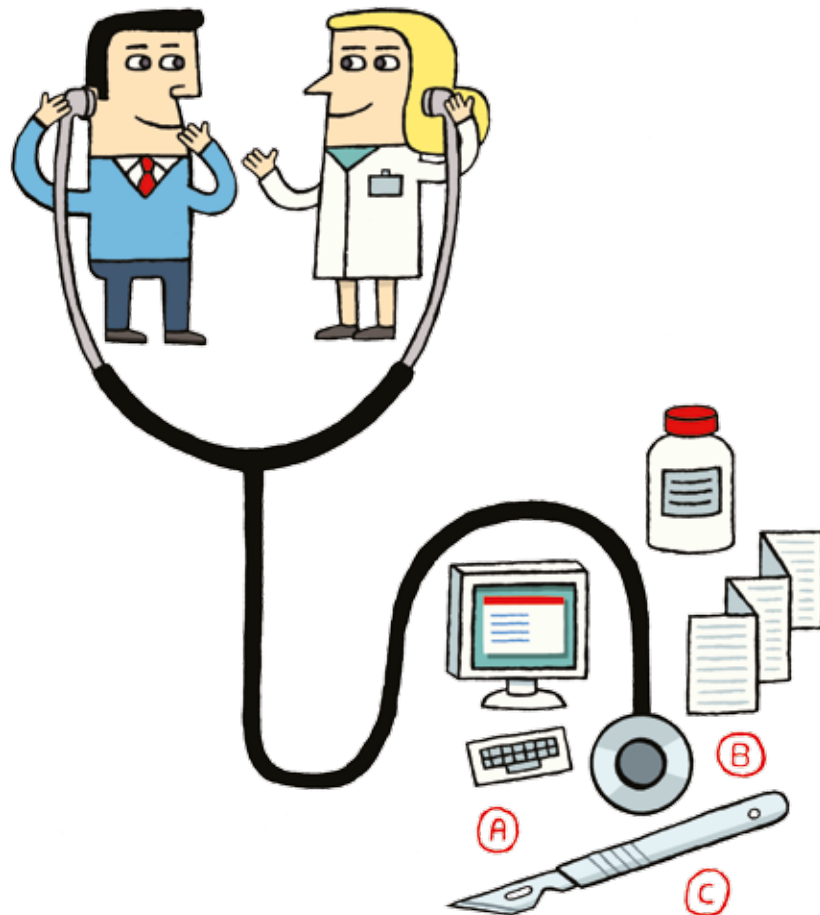
Hospital-based teams

- Nurse-led urology clinics at Freeman, Wansbeck and North Tyneside hospitals
- Cardiff Hospital's paediatric tonsillectomy team
- The obstetrics team at Newcastle Hospital
- The breast care team at the Cardiff and Vale Breast Centre, University Hospital, Llandough



The stories explore the participants' experiences of the MAGIC programme, and of implementing shared decision making in practice. Each story explains why the team wanted to take part in the programme, what they did, what improvements they saw as a result, the challenges they encountered, and how they dealt with them. Each ends with a short section on useful tips drawn from the teams' experiences. We hope they will be useful for other clinical teams implementing SDM, whatever their starting point. However, it should be noted that the stories reflect participants' perceptions of what has changed, and why; they are not an attempt to evaluate the impact of the programme or of SDM more widely.

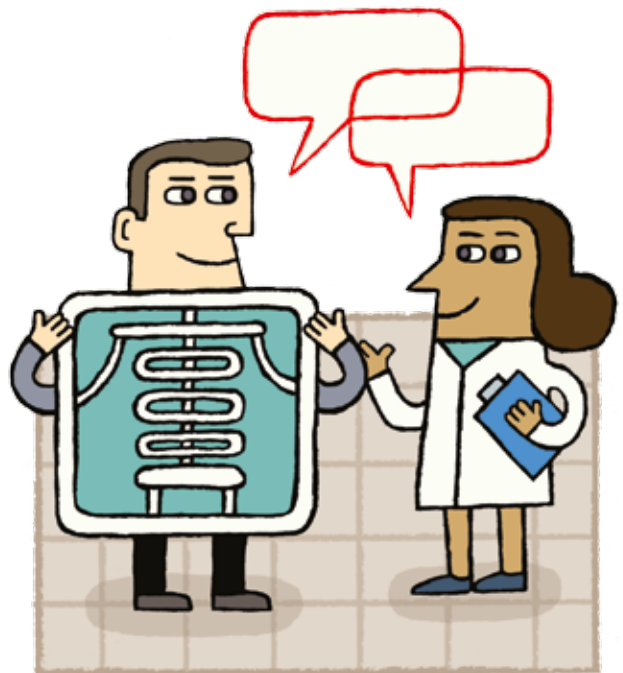
The two teams in Newcastle and Cardiff are now more than halfway through the second phase of the MAGIC programme. They are developing their models to support a change in culture, a change in practice and the adoption of tools and behaviours that will enable a new relationship between people and health services. We will continue to share the lessons and resources from their work on our shared decision making resource centre (www.health.org.uk/sdm).



Glossary

Activated patients	Patients who are activated believe they have important roles to play in self-managing care, collaborating with providers, and maintaining their health; they know how to manage their condition and prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health, and access appropriate and high quality care.
Ask 3 Questions	<p>A specific marketing campaign to raise awareness among patients about their role in shared decision making and encourage them to ask three key questions about their health and healthcare options.</p> <ol style="list-style-type: none"> 1. What are my options? 2. What are the possible benefits and risks of those options? 3. How likely are the benefits and risks of each option to occur? <p>These are guide questions and local variations have been created, depending on what works for the local population, eg ‘How can we make a decision together that is right for me?’</p> <p>These three questions were chosen based on existing evidence which showed their efficacy in improving the quality of information about therapeutic options and their benefits and risks. The MAGIC teams developed a suite of Ask 3 Questions materials, including flyers, handouts, pens, posters and materials. These were piloted by a number of the clinical teams.</p>
Decision aids/ decision support tools	<p>Shared decision making tools or decision aids provide facts about a healthcare condition, the options for treatment or screening and their outcomes, risks and probabilities. They help patients to think about which outcomes or factors matter most to them and guide patients through a process of personal deliberation.</p> <p>These tools can take many forms, from high-tech web applications, computer programmes and DVDs, to face-to-face counselling sessions and brief decision aids, booklets or option grids (see below). They can be anything that helps a patient make an informed and considered decision about their own treatment.</p>
Decision quality measure (DQM)	<p>Decision quality refers to the extent to which patients are knowledgeable about the key options open to them and involved in decisions about their care, and the extent to which the treatment they select matches their preferences.</p> <p>Decision quality measures are questionnaires to assess this.</p>
Option grids	<p>Option grids are based on the questions that patients frequently ask, and are designed for use within clinical encounters.</p> <p>Brief information about the key features of each option are organised into a table against the questions that patients most frequently ask. It is presented so that information about reasonable treatment options can be rapidly compared.</p> <p>For more information, see www.optiongrid.co.uk</p>
Shared decision making (SDM)	Shared decision making is a process in which clinicians and patients work together to choose tests, treatments, management, or support packages, based on clinical evidence and patients’ informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients’ treatment preferences. It is appropriate in any healthcare setting in which more than one option is available, including the option to do nothing.

The improvement stories



1

Collingwood Surgery, North Shields

Collingwood Surgery, in North Shields, north-east England, is a large practice with around 16,500 registered patients. The catchment area includes affluent as well as deprived communities. Staff observed that patients from more affluent areas tend to be well educated, internet-savvy and have strong opinions about what they want, whereas less affluent patients are more likely to defer to their doctor or nurse to make decisions about their treatment and care.

Some clinicians at the practice were already interested in SDM and had been trying to help patients understand and consider the risks associated with different treatments. With support from the MAGIC programme, the practice trialled and adapted brief decision aids (BDAs) used in the management of carpal tunnel syndrome, smoking cessation, menorrhagia, contraception use, and benign prostatic hyperplasia (BPH). The practice pharmacist also adapted several BDAs to use during NHS Health Checks, a screening programme for people aged 40-70, and in appointments with patients who typically had long-term conditions and an established diagnosis. They also began to monitor and evaluate how SDM was being implemented and raised patients' awareness of SDM by using Ask 3 Questions campaign materials.

Why did they get involved in the programme?

The surgery was approached and invited to participate by the MAGIC core team. The practice team felt that MAGIC had a good fit with their ethos and values, and would help them to become an even more innovative, patient-focused practice. For Collingwood, their participation was less a question of trying to radically change ways of working and more about improving and formalising

existing SDM practice. As one clinician said: *'We probably don't do shared decision making as well as we think we do or as much as our patients want us to.'*

What did they do?

They trialled and adapted brief decision aids

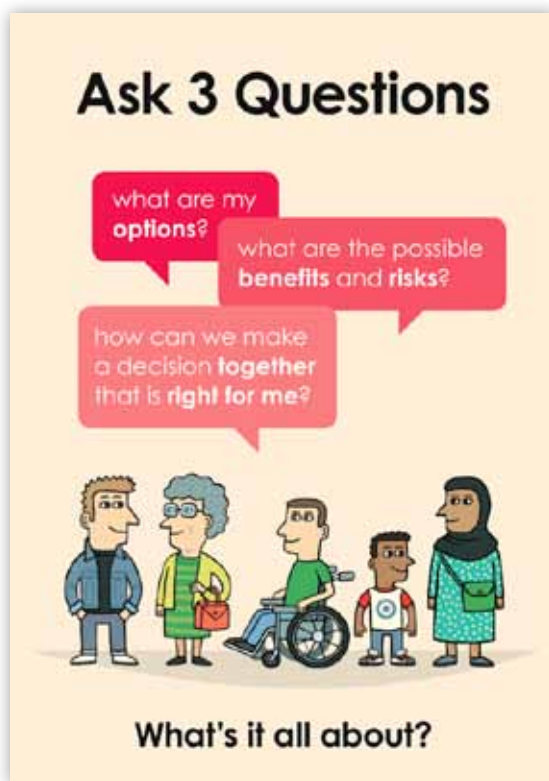
Practice staff trialled and adapted condition-specific SDM tools of their own choosing. To date, GPs have successfully developed several brief decision aids (BDAs) – setting out the pros and cons of different treatment options for patients. These have been used to support the management of carpal tunnel syndrome, menorrhagia, contraception use, and benign prostatic hyperplasia (BPH). Staff are also keen to use SDM tools in new areas, and are adapting a smoking cessation BDA that has been actively taken up by the healthcare assistants and practice nurses. The team is also interested in developing a tool that sets out the pros and cons of using quinine for the treatment of nocturnal leg cramps.

They monitored and evaluated how SDM was being implemented

At first, the practice introduced an EMIS code for logging SDM consultations ('Patient offered choice of treatment'). Clinicians were encouraged to use the code and the results were fed back to the team monthly. The next step was to negotiate with EMIS nationally to provide the practice with three SDM codes to collect more accurate and meaningful data. The MAGIC leads at Collingwood had also conducted an audit of three months' worth of coding data and fed back the individualised results to the whole clinical team. This helped to keep SDM on the agenda and presented clinicians with hard data, allowing them to critically reflect on their practice.

They introduced the Ask 3 Questions campaign

The Collingwood team decided to use the Ask 3 Questions campaign materials (see below) to let patients know about SDM and 'activate' them. They fine-tuned the wording of some of the questions, and trialled the tool in their consultations.



They sought patient feedback on SDM

The practice was keen to elicit critical feedback from patients about their experience of SDM. Therefore, early on, they administered a five-minute SDM patient experience questionnaire to 25 patients per clinician each month. This used a series of closed questions which asked patients to assess how far they had been involved in making decisions about their care and treatment in their appointment, using a five-point scale.

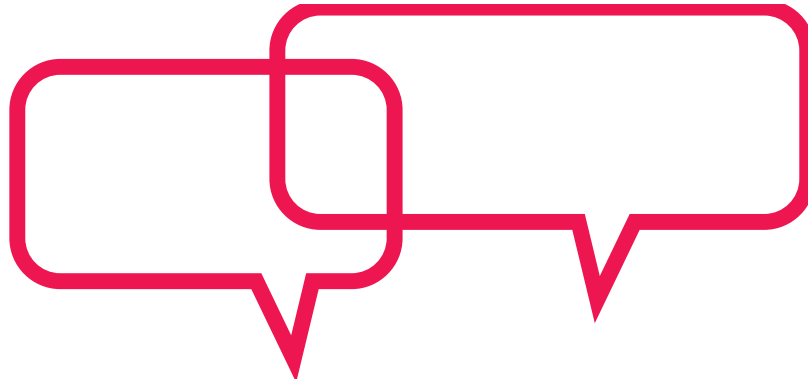
On reflection, staff felt that introducing this questionnaire so early on was not helpful, as it gave the false impression that SDM was more of a research exercise than a tool for driving improvement. Some staff were frustrated that the questions weren't always applicable to their consultation, and felt they were burdensome to administer. Clinicians also questioned the value of the data, pointing out that the survey findings were not meaningful enough to drive changes. With hindsight, interviewing a smaller sample of patients about their experience of SDM in more depth might have proved more useful.

What improvements did they see?

A new dynamic between patients and clinicians

Clinicians said the MAGIC programme had helped them become even more patient focused and, in some cases, it had challenged individuals' perceptions that they were already practising SDM. As one GP said: *'I probably... haven't involved patients as much as I have thought in the past or haven't made them as aware of all the different options.'*

One of the patients interviewed was very positive about how SDM had changed the dynamics of the consultation. He talked about how he had always had to argue his case in the past (about not taking statins), which went against what the doctor felt should happen. Once SDM had been introduced, he felt the dynamic changed dramatically and doctors were much more open to discussion.



More structure and consistency to consultations

Using BDAs and other decision support tools provided a structure on which to build a more systematic and consistent approach to conducting patient conversations. For example, the practice pharmacist had already been using Cates Plots (a visual way of conveying information to patients) when discussing options and possible risks with patients. But she noted that these tended to be fairly free-flowing discussions, and it was difficult to be confident that patients fully understood what she was trying to say, or had retained key information.

As well as helping to create a more structured consultation, the BDA is a readily accessible tool (a short handout) that enables key discussions and preferences to be documented, and which the patient can take away and go through in their own time. This means they are less likely to forget important information, or can ask questions they perhaps didn't think of during the consultation. The BDA handout has proved particularly useful in consultations with patients with hypertension, where there is a lot of information to convey and the options are quite complex.

Encouraging a readiness among patients to consider different lifestyle options

The nurses and pharmacist noted that effective SDM is very much about active listening, rather than talking 'at' the patient. It's also about putting information in the context of patients' lives rather than simply presenting 'standardised' information. They noted that more structured consultations are enabling patients to consider the option of lifestyle changes that may be more likely to lead to longer-term health benefits. In many cases,

patients were choosing not to use medications that they would have demanded in the past. The BDAs, which include risk percentages for each option, seemed to help patients properly consider all their options and decide whether to take medication, accept a lifestyle change, or do nothing at all. As one nurse said: *'I have just had a gentleman downstairs who is quite a heavy drinker and smoker and I think, just by working through the options... we began to discuss little changes that he could make... He wasn't even aware of the options available to him.'*

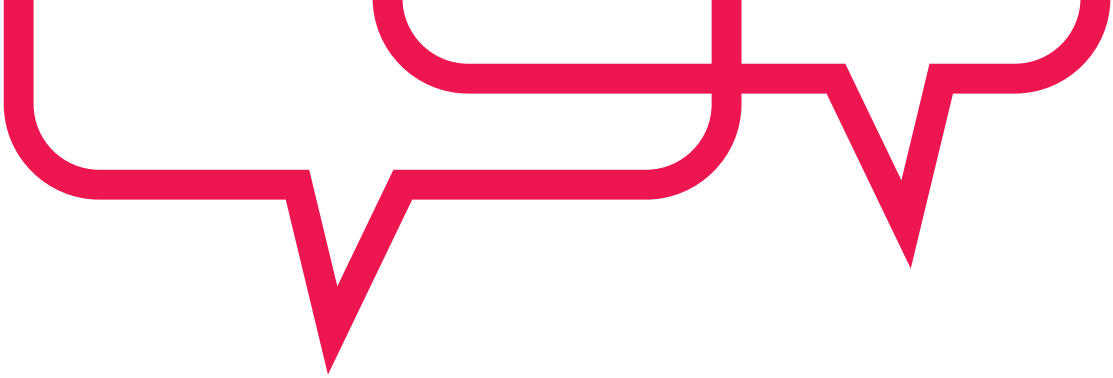
Access to information on new treatments

Clinicians commented that participating in the MAGIC programme, and developing decision aids themselves, allowed them to gain a better understanding of some of the treatment options available in a fast-changing environment. Previously they may have wanted to make a shared decision with the patient but felt they had insufficient knowledge themselves about a particular procedure or option. As one GP said: *'Because things move on so quickly, it can be difficult to be aware of the latest trends and treatments. But with MAGIC, you can get that sort of information.'*

What challenges did they encounter?

Patients not ready for shared decision making

Some patients either lack the confidence to take more responsibility for decisions about their health, or feel they don't have sufficient medical knowledge. As one clinician said: *'I have had people say to me things like "I take my car for an MOT and the mechanic tells me what's wrong with it and I pay for it and sort it." That's why I've come here – I just want you to tell me what to do.'*



Clinicians found that they could overcome patients' reluctance by asking them to 'take a step backwards' and explore what is important to them and why. One of the nurses said it helped to remind each patient that they are the expert when it comes to making a decision about what's important to them, in their life.

Good listening skills were also important, enabling clinicians to pick up on what can often be quite subtle cues from the patient about their experience or preferences. For instance, if a patient has a long history of undergoing debilitating surgical procedures, it is possible to find out – by taking enough time to talk about their experience – whether they would prefer an alternative to surgery.

Concerns about adding to workload and consultations taking longer

As patients are given more information about the details of different options, there is inevitably more to discuss, which means consultations may take longer. This concern was mentioned more often by practice GPs than nurses, as GPs felt they often have less time to spend with each patient than the nursing team. One GP commented: *'You've got to weigh up the benefits of spending longer with one patient against falling behind with the day's appointments, and that can be frustrating.'*

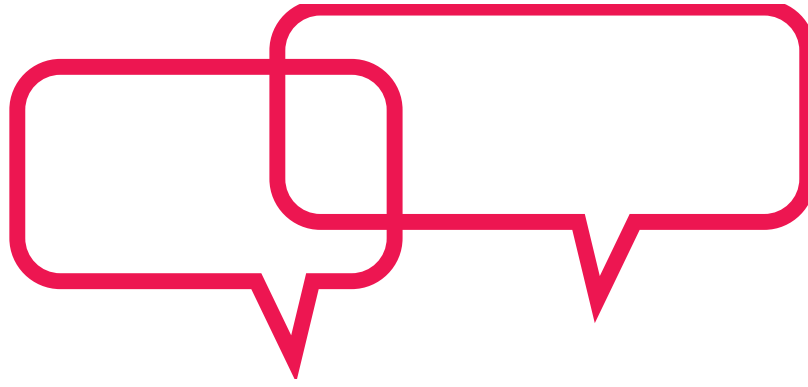
Several clinicians felt that spending a little bit more time with a patient in order to reach the right decision was worth it, as it reduced the chances of having to revisit the decision further down the line and would ultimately lead to a better outcome. But as yet there seems to be limited hard data available to demonstrate improved clinical outcomes as a result of SDM – something the team felt would be very powerful in persuading any sceptical colleagues to commit to it.

Space to practise SDM skills and receive feedback

One clinician talked about how he had been influenced by the values and principles of SDM but didn't yet feel confident about using decision aids during consultations. Other staff echoed his view, admitting that it can be daunting to start using a tool without having had the chance to practise using it. Staff felt they need some protected time for training on how to conduct SDM consultations, especially using decision aids. Having the time to rehearse different scenarios, refine their SDM techniques (eg, by recording role plays for discussion), and get critical reflection from peers would be extremely valuable. Some clinicians would also welcome being able to observe consultations led by experienced colleagues who are successfully using patient decision aids.

Managing competing priorities and agendas

Staff at Collingwood felt that it was a difficult time to introduce SDM, given the system-wide changes taking place, particularly in commissioning. But some suggested that new clinical commissioners could use this period of change to look at whole system pathways and care mapping processes to find ways of embedding SDM within newly commissioned services and pathways.



What advice would they give others?

Gain staff commitment and buy-in

A half-day training session on SDM early on in the programme proved really helpful in engaging staff. Encouraging colleagues to find their own SDM tools to adapt and trial helped build ownership and commitment.

Keep written information short and simple

Decision aids were felt to work best when they were short, simple and user friendly. Adapting tools often involved editing them down so that they were no more than one page long.

Staff need space and time to practise and develop their SDM skills

The MAGIC programme's action learning sets proved particularly useful in creating such a space.

Go at the patient's pace

Clinicians need to pace discussions and decisions appropriately, depending on the patient's needs, as not all patients will be able to make a decision in a single consultation.

Make SDM tools readily available

As well as placing tools on the practice intranet, all consultation rooms had concertina files so that clinicians could quickly and easily put their hands on the materials they needed for SDM.

Monitoring and evaluation is important but challenging

Using several EMIS codes allowed the team to accurately log their SDM activity, and the resulting data are helping to drive further adoption of SDM. But capturing data accurately still depends on reliable data entry – not all clinicians who are using SDM are recording the fact that they use it.

Committed and proactive leadership

The surgery would not have achieved what they did in implementing SDM without a committed core team (comprising a lead GP, the practice pharmacist, a lead nurse and the practice manager). This team were able to persuade colleagues of the benefits of the approach, organise training sessions, and keep SDM high on the practice's agenda.

2

The Practice of Health, Barry, Glamorgan

The Practice of Health is a medium sized practice with 21 clinical and administrative staff. The catchment area covers Barry (approximately 48,000 people) and Sully (approximately 5,000 people), and is characterised by high levels of deprivation. Many of the practice's 7,000 registered patients are young families.

The team were keen to address their high rates of prescribing antibiotics and wanted to reduce re-consultation rates for children presenting with coughs, colds and sore throats. They introduced a decision aid (a booklet called *When Should I Worry?*¹) for use in consultations. They also used a marketing campaign to increase patient awareness and engagement in shared decision making (SDM).

Why did they get involved in the programme?

The practice has a long track record of involving patients in decisions, and many staff have a good understanding of the concept and practice of SDM. However, they wanted to introduce a more structured approach, as well as making patients more aware of SDM. As the practice manager said: *'In a situation where you have possibly only 10 minutes with each patient, having a simple process to follow is essential or it won't happen.'*

The improvements the team wanted to see included:

- higher levels of compliance with recommended treatments
- more empowered patients able to take better decisions about their care
- improved approaches to self-management of care
- fewer unnecessary referrals to secondary care.

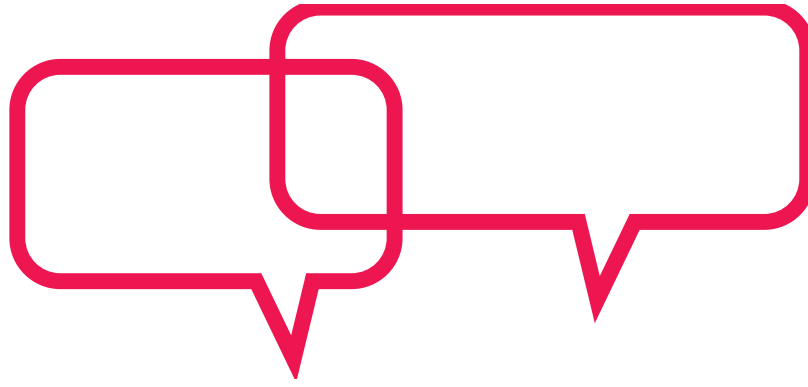
What did they do?

A small team was set up to work with the MAGIC programme. The team included a nurse practitioner as site lead, the practice manager (for expertise on IT and computer systems), one of the GPs and another nurse practitioner. The practice manager and deputy manager provided day-to-day leadership. They used IT and software as a way of embedding SDM into daily practices and providing support, tools and advice on SDM. The team took part in the advanced skills development workshop run by the programme, received direct peer support from an experienced local facilitator, and participated in action learning sets. Practice team members were introduced to quality improvement (QI) methodologies as a way of structuring and focusing their improvement activities.

They used a decision aid

The team chose to pilot the use of a decision aid, a booklet called *When Should I Worry?*, which was developed by academic staff working in the MAGIC design team. It was decided that one doctor and one nurse would pilot the booklet, and a template was developed to record these consultations. To help them do this, the team revised the software package used by the practice so that it prompted clinicians to register use of the booklet directly into the patient's records during a consultation. This served two purposes: it reminded the clinician to make a shared decision with the patient, and enabled the practice manager to audit use of the booklet. The GP could also print a copy of the booklet for a patient's parent(s) to take home and read.

¹ www.whenshouldiworry.com



The practice manager then reviewed the patient's records after consultations and assessed the extent to which the booklet had been used, whether a shared decision had been taken, and whether there had been any further consultations and prescribing of antibiotics for that patient following the initial appointment.

While the booklet was initially thought to be a good tool to test SDM, the low number of patients who presented with upper respiratory tract infections (URTIs) in warmer months meant there was a limited number of patients with whom the booklet could be trialled. Also, while the booklet provided useful information about the best treatments for colds, sore throats and earaches, it did not necessarily give GPs the opportunity to test out their SDM skills in any great depth. As one of the nurses said: *'The... booklet feels like it is more about promoting better self-care, and less about going through different care options in some detail.'*

In light of this, the practice is now starting to test another type of decision aid, an option grid, for the treatment of knee osteoarthritis (KO). This should give GPs more scope to practise their SDM skills as it requires them to explain several treatment options to patients. The team are also considering introducing SDM techniques for the treatment of patients with chronic pain.

They raised patients' awareness of SDM

In the first few months of the programme, the practice tried to raise patients' awareness through a marketing campaign with posters and flyers – the Ask 3 Questions campaign.

While some patients were aware of the poster campaign, the nurses felt that many patients still did not understand what SDM meant for them. As the practice manager said: *'We asked*


quite a few patients about the poster campaign, and most of them did not understand what the three questions were. They were keen to say that they want the doctor to ask these questions.'

However, when the Ask 3 Questions flyer was explained to patients, they reported having a much better understanding of what SDM was and felt that it was a good idea.

The team recognised that simply providing information was not enough. Patients needed to have SDM explained to them and be actively encouraged to ask questions about their care options – to be 'given permission' to ask about treatment options. This was not necessarily easy to achieve, as when a typical patient arrives at a consultation with the GP they may not feel they have the time, or the confidence, to ask questions. One patient commented: *'I think it makes sense [the Ask 3 Questions flyer]. Now I come to think of it, I would use this. Maybe need to get this with plenty of time to get my head around it. It's a good idea.'*

To further engage patients in SDM, the practice worked with small groups of patients who regularly attend clinics for the treatment of certain long-term conditions, such as pain management and diabetes. Patients in this group are easier to send information to in advance. As the practice manager explained: *'Those going to a pain management clinic or diabetes clinic provide a large and ready-made audience for SDM. We know when they are coming, we can send them information, and we can introduce the concept to them as a group.'*

The practice found that providing written information was not appropriate for some patients such as those with learning disabilities or low levels of literacy. To overcome this, they are now piloting the use of a short film that tells patients what SDM is and what it means for them, which is played on a loop in the waiting room.



In addition, the team were aware that they need to involve patients in SDM on a longer-term basis, especially creating a cadre of patients to act as advocates for SDM, spreading the word through networks and friends and family. The practice is currently exploring ways to establish a patient forum to promote SDM and to feed back to clinicians on the quality of their SDM consultations.

What improvements did they see?

Staff reflecting on their SDM practice and skills

The team felt they had increased their knowledge of and skills for implementing SDM, and felt they really benefited from training and action learning sets. As one nurse said: *‘The training made me question whether we are actually doing SDM in practice and allowed us to reflect on our own communication and consultation skills.’*

More empowered patients

GPs and nurses felt that their patients were becoming more empowered as a result of SDM. A small-scale audit of the use of the *When Should I Worry?* booklet showed a fall in re-consultation and prescribing rates, although more evidence would need to be gathered to draw any firm conclusions about this.

A shift in the clinician–patient relationship

Some staff felt they were seeing the beginnings of a shift away from a paternalistic approach to care giving towards one where clinicians and patients both understand the shared role they play in improving health.

What challenges did they encounter?

Inconsistent use of the booklet

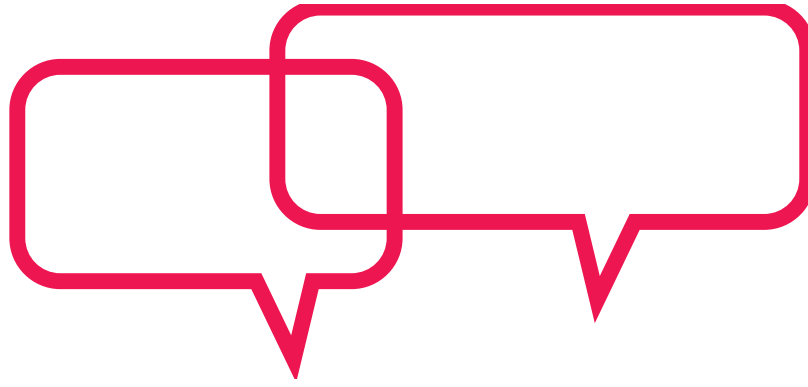
Because not all practice GPs were actively involved in the programme, the decision aid booklet was not being used consistently. This led to concerns that patients would become confused as to how far they could push for the treatment option they wanted, and whether it depended on which GP they saw. As one nurse said: *‘You can’t really have one or two people doing it and everyone else completely the opposite... You will find that patients get to know the ones who offer a shared decision and those that don’t. So in the case of antibiotics, some patients will go to those who always give the antibiotic as opposed to those who set out why it might not be the best course of action for them.’*

Engaging patients in SDM

Many of the practice’s patients have a deferential approach to receiving care (doctor knows best) and do not necessarily have the confidence and health literacy required for them to participate fully in SDM.

Staff concerns that SDM would make consultations longer

Doctors or nurses have limited time with patients – typically no more than 10 minutes. Some GPs who were not directly involved in the programme were concerned that using the booklet would make consultations longer, and encourage unmanageable expectations from patients.



Measuring the impact of SDM

The practice used a decision quality measure (DQM) produced by the MAGIC programme to find out how well patients understood their treatment options, their preferences (what was important to them), and whether their preferences and choices were aligned. But they found it too onerous to administer, and were doubtful as to whether patients really understood the questions in the DQM. They are considering adapting the Ask 3 Questions flyer so that it can be used as a simple self-completion survey by patients after they have seen the doctor or nurse.

Lack of formal incentives to use SDM

While encouragement for staff and good leadership are important, it was felt that existing incentive structures (under the Qualities and Outcomes Framework) do not necessarily support SDM. As a nurse at the practice said: *'You may have 10 minutes with patients and you have got an agenda that is dictated by QOF to make sure that certain issues are covered, such as asking the patient about stopping smoking and taking blood tests. This uses up time.'*

What advice would they give others?

Training on SDM needs to be relevant and tailored to clinicians' needs

Training of GPs is more likely to work when it is provided at convenient times, on site where possible. Visits or training from senior clinical experts who have used SDM is one of the most effective ways of engaging GPs. Nurses involved in the programme found the external training events and action learning sets really useful.

Information alone is not enough

As well as providing information, patients need to have SDM explained to them and be actively encouraged to ask questions about their care options – to be 'given permission' to ask about treatment options.

IT can help embed SDM into daily practice

Information technology (IT) packages can make it easier for GPs to use SDM. For example, they can provide prompts for staff about when to use SDM, information that can be downloaded, and a way of recording SDM consultations.

3

Central Surgery, South Shields

Central Surgery is a large GP practice (with 15 GPs) in the coastal town of South Shields, north-east England. Its catchment area includes deprived communities and patients often have multiple and complex health problems. Practice GPs and other staff felt that patients would benefit a great deal from shared decision making (SDM), as many patients tended not to ask questions or negotiate with clinicians about their treatment and care.

Before being involved in the MAGIC programme, the surgery had tried to improve the information they gave patients, but had no experience of using decision support tools. During the programme, they sourced, adapted and then trialled various decision tools covering a range of health issues. They also tried to engage or 'activate' patients for SDM, using the Ask 3 Questions campaign materials. And they devised some quick and easy ways to monitor how many consultations (and which GPs) were using SDM, as well as some innovative incentives.

Why did they get involved in the programme?

The practice had recently moved premises to the newly built Cleadon Park Primary Care Centre, and felt that the MAGIC programme was an opportunity to improve the service they offered and to improve patient outcomes. The move meant they were now able to provide a comprehensive community-based health service, giving patients various treatment options.

Another reason for getting involved was that one of the practice partners (the MAGIC lead) had a strong research background and was committed to driving innovative change. His experience motivated him to get involved: *'I've always felt kind of displeased when I hear*

that... patients have been given prescriptions... or receive referrals where it looked like it was just a kneejerk response from... the clinician, and the patient wasn't really involved.'

Now that clinicians are taking on commissioning budgets, GPs were also interested in finding out whether SDM could help to reduce inappropriate referrals and prescribing budgets.

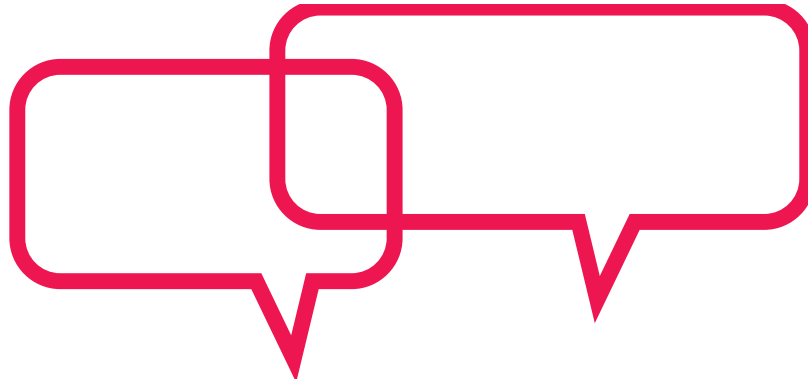
What did they do?

They sourced, adapted and trialled patient decision aids

One of the first things the lead clinician did was to introduce an SDM decision tool for respiratory tract infections. But this was soon withdrawn due to staff concerns that it was leading to over-prescription of antibiotics. (When given the choice, patients frequently opted for antibiotics despite the fact that the chances of contracting pneumonia are estimated to be about one in 10,000.)

The lead clinician then changed tack and asked GPs and nurses to find their own decision support tools and adapt them so they could be trialled. They did this using the plan-do-study-act (PDSA) cycle to document and evaluate their progress. Staff chose to trial a range of tools linked to their caseload and specialist knowledge, which covered a broad range of health issues. While clinicians were familiar with some of the principles of SDM, taking a structured approach that involved learning how to put decision aids and data collection tools into practice took a great deal of time and effort up front.

The team have seen some good results from using SDM, including in sexual health and contraception, managing low mood disorder, and for osteoarthritis of the knee, which lends



itself to SDM as there are a range of treatment options (physiotherapy, joint injections and replacement). Practice nurses have found an option grid for statins particularly helpful in their cardiovascular disease (CVD) assessments, as the grid makes it easier to highlight the risks and benefits of the different options and discuss these with patients.

They are activating patients for SDM

Engaging or ‘activating’ patients for SDM is a priority for Central Surgery. As one of the GPs explained: *‘In the next phase... we really need to get it [SDM] being pushed by patients as opposed to being pulled by clinicians, because I think if patients start to expect it... and almost demand it as a normal part of their experience, then I think clinicians will start to do it more routinely.’*

To help develop this ‘push’ factor among patients, the surgery launched the Ask 3 Questions campaign. Posters, leaflets and other materials were put up or handed out, encouraging patients to ask these three key questions:

- What are my options?
- What are the possible benefits and risks of those options?
- How likely are the benefits and risks of each option to occur?

The practice is also planning to show a short film on SDM to patients in the waiting areas to get them to start thinking about what they want to ask before they see the doctor or nurse.

It’s too early to say whether these efforts to engage patients are making a significant difference, but there’s anecdotal evidence that Ask 3 Questions certainly has the potential to lead to more collaborative and informed decision making. As one patient said: *‘In the past, I’ve just been quite happy to take the*

doctor’s advice. But there have been times when I’ve come out and thought, “Well, I didn’t really want to do that. Perhaps I should have asked if I could do it this way,” and probably, if I had asked, they would have said, “Yeah, that’s fine.” So really I think I just need to be a bit more vocal and say, “Is that the only option...?”’

They are involving the whole team

Reception staff have shown an interest in SDM, and are playing an important role by helping to introduce choice at the very start of the patient journey. They give patients the choice of seeing someone at the nurse-led, same-day clinic or ask if they would prefer to wait and book an appointment with a clinician of their choice. They can help patients weigh up the pros and cons and make a decision based on what’s important to them. As the practice manager explained: *‘What we’re finding is anybody under about 30 years thinks “Quick access with anybody is really important to me”, while anybody who has a long-term condition or is perhaps a bit older feels “Actually, I don’t need to be seen today, but I really would like to be seen by doctor X”’.* Reception staff also help with routine analysis of SDM patient feedback questionnaires.

They are monitoring how they implement SDM

The surgery has integrated SDM into its EMIS coding system, which means it can monitor the total number of consultations conducted using SDM and which clinicians are using it. While the numbers are still fairly low, they are steadily increasing. They have even introduced some light-hearted incentives (including the weekly ‘MAGIC Cup’ for the staff member who has delivered the most SDM consultations that week) and developed SDM ‘performance’ badges (bronze, silver and gold) for staff.



They are introducing quality control

Gathering evidence on SDM and demonstrating its impact across the practice has proved difficult. While the MAGIC team lead wanted to keep a hands-off approach early on to avoid being too critical of how individuals were implementing SDM, after the first year, they felt the time was right to begin a 'quality control phase'. This means clinicians signing up to a set of quality standards for particular tools, and some extra work around making the collection of SDM data more routine and user-friendly.

What improvements did they see?

Documenting conversations with patients about risk

Using SDM has given practice staff a way of formally documenting that patients have received key information about the potential risks of different treatment options. This may be important should complaints (or, in rare cases, litigation claims) be made subsequently.

Patients making more informed decisions

While staff reported that a some patients continued to defer to their GPs, there are many more examples of patients playing a more active role in decisions about their treatment and care. Nurses felt that the option grids were helpful in discussing the risks and benefits of each option available to a patient.

Using SDM is also helping patients feel more comfortable about asking questions and expressing their preferences – all of which means they are making more informed decisions. As one of the nurses said: *'I would say to them "Did you have any ideas about*

how this could be treated yourself?" And they may say "No". But then when you start talking about options they say "Well, I'd thought about that actually", and then it kind of gives them permission to talk about a particular thing that they'd thought about...'

What challenges did they encounter?

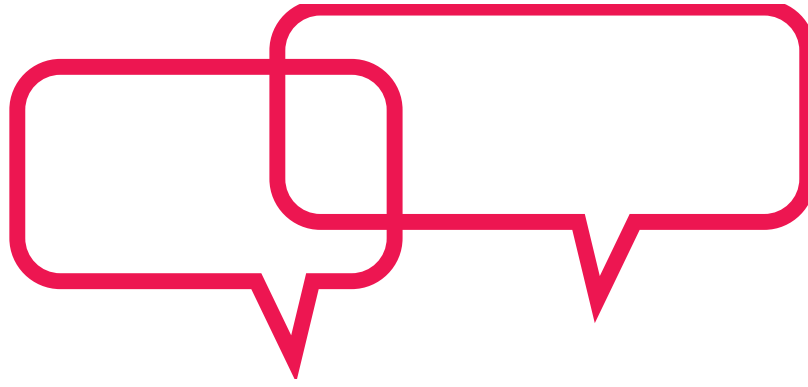
Recording patient feedback to help demonstrate impact

Staff felt that many patients still have a deferential attitude towards their doctor or nurse and are reluctant to criticise them. This has meant that SDM patient feedback questionnaires – which use standard patient satisfaction rating scales – have not generated the kind of detailed and critical data that could really help clinicians to monitor and evaluate their SDM performance, and see what areas they need to improve.

The SDM patient feedback questionnaires used by the programme did provide some useful feedback for individual GPs. But to get more meaningful feedback that can really help to integrate SDM in everyday practice, the surgery is planning to introduce patient-led evaluation. As one GP said: *'I think clinicians generally respond to what patients are saying. The patient voice is quite powerful, particularly in this practice I think – people will sit up and really listen to that.'*

Pressure of time, and managing competing priorities

As in many primary care settings, the care agenda at Central Surgery is *'absolutely crammed'*. At their busiest times, staff talked about reverting to their old 'comfort zones', where they perhaps didn't involve patients as much as they could. Being able to get hold



of SDM tools and decision aids quickly and easily during a consultation was felt to be one way of getting around this problem.

Consolidating progress and maintaining momentum

After a year or so of being involved with the MAGIC programme, the team at Central Surgery felt they needed to focus on

consolidating the improvements they had made so far and maintaining momentum. They are planning to hold regular 'Show and Tell' sessions at their monthly educational meetings, where staff can share and reflect on their learning and progress in implementing SDM.

What advice would they give others?

Involve staff in choosing SDM tools

Allowing staff to source and trial SDM tools and approaches that reflected their caseload and specialist knowledge helped to encourage ownership and buy-in.

Align SDM with wider objectives

It's helpful to align SDM with wider objectives such as the drive to develop patient-centred care and reducing the potential for litigation and complaints.

A few committed SDM enthusiasts can make a difference

All staff (clinical and non-clinical) have a role to play in SDM, but it's helpful to have a few committed enthusiasts who can keep SDM on the organisation's agenda and let everyone else know what's happening (eg, regularly updating information on noticeboards and in waiting areas).

Incentivise staff

A bit of 'nudging' by the programme team, and a healthy degree of competition among staff to demonstrate how well they were doing in implementing SDM, helped to maintain momentum, which is really important given the competing priorities staff have to grapple with.

Getting the benefits of SDM requires some time and effort up front

Using patient decision aids requires some time and effort up front so that clinicians are comfortable using the tools and can integrate them into their everyday practice. Staff may also need protected time and support to practise using the tools and reflect on their SDM skills.

Patients need to be 'activated'

For successful SDM, sufficient resources need to be invested in engaging or 'activating' patients so that they expect to be more involved in decisions about their care, and understand the benefits of doing so.

4

Urology clinics, *Freeman, Wansbeck and North Tyneside hospitals*

Nurse-led urology clinics at the Freeman, Wansbeck and North Tyneside hospitals treat patients with a wide range of urological problems. They provide a 'one-stop' shop, making assessments, diagnoses and treatment decisions with patients all on the same day. Most patients are seen and managed by specialist nurses, but those with more complex conditions are seen by a hospital consultant. Patients are often men who present with an enlarged prostate (or benign prostatic hyperplasia (BPH)), having been referred by their GP.

The clinics work on a 'hub and spoke' model: the Freeman Hospital is the hub, serving five local hospitals (spokes) across the north-east of England. The Wansbeck urology clinic, which covers the districts of Ashington, Bedlington and Newbiggin-by-the-Sea, serves a mostly white working class population, including former mining communities.

Staff at the Wansbeck clinic decided to use shared decision making (SDM) to help patients with benign urological problems decide one of three clear treatment choices.

- Conservative management/self-monitoring. This involves the patient making lifestyle changes (eg, modifying their fluid intake and monitoring the impact on their symptoms).
- Medication. This involves alpha blocking medication, which can have significant side effects (including dizziness, erectile dysfunction and retrograde ejaculation).
- Surgery. This involves transurethral resection of prostate gland (TURP) or laser surgery.

Why did they get involved in the programme?

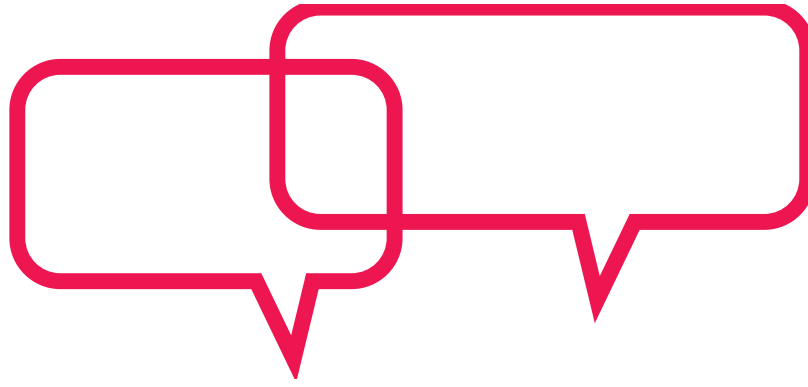
The clinical team were approached and asked to get involved by the urology clinical lead for the MAGIC programme in Newcastle, who had a good working relationship with some of the staff. They agreed to take part, despite being somewhat unsure at first of the benefits it might bring. Some staff were worried about how they would implement SDM given severe resource constraints. They were also worried that SDM might lead to a big increase in the number of patients opting for more expensive surgical treatment or medications.

Some staff felt they were already reaching shared decisions with patients, while others were concerned that patients would not welcome SDM, and instead still expect the doctor or nurse to tell them what treatment they need. As one nurse practitioner put it: *'... a lot of them have worked down the pits all their lives. They think they are coming to hospital to see the bloke with a bow tie on... and then when they see... a nurse in their clinic and she's going to feel [their] prostate gland, that's enough to throw them – never mind me then asking them to start making decisions.'*

What did they do?

They changed the patient pathway

Taking part in the introductory MAGIC session gave the clinical team a chance to reflect on their 'one-stop shop' approach, which was possibly asking too much of patients (receiving a diagnosis, taking it in, then deciding what to do – all in one appointment). As the nurse practitioner said: *'When we learnt more about SDM, we wondered if [the one-stop shop] was an area where maybe we were rushing the patients into a decision... We certainly now think that...'*



patients maybe weren't given the time to fully think through what it was that they were basing their decision on and what their values were.'

So they decided to change the patient pathway. Now, patients receive their assessment and are given an information booklet to take home and read, think of questions they want to ask, and then make a decision.

They introduced a decision support booklet and DVD

The team started giving patients a new decision support booklet and DVD (produced by the NHS) on benign prostatic hyperplasia (BPH), which they could take home after their diagnosis. The booklet and DVD were felt to provide good background information on the causes of urological problems and the treatment options available to patients (including a questionnaire), even though some staff were concerned that some patients might not understand some of the language used (or even have a DVD player at home). A week later, one of the nurses would phone the patient to ask if they have made a decision about treatment. If so, the nurse then writes to the patient's GP to let them know what the patient has decided.

The booklet serves two purposes.


- It helps patients to understand their treatment options and, in some cases, suggests they involve spouses or partners who may be affected by their symptoms in deciding what treatment to choose.
- For the clinical team, the questionnaire in the booklet allows them to check how well patients have understood the information given to them during their visit to the clinic, and make changes if need be.

What improvements did they see?

Better quality, structured consultations

Team members felt that implementing SDM improved the quality of consultations and was beginning to change the nature of interactions between clinicians and patients. Even simple changes like asking patients open-ended questions seemed effective. Clinicians also felt they were actively listening to patients, as SDM encouraged them to focus on understanding patients' personal circumstances and priorities, rather than quickly prescribing a standard treatment pathway. As one nurse said: *'I think that's been... the biggest thing for me. It's given me permission to actually take more time rather than trying to get that decision made within one appointment.'*

The team also felt that using SDM – particularly going through the standard set of topics in the BPH booklet – gave consultations more of a structure, and helped them flow. The nurses felt clearer about what they needed to cover and said it meant they were less likely to 'jump about' in discussions. The more structured approach had also given them space to reflect on how they can best meet a patient's needs. For example, the lead nurse practitioner said she now places more emphasis on conservative treatment options: *'... before, I skirted over the conservative management option... With shared decision making [I realised that] there are a substantial number of men who just want to do the lifestyle changes rather than medical intervention and they do, in fact, make a significant difference to their symptoms.'*



She also said she now puts more emphasis on explaining the risks associated with each treatment option so that patients can make genuinely informed decisions: *'Before [SDM], I would skirt round the side effects... now I have to actually mention the downsides, and the risks of taking the treatment. For example, I have to tell them that they are going to get retrograde ejaculation and it's at that point they say "Well, I don't want that"... It's made me actually state what the risks and benefits would be, which I don't think I properly did before.'*

A more flexible patient pathway, giving patients more time to consider their options

Implementing SDM led the team to make some changes to the patient pathway to make it more flexible. Now, depending on the patient's preference, they can either make a decision about treatment immediately or take the information home to consider their options before making a decision.

Making this small change also brought other benefits. Giving patients the NHS booklet to take home gave them the chance to discuss their treatment options with other family members (who may be affected by their symptoms) before making a decision. This can be especially important for urology patients, whose spouses may be affected by the patient's symptoms (for example, frequent urination at night) or the possible side effects of treatment (in particular, those relating to erectile function).

What challenges did they encounter?

Convincing sceptical colleagues

One of the biggest problems the team encountered was scepticism among colleagues about the value of SDM, especially

as many believed they were already involving patients in decisions. They dealt with this partly through good cross-organisational relationships (across the hub and spoke model and other regional networks), which meant team members could communicate how SDM had been successfully implemented to other clinics.

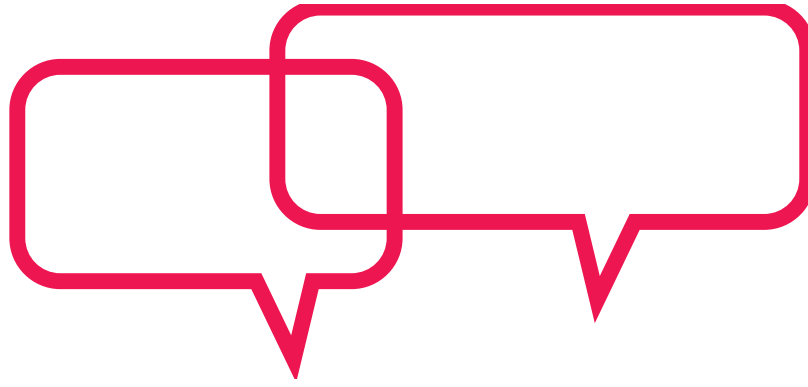
Patchy knowledge of SDM

The team also felt that awareness of SDM among colleagues in secondary and primary care in their local area was patchy at best. They suggested trying to improve this by engaging with colleagues to 'move SDM up the pathway to primary care' so that patients have the chance to consider whether they want to be referred to secondary care or whether they would like to pursue conservative strategies instead and wait to see the results.

Patients not engaging with SDM

This was felt to be one of the biggest challenges the team faced, as older patients attending the clinic, often from working class communities, stuck to the traditional view that the doctor – or nurse – would make the best decision for them and they were uncomfortable about being involved in making the decision.

The team had mixed views on how to deal with this problem. Some felt that where patients were reluctant to engage with SDM, they should be given the chance to take part in decisions as much or as little as they liked. As one consultant explained: *'I think some people take a little while to get used to the fact that you are going to make a decision together... As long as they feel happy with the amount of input that they have had... I'm not too worried about how much they decide themselves as long as the process helps them feel that they've... made the right decision.'* But other team members felt



they should actively try to secure the patient's engagement with a decision even if the patient was very resistant to it.

The clinic nurse talked about the need to tease out a patient's preferences during the consultation, reminding them that they (the patient) are the expert when it comes to weighing up the pros and cons of different treatment options and what impact the possible side effects might have on their lives. The nurse also talked about taking cues from a patient's body language. If the patient started to show signs of stress or disengagement, the nurse might then propose a treatment option. As she said: *'I think you've got to be sensible and you've got to be able to read your patients.'*

How to measure success in implementing SDM

The team found it difficult to get critical feedback from patients about their experience of SDM, which meant it was difficult to measure how well they were doing in implementing it. They used the SDM questionnaires developed by the MAGIC programme to gather feedback from patients, and the response was overwhelmingly positive. But they felt the questionnaire didn't generate the kind of detailed feedback about SDM they would have liked to help them make further improvements – partly because of their patients' reluctance to criticise their healthcare provider.

What advice would they give others?

Flexible patient pathways are needed

Flexible patient pathways are needed to support the implementation of SDM, in order to be responsive to the needs and preferences of individual patients in terms of how much they want to be involved in SDM and how quickly they want to reach a decision.

Patient information

Giving patients well written and well designed information about their treatment options is important for putting SDM into practice, both during and after consultations.

Communication

As some patients are less comfortable with the idea of SDM, clinicians need good communication skills (including being able to read the patient's body language) to enable the patient to engage with it.

5

Paediatric tonsillectomy, *Cardiff Hospital*

For Cardiff Hospital's paediatric tonsillectomy team, one of their key challenges is how to deliver shared decision making (SDM) in three-way conversations, ensuring that parents as well as children are effectively engaged in the SDM process.

The team runs a weekly clinic where they see children (aged 3 to 16) and their parents, referred by their GP. Set up in 2006, the nurse-led clinic carries out pre-assessments for most children (98%) referred with tonsil complaints, thereby reducing doctors' workloads. After a brief assessment by a doctor in the outpatient department, the clinic nurse conducts the pre-assessment to:

- determine the severity of the child's symptoms (particularly the regularity and recurrence of tonsillitis)
- assess the impact of their symptoms
- consider the child's and the parents' priorities
- identify attitudes to the risks associated with a tonsillectomy.

At this stage, the child and their parents are offered two options: to be listed for a tonsillectomy or 'watchful waiting'. The team decided to focus their efforts to improve SDM on this key decision. They designed and tested an option grid (see page 29) based on frequently asked questions (FAQs). They also used a decision quality measure (DQM) to test the outcomes of consultations that used the option grid.

Children are typically referred to the clinic because they have had recurrent bouts of tonsillitis, causing them to take lots of time off school and, potentially, their parents to take lots of time off work. The clinic nurses reported that GPs generally refer patients having assessed that the child's symptoms are

sufficiently pronounced to merit considering tonsillectomy as an option. More exceptionally, GPs have referred children at the insistence of parents, but may not necessarily feel that a tonsillectomy is the most medically appropriate option.

Why did they get involved in the programme?

The paediatric tonsillectomy team had already been working to try and standardise GP referrals to the clinic and improve the information and support they give to patients. Team members involved in this work felt that MAGIC could help them build on what they'd done so far by:

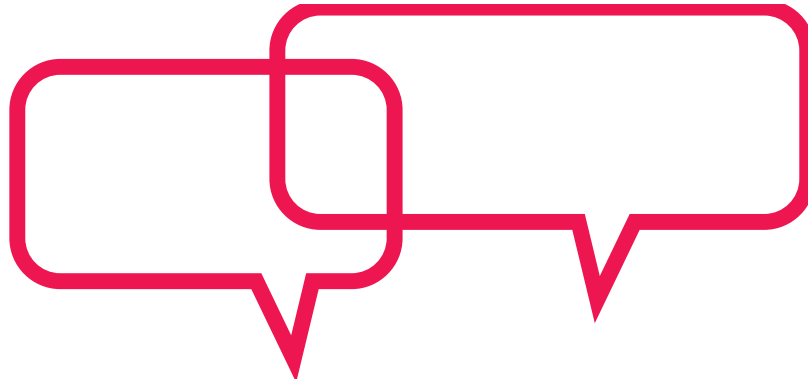
- helping the team be more consistent in applying SDM in practice
- working with GPs to increase awareness about when tonsillectomies are appropriate, thereby reducing inappropriate referrals
- ensuring that patients are fully informed about what tonsillectomies involve, and the main risks and benefits.

While some team members were already sympathetic to SDM, others were sceptical when first approached about getting involved with the MAGIC programme. One of the biggest worries was that it would make consultations longer. But the clinical director was supportive and encouraged the team to get involved.

What did they do?

They developed an option grid

Developing option grids can be very time consuming, so the MAGIC team provided a template that nurses and consultants then



worked together to adapt. This was circulated to colleagues for feedback, and revised accordingly (see Figure 1 on page 29). The team tried to ensure that the language used was appropriate for children and that parents (and, where relevant, older children) could understand the risks as well as the benefits of choosing surgery.

At first, the clinic nurses considered asking parents to read the option grid before the consultation, or take it away to look at after. But as they began to implement SDM, the option grid became central to the pre-assessment consultation itself. The consultation rooms were also arranged such that nurses could put the option grid on the table between themselves and the patient and their parents, and they could all lean over the table to discuss it – reinforcing the shared nature of the decision. Team members felt that the grid really helped parents and children to understand what was being discussed during the pre-assessment. As one nurse said:

‘Parents have this visual representation of the options on the table... [they] also have the verbal explanation of the information that’s provided in the option grid. The grid is not a replacement for the verbal information – it’s just a way of facilitating a conversation around those treatment options.’

Parents and children usually make their decision about treatment during the pre-assessment. But if it turns out they need more time to decide, they can take the option grid home and go through it again there. Patients liked being able to do this, because as one nurse said, they don’t always take everything in during the consultation:

‘[... they] don’t take everything in, so I feel, to actually sit with them [and ask] “Right, is there anything else you want to go through or do you understand it all?”... They can actually

look back through it and they take it away with them. They’re now told that we’ve put the phone number on the back, and if there is anything... that you are not sure of or you didn’t understand, ring us and we’ll go through it again.’

The nurse then contacts them again a short while later to see if they have reached a decision, offering to put them in touch with the surgeon to find out more if that would help.

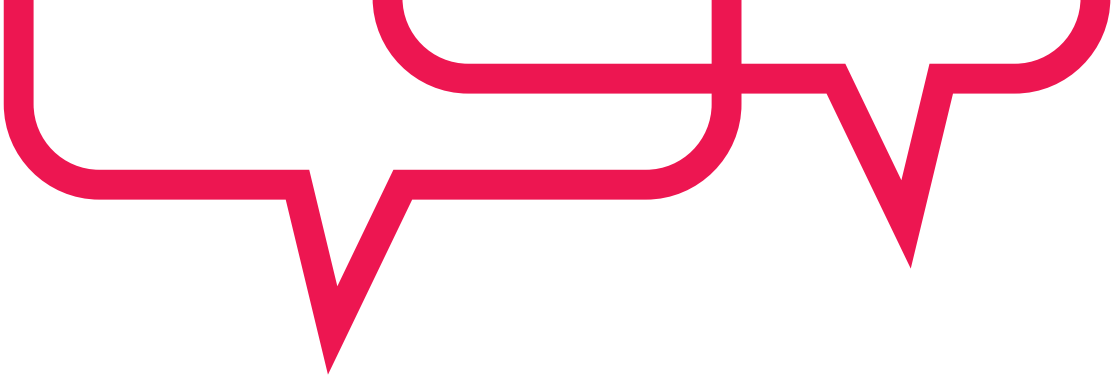
They developed a decision quality measure (DQM)

This is a questionnaire designed to find out:

- a parent’s understanding of the key features of treatment options
- their preferences (what is important to them)
- their readiness to decide
- their preferred choice of treatment.

The DQM is given to parents following the pre-assessment. The resulting data are collected and analysed by the central MAGIC team and results fed back to clinical teams to help them reflect on their practice. At first, the team were concerned that parents might not be willing to complete the DQM, but this has turned out not to be a problem.

Data from the DQMs suggest that shared decision making is being implemented effectively, with parents’ responses suggesting that they have a good understanding of what’s involved in the tonsillectomy operation and its potential risks. Nurses feel the data provide helpful, recorded evidence that parents have been fully informed about what surgery involves, in the (rare) event of any subsequent complaint that this was not the case.



The tonsillectomy team plan to re-administer the DQM to parents before children go into surgery to check how much information they have retained. This should tell them what information they need to emphasise in the future. What they are aiming for is for parents to retain 98% of the information they receive, which would be a marked improvement.

They promoted SDM materials

The team displayed some of the Ask 3 Questions materials (posters, leaflets and cards) in the clinic. Nurses also suggested that SDM materials should be available in different languages and formats, as some patients may not have English as their first language or have good reading skills.

What improvements did they see?

A more patient-centred approach

Team members felt that taking part in the programme had encouraged them to reconsider how they conduct consultations with patients. As one nurse said: *‘... you realise each patient is different and that we need to become less parrot-like and more responsive... We need some time talking and communicating in the patients’ language... It’s about becoming much more aware of how you communicate – this is a considerable change for some of our medical staff.’*

More collaborative decision-making

Looking through the option grid together was a good way of signalling to parents (and their child) that they needed to arrive at a decision together. One nurse said that using the option grid even seemed to change the physical dynamics in the consulting room: *‘... the act of handing over the grid and the fact that people end up huddled around it actually*

quite significantly changes the dynamics in the room... sort of disrupts that relationship between the medical professional and the patient or parents quite significantly.’

The option grid was also helpful as a formal way of recording discussions and decisions.

Improved structure and consistency of consultations

Using SDM has improved the structure and consistency of consultations, both by individual clinicians and across the team.

Securing informed consent

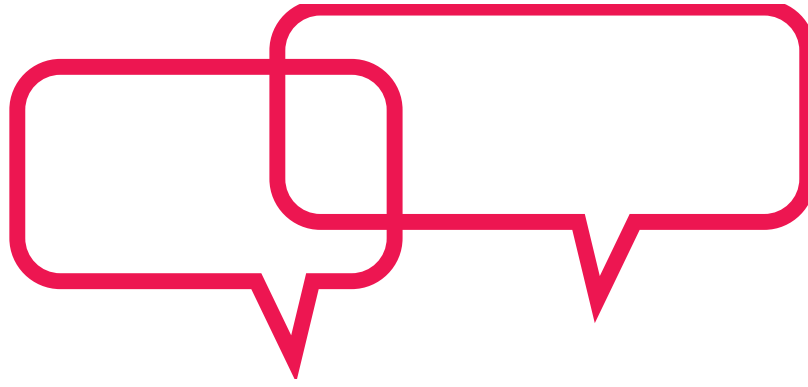
Ensuring that parents have a good understanding of the risks associated with tonsillectomy is helpful in obtaining genuine informed consent on the day of the surgery. Doctors reported that when they knew that the patient had been involved in SDM, they were more confident that the patient was able to give informed consent.

What challenges did they encounter?

Engaging clinicians at the start

Early on, clinicians who felt they had good consultation skills and were already involving patients in decisions struggled to understand how their involvement in the programme could improve what they do. The team dealt with this by:

- being open and transparent with colleagues about the implementation process, including any concerns, and working collaboratively at every stage
- providing evidence of the impact of SDM. The nurses used data from the DQM to convince sceptical colleagues that patients who have been involved in SDM have a



better understanding of the options available to them and the risks and benefits of each option. Being able to see data improvements in service quality in their own setting was especially helpful in motivating some doctors to engage with SDM

- promoting local ownership of the SDM tools (the option grid and DQM), which were created by the team, for them and for their patients, encouraging greater buy-in among all team members
- gaining high level support for SDM from senior management and board members via site visits
- promoting patient involvement and advocacy for SDM by patient representatives
- persevering: nurses persuaded some clinicians to get involved simply by ‘niggling’ them about it regularly.

Language used to explain risks

The team found it difficult to decide on the right language to use in the option grid. They wanted to strike a balance between being clear about the risks of surgery but not alarming parents and children by using words like ‘death’. They dealt with this by using a Plan-Do-Study-Act (PDSA) cycle, updating and reviewing the language used.

Consultations taking longer

At first, the nurse specialists found that using the option grid meant consultations took up to 10 minutes longer. But as they became more familiar with the tool, it took less time to use, which meant consultations were now the same length as they were before the option grid was introduced.

What advice would they give others?

Be open and take a collaborative approach

This helped bring colleagues along on the SDM implementation journey.

Success is most likely where local teams develop and own the SDM tools

Locally developed tools ensure that they are specific to the team’s setting.

Use evidence to demonstrate the benefits of SDM

Using evidence was a good way to engage clinicians to improve their own practice.

Effective SDM early on in a patient pathway can have other benefits

Example of benefits further down the line include securing genuine informed consent, and avoiding or mitigating the impact of any decision regret.

Figure 1: Option grid designed by the paediatric tonsillectomy team at Cardiff Hospital and used in nurse-led clinic pre-assessments



What matters most...

Tonsillectomy or watchful waiting – for children under 16 years old

Your child should only be considered for tonsillectomy if:

<ul style="list-style-type: none"> • All attacks of sore throat have been tonsillitis • There have been five or more attacks a year 	<ul style="list-style-type: none"> • They have had attacks of tonsillitis for at least a year • The tonsillitis has led to time off school or difficulties sleeping
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Frequently asked questions	Tonsillectomy	Active Management
What does it involve?	The tonsils are removed under general anaesthetic.	Appropriate treatment will be arranged by your GP if your child has further episodes of tonsillitis. Your child will be referred for a tonsillectomy if necessary.
How long does it take?	The operation will take about 30 minutes. Your child will need to stay in the hospital for one night.	Until other treatment is considered necessary.
How long does it take to recover?	About two weeks. During this time, your child will need to stay at home to prevent infection.	As with previous episodes, it will take 3-7 days to recover from each event.
Will my child stop having tonsillitis?	Yes, but they may still have episodes of sore throat.	Possibly, 30 out of 100 children will stop having tonsillitis without an operation. They may still have sore throats.
What is the risk from the procedure or process?	As with all operations, there is a risk of serious complications.	There is no real risk to taking this approach.
What is the risk of bleeding?	1 child in every 100 will have serious bleeding immediately after the operation. Most of these will need to have another operation to stop the bleeding. 3 children in every 100 will have serious bleeding in the first two weeks after the operation. Some will need to have another operation to stop the bleeding.	This problem does not occur in this approach.
Will it reduce the number of days missed from school?	Possibly. It depends on how much time your child has been missing from school.	Possibly. As children get older, they often have less attacks of tonsillitis.

Editors: Amy Lloyd, David Owens, Emma Cording, Alun Tomkinson, Valerie Willmott, Graham Roblin, Gareth Williams, Glyn Elwyn

For more information about how Option Grids are developed, visit: <http://www.optiongrid.org/about.php>

Evidence document: http://www.optiongrid.org/resources/tonsillectomy_evidence.pdf

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6

Obstetrics, *Newcastle Hospital*

The obstetrics team at Newcastle Hospital focused on how they could embed shared decision making (SDM) by making changes at specific points in the care pathway. They developed and piloted an information pack (including a decision aid) to help pregnant women who had previously had a caesarean section decide whether to choose a vaginal delivery for their current pregnancy or an (elective) caesarean. They felt women were more likely to be prepared to discuss the risks and benefits at the consultation and reach a decision if they had the SDM information pack prior to their appointment.

They decided to pilot the information pack with a small number of women at first, intending to trial it more widely in due course. But they were aware that making SDM part of their everyday practice would require a major culture change, involving clinicians as well as other staff and patients. They developed a decision quality measure (DQM) to give them the information they needed to engage all staff across the directorate and help them design further service improvements. Early on, some staff were worried about the impact of SDM on their workload. Now, they see it as a *'different way of doing something you do already, but with better outcomes'*.

Why did they get involved in the programme?

Team members felt that although they already encourage patients to make informed choices throughout pregnancy and delivery, there was some scope for women to be even more involved in such decisions.

As one midwife said: *'We don't do it as well as we think we do. We're good at giving information and helping women make informed choices, but making sure they understand what's being discussed, and*

capturing their understanding of that, could be improved.' They were also keen to formalise their SDM practice.

The decision for women who have already had one caesarean about how to deliver their subsequent pregnancy was felt to be one that lends itself to SDM – there is a genuine choice of two options, both of which have risks and benefits, with neither being necessarily 'better'.

Some members of the team also had previous experience and knowledge of SDM in other settings. Although they were aware of its potential benefits to patients and how it had improved practice in other settings, they were keen to gather evidence about how it could improve practice in their own setting. The obstetrics team were fortunate to have some enthusiastic clinicians and midwives to promote SDM.

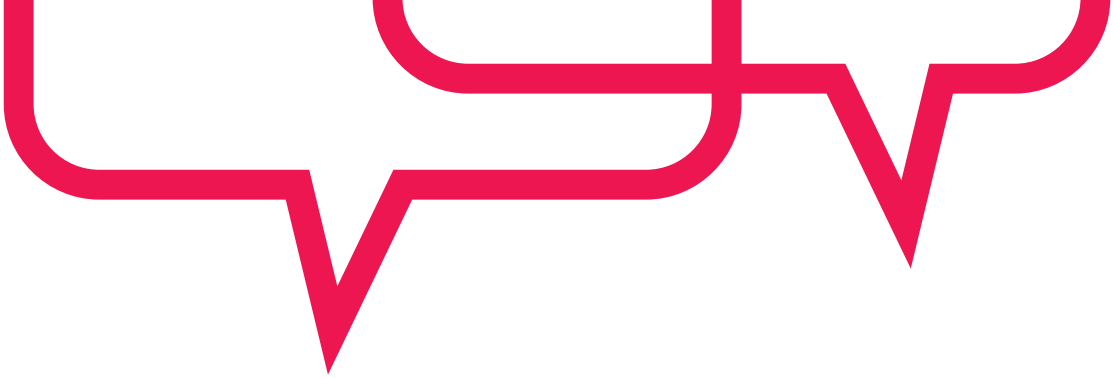
What did they do?

They developed and piloted an SDM information pack

The pack included a leaflet outlining the risks and benefits of each option, stories from other women about what they chose to do and how they decided, where to get more information (eg, useful websites), and a decision support tool (the Ottawa decision guide, adapted by the team). The decision guide is an established tool that helps patients assess their needs, plan the next steps, and track their progress.

They also made some changes to specific points in the care pathway:

- Administrative staff are responsible for identifying women who have had a previous caesarean and sending the SDM information pack to them at 18 weeks.

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- A midwife-led appointment is held in the ‘previous caesarean clinic’ at 20 weeks. Women are asked to review their decision tool (included in the pack) and bring it with them to aid the discussion.

All women attending the clinic were to receive and complete a generic SDM questionnaire (although this was subsequently dropped).

What improvements did they see?

Better decision making

Feedback from women who used the SDM information pack was very positive, indicating that they were more confident about having made the right decision. Most of those attending the clinic (91%) had read the information before their consultation and 81% had used the decision guide, completing it even if they had already made their choice. They felt better informed, asked constructive questions and were able to justify their choices. This evidence was helpful to the team in encouraging other colleagues to engage in the MAGIC programme and SDM.

Clinicians commented that patients who read the information pack before their appointment were much more engaged: *‘They have explored the issues fully and are taking responsibility for their decisions – leading to, I believe, better quality decisions.’* Lead consultants reported that where women had had the chance to prepare for the consultation in this way, it tended to be shorter and more focused. Some even felt that prior to piloting the information pack, they had ‘bombarded’ women with information in the consultation. As one obstetrician said: *‘It’s hard to see why we didn’t do that [send information prior to appointment] in the first place; it seems such an obvious thing to do. You must think about the patient experience...’*

Better everyday practice

Despite the extra time needed to develop and practise using new skills, consultants and midwives commented on improvements in the team’s everyday interactions with patients as a result of their involvement in MAGIC. As one obstetrician said: *‘In the early stages it takes longer... But you soon become aware of what phrases are helpful and more neutral, and you soon get the handle of talking in a more unbiased fashion.’*

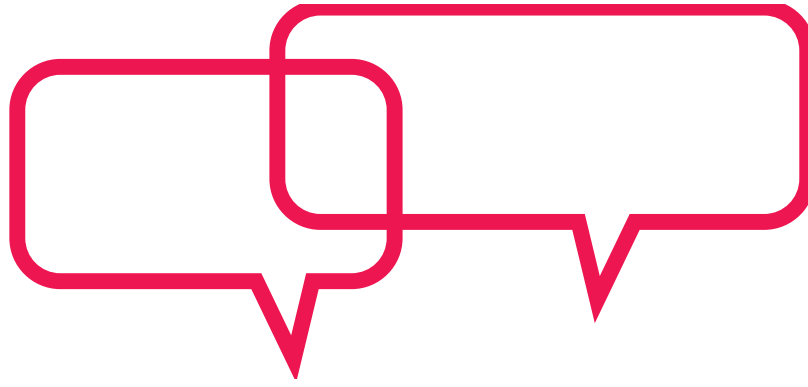
Getting more staff engaged in SDM

Promoting SDM has helped raise awareness more broadly among clinical colleagues and is inspiring other initiatives within the team. SDM is being considered for decisions on prenatal screening, the management of breech presentation, and choice of place of birth (for low-risk women). As the benefits of SDM are becoming evident, the team have observed an increase in the number of engaged people within the directorate, which is helping move the agenda forward.

What challenges did they encounter?

Engaging clinicians and changing work culture and practices

The team often came up against a ‘we’re already doing it’ attitude, because obstetrics is a field where informed choice is part of the culture. So it was difficult to engage some colleagues, as they couldn’t see how their existing practice could be improved. But others acknowledged there was always room for improvement, with one midwife commenting: *‘If I can say that I’ve done it for ages but could do it better – then I think everyone can.’*



Some clinicians (and administrative staff too) were concerned that implementing SDM would add to their already heavy workload. Using ‘hard’ and ‘soft’ data about how SDM can improve practice is one of the most effective ways of persuading sceptical or reluctant colleagues. As one midwife said: *‘Clinicians need to see the evidence base more clearly, they need clarity about their gap in practice... They can then focus on filling that gap.’* But this can lead to other challenges. For instance, they found it difficult to decide which data to collect to demonstrate improvements in their SDM practice – particularly as there were no baseline data to enable ‘before and after’ comparisons.

To deal with this problem, the team used patient feedback to persuade colleagues about the value of SDM. At first, they used the general SDM patient questionnaire developed by MAGIC and used at a number of the participating sites. But after some time, they felt the results were telling them little beyond a general degree of patient satisfaction. To get more useful data on the patient experience, one of the midwives set up her own informal system. She kept a database of all the women she saw and the decisions they made, including whether they had read the information leaflet, and whether they used the decision guide. She then followed up to track each patient’s outcome (a vaginal birth or another caesarean).

Another challenge was encouraging staff (particularly those who were already ‘doing’ SDM) to find time in their busy schedules to attend the MAGIC skills development workshops. Staff who did attend the workshops found them very helpful, as it gave them a chance to practise SDM skills and techniques (and learn by seeing others practise them). At the workshops, participants also got instant feedback on their technique, helping them to identify areas they needed to improve.

To encourage staff to attend the workshops as a team, MAGIC workshops and skills development sessions were scheduled at convenient times and locations. The clinical lead also revised the content of the introductory workshop to make it shorter and to encourage staff to attend the subsequent advanced skills workshop.

Negotiating colleagues’ time

The team envisaged that reception staff in the antenatal clinic would send out the SDM information pack with the routine 20-week appointment letters. But they knew this would add to the reception staff’s workload quite considerably – something that would most likely be resisted. The team used a plan-do-study-act (PDSA) cycle to help them deal with this problem and understand how to secure buy-in to SDM from the reception staff.

The lead midwife also approached the head receptionist to discuss how reception staff could be involved. She spoke to all receptionists at a short informal meeting, explaining what MAGIC was and how they wanted to use it to help women at the clinic. Nine of the clinic’s receptionists attended this talk, and had a positive response to the idea of SDM. But they were concerned about the time needed to scan all pending appointments to identify women with only one previous caesarean section. For this reason, they were reluctant to take on this task. Eventually, a trial period was agreed, whereby one receptionist would help the SDM team to understand exactly how much work is involved in identifying which patients need to receive the information pack with their 20-week appointment letter. An alternative was to include the SDM pack in the information midwives give to pregnant women at their booking-in appointment.



Incorporating SDM into training and professional development

The large number of trainee doctors involved in the team's work presented another challenge. One obstetrician noted that he could typically be working with up to 20 trainees, most if not all of them unlikely to have had formal SDM training, or to have seen it practised by other teams: *'It's getting them to understand the principle of it... a lot of colleagues go in and convince a woman to have a vaginal birth. I need to get them away from that, but it's how they've been trained. Trainees also have to work with clinicians that aren't on board with SDM. If only a few [clinicians] are, then the trainees are less likely to go with them, and more likely to go with the majority not practising SDM.'*

The obstetrics team stressed that the only way of getting trainee doctors fully engaged and to attend the SDM training is to include it as part of their continued professional development so that it *'ticks a box in their portfolio of training'*.

Changing traditional views about providing care to patients

The team were aware that implementing SDM involves clinicians (and patients) being prepared to move away from the traditional 'paternalistic' way of providing care to patients. Many staff admitted that they struggled with this. One midwife described how she approached this:

'In the VBAC clinic you have to try hard to put personal thoughts to one side and focus on the women... It does test you, you have to reflect... about the types of terms you use. You can be quite influential without realising, and they see you as the expert... When they leave the room, on a personal level, I sometimes feel disappointed. However, they feel empowered, and that's the most important thing.'

What advice would they give others?

Data on how SDM can improve practice can help convince sceptical colleagues

Collecting 'before and after' data on antenatal consultations could have showed efficiencies and improved decisions, which would have been useful to encourage buy-in from other colleagues.

Start small and simple

Start SDM with a small patient group and broaden it out when you are more confident in what you are doing. Even small changes can be important in delivering SDM, so don't be too ambitious. Sometimes getting everyone to make a small change is better than getting a few people to make a big change.

Senior buy-in is helpful

Having a 'champion' at senior level (in the team and the wider organisation) can help prioritise SDM. As one of the team's obstetricians said: *'Once you use the big names, the well-respected consultants, people sit up and listen. That's needed.'*

There needs to be a critical mass to move forward

There has to be a critical mass to drive SDM forward, from administrative staff right through to management and trust-level consultants.

Involve staff in developing SDM tools

Staff find it easier to engage with SDM if they are involved early on in developing SDM tools to be used by the team.

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Cardiff and Vale Breast Centre, *University Hospital, Llandough*

Cardiff and Vale's one-stop breast clinic at University Hospital, Llandough – the only centre of its kind in south-east Wales – opened in October 2010. Patients (men and women) who discover a lump in their breast can go to the clinic and have a mammogram and ultrasound on the same day as their initial appointment. The team – five surgeons, two consultant radiologists, one consultant nurse, five breast care nurses and a frequently changing group of junior doctors – have always tried to involve patients in treatment decisions, but felt they weren't always going about it consistently.

With support from the MAGIC programme, they tested a decision quality measure (DQM) for those patients who had to choose between having a mastectomy or a lumpectomy with radiotherapy. They also developed an option grid, using simple language to describe the key features, risks and benefits of different treatment choices so that patients can compare them more easily and reach the right decision. This represented quite a change, as one consultant surgeon said: *'The patients can now actually see... the differences in the choices they have... on a piece of paper. Previously they had to imagine them.'*

Why did they get involved in the programme?

The team were keen to build on their previous involvement in a project called BresDex, an interactive, online decision making tool created in 2009 to help patients recently diagnosed with breast cancer to choose between breast conservation surgery or mastectomy. Involvement in the BresDex project meant that many team members were already experienced in implementing shared decision making (SDM) in their day-to-day work. They also felt that SDM 'fitted well' with the care pathway in their clinical setting,

as patients were generally keen for shared decision making to happen where more than one treatment option was available to them. As one consultant surgeon said: *'It's emotive, it affects so many women, and backgrounds. People aren't ill initially, so they are able and willing to make decisions.'*

Some clinicians wanted to participate because they thought the data collected through the MAGIC programme and SDM would prove that the team's higher than average mastectomy rate (which they felt pressure from some quarters to bring down) reflected genuine patient choice rather than clinicians' preferences. Also, some of the nurses in the team were keen to find out the value of home visits to patients, which at that time were under threat due to funding cuts.

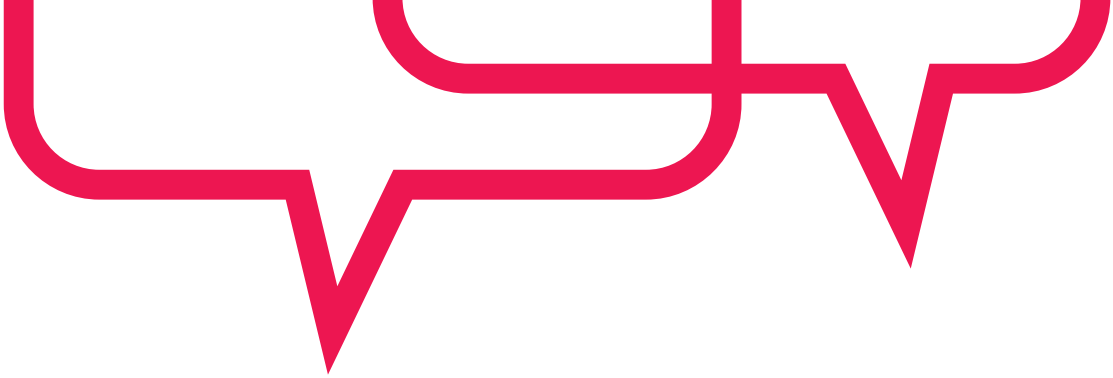
What did they do?

They adapted and tested a decision quality measure (DQM)

With support from the MAGIC programme, the breast care team adapted and tested a decision quality measure (DQM) originally developed for patients with hip and knee osteoarthritis. Clinicians use the DQM tool to assess:

- a patient's knowledge about the key features of two of the available options (mastectomy or lumpectomy with radiotherapy)
- their preferences (what is important to them)
- their readiness to decide
- their preferred choice of treatment.

At Cardiff, the team adapted the DQM to make sure that it was relevant to their local clinical setting. Patients were asked to complete the



DQM twice: first, at the end of their diagnostic consultation (DQM1); and then again, at the end of a home visit by the nurse (DQM2, which patients fill and return by post).

Piloting the DQM was useful, as it gave the team a chance to get feedback about patient satisfaction and reported outcomes. It also allayed some nurses' fears that handing the DQM1 form to patients to fill in at the end of their first consultation might cause upset and distress: *'Initially we were anxious and uncertain about asking the patients to complete the questionnaire just after their diagnosis of breast cancer. But we took a leap of faith; we phrased it in a positive way, "Do you mind filling this in, it will help us when we come and see you later", rather than "We're doing a questionnaire and study". As a result, the patients feel that they know why it's being done and they've responded very positively in the main.'*

The pilot data showed that patients had better knowledge and were more ready to decide on treatment options, and had increased confidence in their choice across the two points in time (between DQM1 and DQM2). The pilot data also highlighted the benefits to patients of home visits, in that having this dedicated time talking to a nurse in their home environment helped patients to better understand their treatment choices. Overall, the pilot data helped to maintain the team's motivation and interest in the MAGIC programme, and in SDM more widely.

Another reason why the pilot was helpful was that it showed up some areas that still needed further improvement. For instance, where the data showed that patients' knowledge seemed to be low, or there was poor alignment between their preferences and actual choices, the nurses wanted to find out whether this was because patients didn't fully understand the information they were given, or whether they didn't

understand the questions in the DQM. The team used cognitive debriefing to test whether patients understood the DQM questions, and changes were made where appropriate.

They developed an option grid

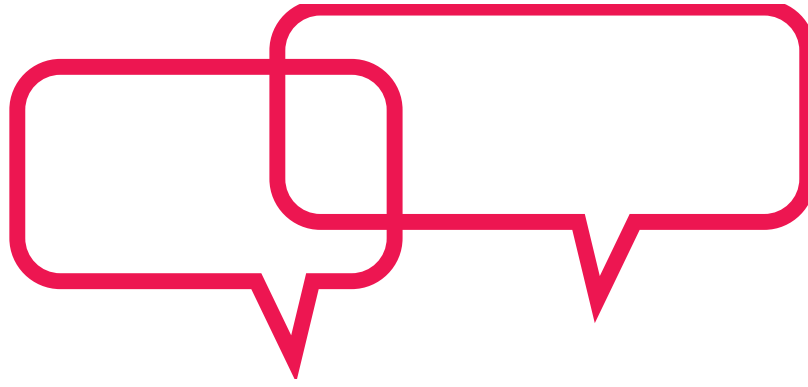
The option grid helped patients to see their treatment options – including the key features, risks and benefits of each choice – set out clearly in front of them. The grid has frequently asked questions (FAQs) and answers, and its wording is regularly reviewed and updated according to the best available scientific evidence.

The grid used by the breast care team developed out of the work they had done during the BresDex project. This online tool included a table that helped the patient compare treatment options, which had proved to be the most popular page on the website. So the team decided to use the table as a standalone tool, although they did make a few changes to it, partly based on feedback from direct observations during consultations with patients.

What improvements did they see?

Changes in practice

Nurses said that the option grids had led to more informed conversations and improved patient knowledge about their treatment options, while the DQM provided a 'real-time' tool to improve patient care, as well as generating useful data. As one nurse said: *'When patients fill out the [DQM] questionnaire in clinic, immediately after they've been given the diagnosis, it helps us to understand what they've taken on board... so that when we go and see them at home we've got some baseline on what they've understood and what we need to go over in a lot more detail.'*



When some of the data revealed low levels of patient knowledge and poor alignment between patients' preferences and choice of treatment, the nurses picked up on this and began to change the way they presented information to patients: *'We would never have measured how well information is understood before and it's useful for us to know that kind of thing, a lot of assumptions are made otherwise. We now know that the patients have made decisions based on proper knowledge...'*

Better communication with patients

As one breast care nurse said: *'The questionnaire is a very useful tool... It emphasises what the patient's views are, and helps us to focus our consultation time – that's the strongest benefit.'* Being involved in the programme has also encouraged clinicians to reflect on their own practice. One consultant surgeon commented that: *'MAGIC helps you to think about your practice, it's helped me to think about how I can get the message across to the patients better.'*

Patients also welcomed the DQM questionnaire: *'Using the questionnaire was good. At the beginning I definitely wasn't taking it all in. But then, you know you don't have to make decisions on the spot, and it helped clarify everything. And you know that when you do actually have to make decisions, you will understand things a lot more.'*

A more formalised approach

The breast care team had already been practising SDM to some extent. But doctors and nurses alike felt that being involved in the MAGIC programme and using the SDM tools had helped them deliver patient care in a better, more structured way. As one of the nurses said: *'We're doing it now in a more formal way; they [the patients] can understand it much better.'* And a consultant

surgeon commented: *'For me, it's made it more structured, rather than having to ask the nurses if I've missed something!'*

Better informed patients

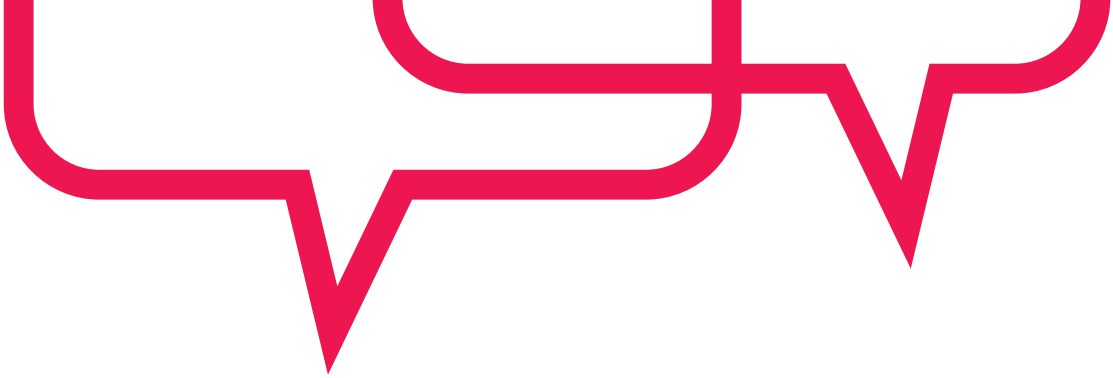
DQM data supported the team's view that they now have better informed patients who are making decisions. The DQM data for one year, from February 2011 to the end of January 2012, showed a gradual and persistent improvement in patients' understanding of the key features, risks and benefits of different treatment options. The team also felt that their efforts had resulted in a better patient experience. According to one consultant surgeon: *'The process of SDM gives patients the permission to ask questions and query things that they might not have done before.'*

And patients were beginning to appreciate the difference made by SDM, as one breast cancer patient commented: *'In the beginning, I was a bit surprised, but deep down I thought that I should be the one making the decision. It was good, I was expecting them to say, "This is what we're going to do", but you actually decide yourself.'*

What challenges did they encounter?

Engaging staff across the team

The MAGIC team found it difficult to engage all members of the breast care team, as some initially felt that the concepts behind SDM were too vague and it offered few tangible benefits. One of the problems was that staff rarely meet together as a whole team, so it was difficult to discuss proposed changes or issues with all staff together. It also meant the team were not able to attend the MAGIC workshops together. The high turnover of registrars was also problematic as, for example, new



registrars were less likely to use SDM – particularly when only a small proportion of patients are given the option of a mastectomy or lumpectomy.

This problem was dealt with partly by having key ‘influencers’ within the team who continued to make the case about why SDM was important. The breast care nurse manager in particular – a longstanding and respected staff member – played a key role in leading the team through the implementation of MAGIC programme activities. Her previous experience with the BresDex project meant she was able to tap into the right people, at the right time.

Allaying concerns

As well as some clinicians initially believing that using SDM would make consultations longer, others felt uncomfortable with presenting options where the clinical outcomes may vary widely. Some were particularly reluctant to offer the option of ‘doing nothing’ where it could compromise a patient’s health and, ultimately, their survival. To allay these fears, the MAGIC team decided to focus on the choice between a mastectomy or lumpectomy with radiotherapy.

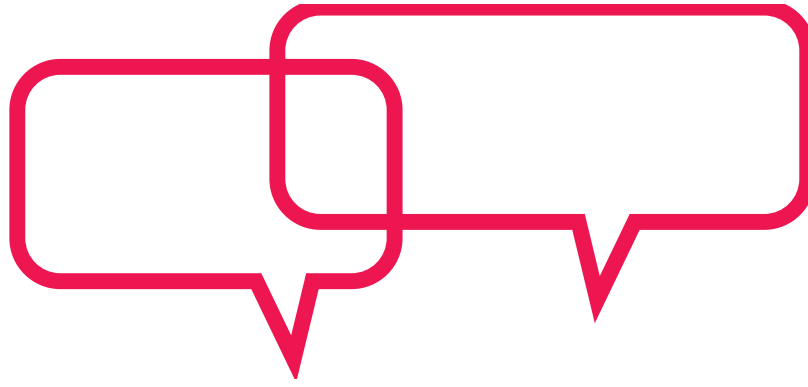
Managing competing priorities

Implementing SDM through the MAGIC programme was just one of a wide range of competing priorities for the breast care team. When the programme started, it coincided with the team moving buildings (to the new centre), which itself created a big upheaval and lots of extra work, so activities under MAGIC were not always a priority. But the enthusiasm of a small core of team members ensured that activities continued through the upheaval.

Using the option grid

The team found it difficult to get clinicians to use the option grid systematically during patient consultations. Some clinicians were not involved in developing the tool and were not satisfied with its content. Some consultants also felt that the grids were too prescriptive. The team agreed that consultants might have used the grid more enthusiastically and systematically if they had been more closely involved in its development. This also meant the grid was not being used consistently across the team (some staff were using it more than others), not helped by the fact that the option grids were not always available in the consulting room.

To address this problem, the nurses included the grid in the standard pack of information they take into the consulting room.



What advice would they give others?

Engage both staff and patients in developing decision support tools or measures early on

Successful SDM requires both patients and clinicians understanding how to use the tools. Involving staff in the development of tools, right from the start, helped to increase their ownership and motivation for using them consistently in shared decision making with patients. Patients should also be involved in giving feedback on SDM and the tools used as early on as possible.

Good communication

The team benefited from being a cohesive unit with good internal communication, which helped iron out any differences that arose during their SDM journey. They also worked closely and effectively with the MAGIC facilitator, who provided the necessary support and expertise along the way.

Secure buy-in

The support of senior managers and board members proved valuable for implementing SDM. A site visit from the medical director was a turning point in engaging clinicians beyond those who already had an interest in it. If the evidence generated by SDM tools is going to be used effectively, the team needs to include (or have good access to) someone with enough influence to change the way things are done – not just within the team but across the wider organisation.

Adapt decision quality measures (DQMs) to your setting

DQMs are not generic measures; they need to be developed for each specific clinical decision. However, DQMs can provide powerful evidence for improvement. The data can measure current SDM practice and help identify areas for improvement.

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