Shared Decision Making
Train the Trainer Online Resource

Home About Modules

http://www.advancingqualityalliance.nhs.uk/SDM/
Welcome!....

....to this Train the Trainer Resource on Shared Decision Making, which is part of a programme commissioned by the Right Care team at the Department of Health as part of the National Shared Decision Making initiative. This resource has been developed by the Shared Decision Making Team based at the Advancing Quality Alliance (AQuA) together with 28 teams from hospital, community and primary care working in the clinical areas of: maternity, musculoskeletal and renal.

This Resource is a result of the learning pulled from the work of these teams. It is intended as a complete ‘off the shelf’ resource for a team/department/practice or organisation to use to help them implement Shared Decision Making and its benefits.

The Resource is composed of a series of modules:

1. Introduction and background to Shared Decision Making
2. A training session for health professionals to understand and practice Shared Decision Making. This module is supported by presentation slides and highlights the use of option grids and decision aids
3. Module 3 looks at organisational support to implement Shared Decision Making, how to set up a project group, identifying roles and engaging staff/patient groups
4. The fourth module covers communication and engagement using a range of materials – films, printed materials, press releases and social media
5. Modules 5 and 6 look at systems and processes – recording, measurement and governance
6. Module 7 covers some frequently asked questions about Shared Decision Making

There are a large number of resources referred to throughout the text which have been developed during the Shared Decision Making Collaborative including examples of work from participating trusts and universities. These can be photocopied and customised to help you develop your local approach to embedding this transformative patient centred approach into your organisation.

David Fillingham,
Chief Executive,
Advancing Quality Alliance.
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Shared Decision Making
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With thanks to:

- 5 Boroughs Partnership NHS Foundation Trust
- Aintree University Hospital NHS Foundation Trust
- Barts Health NHS Trust
- Blackpool Teaching Hospital NHS Foundation Trust
- Bolton NHS Foundation Trust
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- Salford Royal NHS Foundation Trust
- South Manchester CCG
- University Hospitals Birmingham NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust
- West Cheshire Clinical Commissioning Group
- West Midlands Renal Network and Heart of England NHS Foundation Trust
- Wrightington, Wigan and Leigh NHS Foundation Trust
- Yorkshire and the Humber Renal Network

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Shared Decision Making
Train the Trainer Online Resource

Home About Modules

Modules

Module 1 – Introduction and Background
Module 2 – The Training Programme
Module 3 – Organisational Support to Implement Shared Decision Making
Module 4 – Communications and Engagement
Module 5 – Systems and Processes to Support Shared Decision Making
Module 6 – Governance
Module 7 – Frequently Asked Questions

References

http://www.advancingqualityalliance.nhs.uk/SDM/
Module 1

Introduction and Background

1.1 What is Shared Decision Making?

Shared Decision Making (SDM) is a process in which patients are encouraged by their health professional to participate in selecting their appropriate health treatments or care management options. Not being properly informed about their illness and the options for treatment/management is the most common cause of patient dissatisfaction (Coulter and Cleary 2001). Most patients want more information and a greater say in decisions about how they will be treated.

In Shared Decision Making patients are involved as active partners with their health professional in clarifying acceptable clinical options and choosing a preferred course of care (O’Connor et al 2007). Shared Decision Making is appropriate in any situation where there is more than one reasonable course of action and no one option is self-evidently best. This situation is common as there are many ‘preference-sensitive’ decisions about treatment and care. In these cases the patient’s attitude to the likely benefits and risks should be a key factor in the decision.
1.1.1 Shared Decision Making relies on two sources of expertise:

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

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

There is documented evidence that Shared Decision Making increases knowledge, realistic expectations, and participation in decision making. It reduces decisional conflict and indecision post-intervention compared to usual practice. Not only are there benefits for patients – empowering them to make optimal decisions with their health professionals, but there is the potential for significant financial benefits to the NHS. Reducing unnecessary elective procedures can provide a nationally scalable solution at no additional cost to the NHS. Research shows that patients who have used Patient Decision Aids (PDAs) are more likely to opt for conservative options, thus reducing costs without related adverse effects on health outcomes (Auvinen 2004, Whelan 2004).
Module 1 (continued)

1.2 Why do Shared Decision Making?

Increasingly, patients want to be involved in making decisions about their own healthcare, and research has shown that, when they do so, they select less hospital care and report better hospital experiences.

"Using Shared Decision Making has changed my practice, I have always suggested what is best for my patients but now I give them the options and we discuss to come to a decision suited to the patient", Mr Shahid, Consultant Obstetrician, Wrightington, Wigan and Leigh NHS Foundation Trust

Some of the benefits of Shared Decision Making are outlined below:

1.2.1 Increased Patient Involvement and Engagement

Although patients are far more informed than they were even 20-30 years ago, some people express frustration and dissatisfaction with their care because they do not feel that they have adequate (if any) input into the decisions that health professionals are making about their health and their lives. One element of this problem is that patients often do not know enough about their treatment options to make truly informed decisions. In particular, they may not understand the evidence base and risks and benefits underlying the decisions they are being offered.
Angie from Islington said; “I felt really positive about using Ask 3 Questions (see section 4.3). It meant I got more information out of my appointment with my consultant, and I felt more satisfied at the end of the appointment, even though I still had no real answers – it was a more rounded consultation and the dynamic felt very different, but in a good way.”

Another contributing factor is that the NHS is not always as supportive as it might be of patient involvement in the decision-making process. In some cases, health professionals are supportive of the concept but do not know how to make it happen.

“Shared Decision Making has provided some structure to the decision-making process.” Mr Phillip Wykes, Clinical Lead Orthopaedic Surgery, Bolton NHS Foundation Trust

Shared Decision Making operates under the premise that armed with good information, patients can and will participate in the decision-making process by asking informed questions and expressing personal values and opinions about their condition and their treatment options.

While some critics of Shared Decision Making maintain that patients are not able or willing to make their own health care decisions, there is considerable evidence that patients want more information and greater involvement in decision making in partnership with their health professionals (Deber et al 1996, Guadagnoli 1998, Coulter, 2002).
Many health professionals also have concerns about how much time Shared Decision Making takes, however the evidence suggests that using patient decision aids makes little difference to the length of consultations.

“I thought discussing things in depth and giving choices is going to be time consuming but now think this will reduce time in consultations as focussing on what the lady wants to discuss will save time.”

“I was worried re: time/ work load, but the pilot has demonstrated that investing time- saves time as the women talk about what matters to them rather than us lecturing at them about a lot of subjects they aren’t bothered about.” Maternity team, Blackpool Teaching Hospital NHS Foundation Trust

Improved quality of medical consultations has been found to have a positive effect on the quality of treatment decisions, the quality of patient-health professional communication, and the satisfaction of both patients and health professionals. Specifically, research on the impact of this intervention has found:

- Patient participation can increase patient satisfaction and lead to better health outcomes
- Patients who are empowered to make decisions about their health that better reflect their personal preferences often experience more favourable health outcomes such as decreased anxiety, quicker recovery and increased compliance with treatment regimens (Guadagnoli 1998)
- Greater consumer involvement in decision making leads to lower demand for health care resources (Devine and Cook 1983).
Research also suggests that the use of interactive resources can increase the complexity of discussions between health professional and patient. In one study, both patients and health professionals benefited from an increased level of understanding that allowed discussions to focus on the key trade-offs between risks and benefits rather than simply describing treatment alternatives.

“In terms of using with patients: I recently had a discussion with a patient about a very difficult and complicated decision regarding the possible use of a second course of strong immune-suppression for a long term condition. The choice/option/decision structure was very helpful as a way both to approach the consultation and to reflect on the discussion in my letter to the patient afterwards.” Renal Consultant, King’s Health Partners

Once the patient is informed of their various options, the second step is for the health professional to involve the patient in the decision-making process. However, while the right of patients to be informed decision makers is well accepted, it is not always well implemented (Institute of Medicine 2001). Shared Decision Making requires a “modification of the relationship between patient and health professional and recognition of the ability of the patients to participate in making choices that affect their lives” (Deber et al 1996).

Thus, one key to success lies in training health professionals to help them understand how to facilitate the Shared Decision Making process and to ensure that they appreciate the importance of respecting patient’s values, preferences, and expressed needs (Towle et al 1999). It is also helpful to use a team approach to Shared Decision Making so that the health professional’s time is used appropriately.
Module 1 (continued)

“I feel Shared Decision Making is something we think we have always done, but when considering Shared Decision Making probably never have shared choices fully. I think this gives a good template to guide discussions.”

“It has improved working together with the vulnerable team. It has improved discussions with the women who have engaged with the Shared Decision Making Project.”

“The women have been really receptive to it. I feel that they have responded well to being involved in decision making. I feel this is particularly positive with the vulnerable women that we work with.” Midwife, Maternity Team, Blackpool Teaching Hospital NHS Foundation Trust

1.2.2 Improved Communication

As Shared Decision Making enables health professionals to focus on what is important to the patient it often results in better consultations and more appropriate decisions as there is more effective and realistic communication of both the benefits and risks of a procedure/treatment which has been shown to reduce the incidence of potentially unnecessary elective procedures.

“In the past we would often have known the patient’s preferences, circumstances or values because we had worked with them over a long period of time as their GP. Nowadays however, patients do not always see the same clinician because the practices are so large or because there are trainee GPs in the practice, so perhaps we do need to be asking them what their preferences and values are.” General Practitioner, NHS Trafford

http://www.advancingqualityalliance.nhs.uk/SDM/
Both health professionals and patients find it challenging to talk about risk. Shared Decision Making, which incorporates risk communication, plays an important role in enhancing patient safety and communication. Eliciting patient preferences and using decision aids to share knowledge on short and long-term benefits and risks, enables patients and their health professionals to make decisions that have the highest likelihood of achieving desired patient outcomes and more accurate risk perceptions by patients (Ruland 2004, Gigerenzer et al 2008, 2010, Carling et al 2009, Akl et al 2011).

There is also evidence to suggest that it is particularly effective in improving health literacy amongst populations with traditionally low health literacy levels (Kim 2001, Price-Haywood et al 2009) as it is shown to increase the patient’s knowledge, produces more realistic expectations and reduces decisional conflict.

“I love Shared Decision Making. In the past I felt like I was persuading people and if they opted for a home birth I was worried, because if something went wrong you feel responsible that you persuaded them to take that option. Now I feel much more that it is the patient’s choice and I’m happy with that. It’s informed choice.” Diane Davis, Midwife, Central Manchester University Hospitals NHS Foundation Trust

1.2.3 Reduction in Complaints and Litigation

Barry et al (2008) simulated a hypothetical malpractice suit in the USA alleging failure to perform a prostate specific antigen (PSA) test to assess the reaction of potential jurors.
The results were as follows: in the scenario where a decision aid was used, only 3/47 (6%) potential jurors felt the standard of care still had not been met. Again subjectively, based on the discussions, the decision aid appeared to serve several purposes:

- It educated the potential jurors about the real complexity of the PSA decision.
- It documented the content of the information that was provided to the plaintiff.
- Potential jurors felt that doctors who used such tools were going to especially great lengths to ensure patients really understood the issues before making an informed decision plus you can go back and look at it.

This small study strongly suggests that the use of a decision aid in the context of making a shared decision, in this case about PSA testing between clinician and patient provides the highest degree of medico-legal protection.

The study did have a number of limitations.

In summary Barry et al conclude that “in the long run the benefits of Shared Decision Making and the use of evidence-based decision aids far outweigh the costs.” Such a system would provide patients and physicians with:

- Clarity of the information required for disclosure
- Ease with which to retrieve it, update it and supplement it
The resources necessary to inform patients of the relevant options without significantly draining physician resources. Patients would experience more autonomy in their medical decisions and more opportunity to consider their own value systems in their treatment options. Physicians will no longer have to guess regarding their legal liability and they can generally improve the health outcomes of their patients by enabling them to be more invested in the treatment choice.

He finishes by saying that “a change of this kind is long overdue and is necessary to realign the legal and medical conceptions of informed consent so that patients, physicians and courts can attain a mutual understanding of legal informed consent obligations, and so the ethical and legal goals.”

“My personal view is that prevention of Serious Untoward Incidences is multifaceted. Whilst the clinical professionals have a duty of care to ensure clinical guidelines are followed and any intervention is delivered in a safe and caring way, I do feel that by encouraging patients to question the care/treatment they are receiving this may help pick up errors such as wrong site surgery. This could, for example, include where the opposite side is marked up during pre-op the patient may question this knowing where they were due to receive surgery etc.”

Simon Jarvis, Head of Patient Engagement, Heart of England NHS Foundation Trust
1.2.4 Ethical Demand Management

Shared Decision Making is effective in ethically managing demand. “Healthcare may be the only industry in which giving customers what they really want would save money. Well-informed patients consume less medicine – and not just a little less, but much less. When doctors accurately diagnose patient preferences, an enormous source of waste – the delivery of unwanted services – is eliminated.” (Wennberg and Marr 2010).

Through Shared Decision Making, patients make informed choices with the help of their health professional based on the best available evidence about the treatments available and the individual’s condition/circumstances. It therefore reduces the need to introduce policies of rationing or the development of thresholds, often using inappropriate tools to help manage demand within the system. Research has shown that patients who use decision aids are more likely to opt for conservative treatment options (Auvinen 2004, Whelan 2004).

As stated in ‘Patients’ preferences matter; stop the silent misdiagnosis’ (Mulley, Trimble and Elwyn 2012). How can commissioners know the proper amount of resources to provide, when they base their calculations on an existing imperfect system, which in the absence of a better mechanism for assessing what patients would prefer were they fully informed, will always struggle?

“We have to listen to our patients and make them decide for themselves when there is more than one option; this will increase patient satisfaction and adherence to treatment.” Attarbashi Shatha, Consultant Obstetrician and Gynaecologist, Wrightington, Wigan and Leigh NHS Foundation Trust
1.2.5 Enhanced Recovery

Enhanced recovery of patients undergoing surgery is a relatively new concept in the UK. It involves a selected number of evidence-based interventions which, when implemented as a pathway, demonstrate a greater positive impact on outcomes than when implemented as individual interventions. Enhanced recovery ensures that the patient plays a vital role as a partner in their own care. It has been applied in colorectal, gynaecology, urology and musculoskeletal surgical specialties, but there is scope for other surgical areas.

The principle is to enable patients to minimise body stress responses during surgery which improves post operative recovery and reduces length of stay. Shared Decision Making can be an integral component of enhanced recovery pathways. At the patient level a patient that has been involved and empowered to make decisions about their treatment pre-operatively will be in the best position to involve themselves, and their necessary support, in their care pathway with clear expectations of their treatment and outcomes.

“A challenge faced by practitioners can be that they can see more potential for recovery than the patient wishes to achieve. Often a patient would not go home unless they could mobilise the “length of the ward”. However, at home the patient only wanted, and needed, to be able to walk a few yards from living room to kitchen! Shared Decision Making will put the patient in the driving seat and practitioners will learn to understand that ‘relevant’ is more important than ‘possible’.” Norah Flood, Professional Lead for Allied Health Professionals, 5 Boroughs Partnership NHS Foundation Trust
1.2.6 Unwarranted Variation

“Patients traditionally delegate decision making about treatments to their physicians, under the assumption that physicians prescribe treatments based not only on medical science but also on an understanding of what is best for the individual patient. Embedded in the idea that the physician knows what is best for the patient is the notion that the physician also knows what the patient wants” (Wennberg 2010). Shared Decision Making helps address this issue.

In the latter part of the twentieth century, dozens of common treatments, including tonsillectomy, hysterectomy, radical mastectomy for early stage breast cancer, arthroscopic knee surgery for arthritis and hormone replacement therapy for menopause have been shown to be unnecessary, ineffective and sometimes more dangerous than the diseases they were intended to treat (Brownlee 2008).

In 2010, the QIPP Right Care programme at the Department of Health also published an Atlas of Variation, showing that similar behaviours and practices were also evident across England.

Equality and Excellence: Liberating the NHS (DH 2010) states “there is a commitment to providing better value from the resources available to healthcare. This requires the NHS to address variations in activity and spend. Such variations indicate the need to focus on appropriateness of care, and to investigate the possibilities that there is overuse of some interventions and that some lower value activities are undertaken.”
The aim in publishing the Atlas is to stimulate, within all levels of the NHS, a search for unwarranted variation, defined as “variation in the utilisation of health care services that cannot be explained by variation in patient or patient preferences” [http://www.rightcare.nhs.uk/atlas/](http://www.rightcare.nhs.uk/atlas/).
“Looking at variation in rates of surgical procedures among geographical regions provides a highly aggregated snapshot of comparative performance. These variations have their origins in the microcosm of the doctor-patient relationship, in the one-on-one exchange between an individual physician and a patient that results in the choice of treatment. When patients delegate decision making, as most now do, physicians are for the most part free to choose their own favourite treatments, so long as the treatment selected falls within the domain of “clinically appropriate” The medical opinions of referring physicians and surgeons who specialize in a specific procedure thus combine to determine the rate for any particular procedure” (Wennberg 2010).

Wennberg argues that these variations in preference sensitive care, (i.e. care or interventions where there is more than one choice, where the outcomes may differ according to the option chosen) and where patients often delegate the decision making to doctors “can result in a serious, but commonly overlooked medical error: operating on the wrong patients – on those who, were they fully informed, would not have wanted the operation that they received.”

“It’s about clinicians “letting go” and allowing patients to make a different choice to the one they may have made.” Chris Goldsmith, Renal Consultant Aintree University Hospital NHS Foundation Trust
1.2.7 National Policy Drivers

There is a range of national policy drivers supporting the implementation and use of Shared Decision Making:

- NHS Constitution (DH 2012) – patients have the right to make choices regarding their healthcare
- Equity and Excellence: Liberating the NHS (DH 2010) – “no decision about me without me” – part of a wider personalisation agenda
- More with the same, not more of the same – (Appleby et al 2010)
- NHS Operating Framework (DH 2011) – Domain 4 – A positive experience
- NICE Clinical Guidelines 138 Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services
- NICE Quality Standard 15 – linked to above guideline – “Patients are actively involved in shared decision making and supported by health care professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them” (QS 15 statement 6). “Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported” (QS 15 statement 7) www.NICE.org.uk, issued Feb 12

Chris Ham, in his foreword to ‘Patients’ preferences matter: stop the silent misdiagnosis’ (Mulley, Trimble and Elwyn 2012), articulates why ‘no decision about me without me’ is much more than a sound bite or political slogan, stating that only by understanding patient preferences and incorporating them into treatment decisions will it be possible to reduce unwarranted variation and deliver appropriate care.
Module 1 (continued)

“When I had my first child, there were a few complications and I ended up having to have a forceps delivery. At the time I didn’t know what was happening to me and I just felt like I was being talked to. This time, again there were difficulties and I once again found myself in a situation where I was having to have a forceps delivery, however this time the Doctor fully explained to me what was happening and explained the different options to me. This meant that me and my partner were able to make a decision and we felt fully informed about what was happening to me and our baby.” Maternity Patient, Liverpool Women’s NHS Foundation Trust
Module 2

The Training Programme

2.1 How to use this Tool

This module provides guidance on how to actually ‘do’ Shared Decision Making, linking closely to the set of training slides (Shared Decision Making Training Presentation). In addition there are also resources to support health professionals with implementation. There are films to illustrate examples of good and bad consultations with prompts in this pack. The information to support the first 1-21 slides within the programme is outlined within Module 1.

2.2 Introduction and Overview (Shared Decision Making Training slides 1-19)

This introductory section includes welcome, group expectations and the rationale for implementing Shared Decision Making Training. It includes an explanation of the National Shared Decision Making Collaborative, variation in treatment and the benefits of using Shared Decision Making. Each slide has brief accompanying notes to provide further detail and explanation.

2.3 Making a Good Decision (slides 20-25)

Shared Decision Making is not just about ensuring the patient is involved with the process it is also about making sure the decision reached is a good decision.
A good decision is one that is approached systematically, that is based on reliable, evidence-based information and where time is allowed to consider all the options carefully. It is important to remember that whether a decision is good or bad is independent from whether the outcome is positive or not. The example chosen is used to help get people to think about making good decisions.

2.3 When to use Shared Decision Making (slides 25-26)

Shared Decision Making is about
• Providing patients with all the information they need about their options
• Eliciting all the information they are able to offer about their preferences and values and then
• Using this information to make a decision about the right treatment together.

It is important to remember that clinical risk will always take priority and not all situations are suitable for Shared Decision Making. The situation may not be suitable for Shared Decision Making if a patient presents in an emergency condition and/or decisions that are clinically required need to be made urgently. Whilst the health professional will clearly discuss options with the patient and gain consent/agreement for treatment within this scenario, there may be a time/clinical pressure which may dictate that the full Shared Decision Making process cannot be carried out.

Within these boundaries Shared Decision Making is appropriate in any case where:-
• There is more than one reasonable course of action
Shared Decision Making
Train the Trainer Online Resource

Module 2 (continued)

Many health and healthcare decisions are “preference sensitive” and in the majority of situations there is time to undertake Shared Decision Making with a patient.

Teams who work with patients with long term conditions may find that there are few discrete decision making opportunities because every consultation is a continuation of ongoing discussions regarding treatment options. However, you can still use the principles of Shared Decision Making and patient involvement to ensure you are not being paternalistic but having a shared discussion with your patient.

2.4 Key Components of a Shared Decision Making Discussion (Slide 27)

In order to ensure you are practicing Shared Decision Making you need the following three key elements:

- Evidence on Options

• The decision is said to be “preference sensitive” – this is where there is uncertain or unclear evidence supporting one testing/screening or treatment option over another
• Options have different inherent risks/benefits
• Where patient values are important in optimising the decision.
Reliable, balanced, evidence-based information outlining treatment options, outcomes and uncertainties. This may be in the form of patient information leaflets or guides, or accredited websites. The tools section below (2.5) details some resources that help you provide this evidence for your patients.

- **Support to Help the Patient to Make a Decision**
  
  Decision support counselling with a clinician or health coach to clarify options and preferences. You will find more information on patient engagement resources and motivational interviewing skills in section 2.6 below.

- **How to Record a Decision has Taken Place**
  
  Some thought needs to be given to a system for recording, communicating and implementing the patient’s preferences. There is detail on how you could achieve this provided in section 5.3.

**2.5  Tools to Help You Provide Information or Options (Slides 28-33)**

You do not need physical tools to achieve Shared Decision Making as it is about a dialogue between a patient and their health professional, but often it is useful to direct patients to physical resources to help them.
2.5.1 Patient Decision Aids (PDAs) (slides 29-31)

Patient Decision Aids (PDAs) are designed to help patients make difficult decisions about their treatments and medical tests. They are used when there is no clinical evidence to suggest that one treatment is better than another and patients need help in deciding which option will be best for them. Research shows that PDAs are really effective in helping patients make informed choices about their healthcare and increase patients’ awareness of the expected risks, benefits and likely outcomes.

For a list of decision aids written by the BMJ group in conjunction with Totally Health see: [http://sdm.rightcare.nhs.uk/pda](http://sdm.rightcare.nhs.uk/pda)

There are always new decision aids in development so it may be that there is not yet one available for the condition your patient wants to make a decision about. This should not stop you from practising Shared Decision Making with your patients however; it just means you will need to provide the balanced, unbiased evidence on each of the options yourself.

2.5.2 Long Form Patient Decision Aids (PDAs)

These are designed for the patient to use on their own, or with family. They can potentially take some time to complete – up to a possible two hours – so are best used by the patient/their family after their initial discussion regarding ‘Choice’ with their health professional.
A long form PDA goes through the background to each condition, the disease process, NICE (National Institute for Health and Clinical Excellence) guidance relating to any treatment options recommended, and any information relating to each risk. This risk message may take the form of likelihood for each treatment outcome relating to a ratio e.g. 1:100, or as a percentage e.g. 10%.

There then follows a section on personal preference which may ask questions relating to the patient’s perceptions of acceptable risk and their core values which may guide their option choices. Finally the patient is invited to save or print out their choices/options for use as a discussion aid with their clinician and/or their family.

Producing a long form decision aid can be a labour intensive task and requires the involvement of both expert clinicians and patients to produce something valid and robust enough for multiple cohorts of patients.

An international group of researchers has been set up to assess the quality and validity of Patient Decision Aids to ensure that they are accurate and present unbiased information. If you’d like more information on this please visit International Patient Decision Aid Standards (IPDAS) Collaboration, http://ipdas.ohri.ca/. NICE are also developing an accreditation system for the NHS.
2.5.3 Decision Grids (slides 32-33)

Decision grids, or short form PDAs, are designed to be used in consultation between the clinician and the patient. They can be used to highlight the treatment options, the risks/benefits of each, allowing the patient to identify what is important to them. These shorter forms can act as an aide memoire to both clinician and patient, whilst unsuitable options can be crossed out, leaving clear options for the patient to decide upon with the help of their clinician.

Patients can take the form home to reflect on the decision, review the information again and possibly use it as the basis of a discussion with their family. This can be particularly useful if the choice made has some impact in relation to family life, or if recalling the complex information about the procedure and the risks/benefits are difficult post-consultation. The option grid can also help the patient to form questions and queries for future consultations with their clinician or care-giver.
There is an example of an option grid below but to see others please view the website: www.optiongrid.co.uk
“We also found that putting a definite structure on our engagement with the women helped to reduce the amount of writing we were doing in consultations. The decision grid has focussed the information shared, and the new documentation has reduced the writing we were doing to record the conversations we had with our women.”
Maternity team, Pennine Acute Hospitals NHS Trust

2.6 Tools to help you Provide Decision Support (Slides 34-38)

2.6.1 Patient Engagement Tools (Slide 37)

Shared Decision Making is all about involving both health professionals and patients together in healthcare choices. It is therefore not just the health professional’s responsibility to elicit information from patients but also the patient’s responsibility to ensure they are providing information and asking about their options. There are resources available in the Communications and Engagement Module 4 that will help you raise awareness with patients so they do get involved.

“Doing SDM with women was a bit of an eye-opener to me, a lot of the women were far more concerned with risks we don’t normally discuss that much in VBAC i.e. laceration of the baby’s head during c-section. I was surprised at some of the reasons why they had decided to try for a normal vaginal birth next time. Having the decision grid made me go through these other options, risks and benefits with the women.”
Maternity team, Pennine Acute Hospitals NHS Trust.
2.6.2 Motivational Interviewing (Slides 36-38)

In order to help you work through the process of Shared Decision Making with a patient, you may find it useful to learn some elements of the Motivational Interviewing approach to health change behaviour / decision making. Even professionals who whole heartedly subscribe to the ethos of Shared Decision Making report that it can often be difficult to put into practice in busy clinical settings or complex situations.

Motivational Interviewing is a semi directive, client centred counselling style that is often used in health settings to help motivate patients to make behavioural and lifestyle changes. Central to both Motivational Interviewing and Shared Decision Making are the following:

- Collaboration between patient and health professional
- Communication occurs in a partner like relationship
- Both seek to create a positive atmosphere where the drawing out of motivation (or decisional thought processes) occurs
- Responsibility for change (decision) lies with the patient
- Change or decision making should arise from within the patient rather than being externally imposed
- Both honour patient autonomy (Dean 2012).
Shared Decision Making
Train the Trainer Online Resource

Module 2 (continued)

DiClemente and Prochaska (1998)
Motivational Interviewing offers the professional a defined set of principles and skills that can help them to communicate with their patients in a manner that is consistent with the philosophy of Shared Decision Making. In essence Motivational Interviewing offers professionals guidance on how to conduct consultations in such a way that they promote and encourage Shared Decision Making.

Key features of the Motivational Interviewing approach include:
- Seeking to understand a person’s frame of reference through reflective listening
- Expressing acceptance
- Recognising the patient’s degree of readiness to change
- Eliciting and reinforcing the patient’s own self motivational statements and affirming the patients freedom of choice and self direction (Dean 2012).

There are several organisations that provide training in Motivational Interviewing which could give you the start you need to begin incorporating the technique into your everyday practice.

2.7 A Shared Decision Making Consultation (Slides 39-46)

Many health professionals already use Shared Decision Making skills to some extent in their consultations. This section is for those who want to refine their skills further or are looking for guidance in how to involve patients in a shared decision. There are films available to illustrate good and bad consultations and highlight the different elements of Shared Decision Making in section 4.8.
Firstly, a few key pointers about how you can conduct a consultation using Shared Decision Making:

- Identify the treatment options in your own mind
- Share your ideas out loud about the options
- Ask the patient what is important to them (their values) – identify their primary drivers e.g. mobility, comfort, pain free, speed of recovery, accessibility to treatment, family/activities/daily tasks and life responsibilities etc.
- Discuss the pros and cons of each option (ideally with explicitly stated likelihoods)
- Be honest in situations where there’s no clear best treatment from your professional viewpoint
- Answer any questions the patient has
- Discuss what the patient’s preferred option is
- State what you see as the decision that has been made and check that the patient agrees.

For more detail, the ‘Choice, Option, Decision (COD)’ structure might be useful:
Module 2 (continued)

"COD"

Choice Talk + Options Talk = Decision Talk

Deliberation

Prior Preferences → Informed Preferences

Decision Support
Short, During Long, External

Good Decision

Adapted from the Model For Shared Decision Making by Elwyn et al and MAGIC Programme (2012).
“One of the really good things that is coming out of this work for us is that all the nurses are finding it is changing the way they work generally. I think you can find that you are just repeating the same ‘patter’ that you say to every patient and it is good to have to make changes to this. I can tell in my home visits that I am consciously changing the way I talk to my patients to avoid that usual patter.” Specialist Kidney Nurse, Salford Royal NHS Foundation Trust

The following sections provide detail of what the Choice, Option, Decision elements are as well as giving some example phrases you could use at each point. Adapted from the work by Elwyn et al and MAGIC Programme 2012.

2.7.1 Choice Talk

1. Establish Diagnosis or Explanation
2. Step Back. Check there is agreement on nature of the problem.

These first two steps should not be any different to what you already do in each consultation with patients; explain the situation and ensure that this has been understood. This is a useful opportunity to check that you have understood the problem too – it may be that the accuracy of your diagnosis is dependent on certain pieces of information that the patient can provide or confirm for you.

“Now that we have agreed on the problem, let’s step back and talk about what to do next.”
3. Explain that Choice Exists. Be explicit – many patients expect to be told what to do.

Consider your usual consultation style – how often do you explicitly state what the different options for the next steps are and how often do you just say “here’s what we are going to do”? Being aware that you should tell patients there are options available will be a good prompt to the next step of actually discussing what those options are.

“There is more than one way to deal with this problem.”

“There is information about these two options that I’d like to share with you.”

“There are a number of options and a fair bit of evidence about pros and cons of each option – I would like to share that with you before we make a decision.”

“Were you aware that there were different options?”

4. Justify Choice

You may find it useful to explain why there are different options.

“Treatments are very different and have different consequences and some of these things will be more important to you than others.” (Preferences)
‘Treatments are not always effective; chance always plays a role ... “ (Uncertainty)

“For us to make the right decision we need to also understand what really matters to you in this choice.”

5. Check Reaction

How does your patient feel about being involved with this decision? Do you think they understand their role in this partnership? You may need to use some motivational interviewing techniques during this ‘choice talk’ to help patients who just want to follow doctor’s orders to find their own motivation for being involved.

“Is this helpful to you? Shall I explain to you about the options?”

“Were you aware there were different options?”

6. Defer Closure

You don’t end the conversation here. In this step you make a conscious and explicit step into the option talk – “you have a choice and now I would like to talk to you about what your options are.”
Module 2 (continued)

“I am happy to share my views with you, but is it OK if I describe the options to you in more detail so that you understand what is at stake? Then we can come back to what might be best to do, and ask you what might matter most to you.”

2.7.2 Option Talk

1. Check Knowledge

What does your patient already know? You don’t want to be patronising to patients who are already experts in their own health, but you also want to make sure the knowledge they have is reliable and accurate. Ask them what they already understand about the situation and be prepared to challenge them gently if you feel they have ill-founded opinions.

“What do you know about the treatment options for X?”

“Have you been searching for or found information on this yourself?”
Module 2 (continued)

2. **List Options**

   For some conditions there are decision support tools available to help you go through the options with each patient. You do not need a decision support tool to share the decision-making process with your patients though. You do need to be aware of your own preferences and ensure that you are providing information on all options, not just those that you feel would be best. If you are using a tool, you may need to highlight which options are clinically appropriate for each patient and indicate (with explanation) those that are not suitable.

   > “There are x things to do in this situation, let me list them quickly before we go into them in detail.”

3. **Describe Options**

   Remember that whilst some patients, particularly those with long term conditions, may have an expert knowledge of their condition or the different options available to them, some will require more explanation. Make sure your patients understand what each of the options is.

   E.g. if options are similar: “*Both options are very similar and involve taking medication on a regular basis.*”

   E.g. if options are different: “*These two options are different and will have different impact on you and your family, let me explain what they involve.*”
4. Risks and Benefits

You may well be familiar with discussing the risks of different treatments with patients in order to ensure you obtain informed consent, and you will have experience in making sure you deliver this information in a way that is meaningful for the patient.

In Shared Decision Making, you need to make sure you are discussing the pros and cons of each option both in terms of clinical risk but also in terms of potential outcomes and how they map on to patients individual preferences. You will need to actively involve patients in this step to be sure they elucidate what their values are, their attitude to risk and what is important to them.

“I am going to describe the most relevant harms and benefits of each option to you, but I’m also [writing them down/giving you more information to take away] ... “

5. Check

Has the patient got a thorough understanding of all the options open to them? Have you got a thorough understanding of the patient’s views?

“Let me just check that I have explained this well enough – can you tell me what you have picked up from what I’ve told you?”
6. Decision Support

You can use the decision aid tools at this stage, if they are available, to recap the information that has been discussed. Or you could write down each of the options and list the pros and cons of each, as appropriate to that individual patient. It is important in this step to reiterate you are providing the patient with the information and support to make a decision in partnership with you – just as you are not making the decision without them, so they should not be expected to make the decision without you.

"Here is a diagram/Decision Grid etc that will help me describe the options to you. I am going to describe the possible harms as well as the possible benefits of each... "

"There is a large amount of information to grasp here. These tools are designed to help you understand the options. Please try to use them and then come back and I’ll try to answer any questions."

7. Summarise

This is a good time to go over all the information that has been shared – both from you as a clinician and from the patient. Check that everything has been understood and offer an opportunity to ask any further questions. This is also a good time to ask the patient if they feel able to make a decision now or if they would like to go away and think the options over / discuss them with family.
“We have discussed two or three options today. People often find it hard to make a decision at this point. It might be a good idea to take some time to think over it, and come back when you’re ready.”

“Do you need more time to digest all this or shall we move to make a decision today?”

2.7.3 Decision Talk

1. Focus on Preferences

Make sure you have provided an opportunity for your patients to consider their preferences and to apply these to each option in order to understand the implications for them. What would a particular outcome mean for them – have they truly understood the implications?

“We have gone over the options, what they involve and the pros and cons of each. I already have some ideas about what matters to you but let me check – What is the most important issue for you in all this?”

“Some people value x, and others value y, what I need to know is what matters to you.”

“Have you had a chance to consider these options, from your point of view, in terms of what is important to you?”
Module 2 (continued)

“Think about them, how you feel about them and how you imagine things will be like if some of the likely consequences occur.”

“We have gone over the options and explored the risks and benefits and we have looked at what is important to you. Where does that leave us? Where do we go from here? Is this helping you to make a decision?”

2. Moving to a Decision

Recap again; explain to the patient that you have discussed all the options, the risks and the benefits of each. Does the patient feel ready to make a decision and do they have all the information they need? Offer them more time or information should they require it.

“We are moving towards a decision. We have gone over the options, explored the harms and benefits, and we’ve looked at what’s important to you – has this helped you make a decision?”

“You seem to have been able to decide on the option that is best for you, are there any final concerns or questions that you want to ask?”

“It seems you have decided to do A. Do you want to have more time to consider this, or ask more questions?”
"Are you ready to decide?"

"Do you want more time to ask more questions?"

3. Review

Once a decision has been made, you may find it useful to review the rationale behind this decision in order to check the patient is happy. You should also make it clear that it is possible to revisit the decision at a later stage – just because they have picked a particular option now does not necessarily mean all other options are no longer available.

"It is possible to revisit this decision after today."

"We can talk about these options again."
2.8 Practicing Shared Decision Making (Slides 47-50)

‘I hear and I forget, I see and I remember, I do and I understand’ (old Chinese Proverb)

As Shared Decision Making is often a new skill for health professionals, it may be helpful to practice it before you start using it with patients. Role-playing or scenario work gives you an opportunity to practice the core skills of Shared Decision Making in a ‘safe’ environment, where mutual support and reflection can take place.

The ultimate goal of scenario work is to refine the language and format of consultations through practice, giving confidence to individuals in using Shared Decision Making within a patient consultation. Research has shown that clinicians in an approximate 40 year clinical career can engage in anywhere between 150-200,000 patient and family consultations (Leonard 2012).

Good communication skills are key to making these consultations and interviews as productive and satisfactory to both parties involved.

“Almost invariably the act of communication is an important part of therapy; occasionally it is the only constituent. It usually requires greater thought and planning than drug treatment and unfortunately it is often administered in sub therapeutic doses” (Buckman 2001)
Scenarios allow clinicians to gain insight into where they currently utilise good engagement and involvement language, but also where they may feel areas can be improved.

Typically it is encouraged that scenarios are done with a triadic model i.e. 3 individuals in the roles as stated below in the diagram; this is to enable objective feedback by the observer on the patient-clinician interaction. There are some basic questions that can help guide reflection (RESOURCE 1). It is also beneficial as part of the scenarios that the individuals rotate and experience each role, feeding back to the group after each full rotation.

2.7.1 Triadic Model

Role (1) Clinician
- Role experience in asking questions, giving information and experimenting with consulting style, and in listening skills

Role (2) Patient
- Gains insight into being handled well or badly. Experience effects of different styles. Practice giving feedback to clinician role

Observer (3) Role
- Practice analysing behaviour and providing accurate feedback in acceptable manner to clinician role
2.7.2 Some general guidelines

**Do**
- Adopt the character
- Adapt to reflect you
- React to the doctor/health professional
- Act naturally

**Don't**
- overreact
- Play hard to get
- Introduce red herrings
- Play to gallery

Things you can do in a role play you can’t do for real
- Try something new without risk to a patient
- Take time out – and reflect or start again
- Get rapid feedback from peers

2.7.3 Tips for feedback

“Practice confirms habits, feedback changes them...”
- Take a few minutes at the end to reflect on what happened
- Use the questions on the form (RESOURCE 1) as a basis for your feedback
- Try to relate your answers to specific behaviours and episodes
- Balance positive and negative comments.
Remember, feedback works best when it’s:
- Personal
- Proximate
- Pertinent

2.7.4 Example Scenarios

There are a number of resources within this training pack for scenarios which include a patient and a health professional guide, plus also an option grid which can be used in conjunction with the latter role. Please see the Shared Decision Making example scenarios / role plays in the resources section, courtesy of the MAGIC programme (Health Foundation) / Prepare to Share (RESOURCE 2).

If you wish to develop your own scenarios for particular clinical areas to enable staff to gain confidence in their consultation settings, there are some general guidelines on the next few pages to assist you in doing this. Developing these specific scenarios can be useful if staff would like to use current resources, or develop a ‘crib list’ to facilitate the COD talk or wish to rehearse how this will work in practice.

Feeling confident in content, format and materials is a key step to implementing them in day-to-day practice.
2.7.4.1 Guidelines – Clinician Brief

Define who you are consulting with:

- Age
- Physical characteristics
- Job role
- Health background
- Positive family history (e.g. familial health history)
- Risk factors / clinical results

Set the scene as to why the patient has come to see you, what pre-empted it (e.g. an occupational health session, GP visit) and what they are hoping to get out of it.

Identify the options through either stating these from NICE guidelines, a PDA, or from an Option Grid you are aware of.

1.
2.
3. etc

Discuss any option that the patient feels they wish to investigate further.
2.7.4.2 Guidelines – Patient Brief

Create a story for your patient, include such information as:-

- Name
- Age
- Marital status
- Children
- Job role/responsibilities
- Life demands
- Health – why they are now seeking advice
- Any other background information you feel would ‘set the scene’ for this patient scenario e.g. fears, worries, previous health issues / family issues etc.
3.1 Introduction

Implementing a successful service improvement or change involves clear aims, specific role allocation, clearly defined objectives and tight time management. The project lead needs to be aware of key roles, choosing the most appropriate individuals and facilitating clear timelines for completing objectives.

It may be useful to complete a RACI matrix (RESOURCE 3), to assist with the allocation and communication of roles and deadlines. Understanding the demands of the project from the outset also allows some thought to be given to providing adequate resources – both financial and time – to the implementation of Shared Decision Making.

Planning distinct points within the project for reflection and reporting of outcomes will enable your organisation to tailor what will work with your own patients, and also to celebrate successes which can then inspire others who wish to implement and engage with Shared Decision Making.
“We always find that for new initiatives aiming to improve patient care, it is advisable to invest in a small amount of protected learning time in advance of implementation. If staff feel more work is being distributed to them on top of their current full schedule without any allowance for protected time, they are unlikely to view the initiative positively. Protected time allows staff to read about the initiative and the reasoning behind it prior to roll out. This increases their own understanding and encourages discussion which facilitates more reasoned feedback at subsequent meetings. It also raises the profile of the initiative. Generally we find achieving staff engagement at the start of a project saves time in the long term.” Ruth Sephton, Consultant Physiotherapist, 5 Boroughs Partnership NHS Foundation Trust

3.2 Co-ordination and Leadership

Some questions to consider:-

- Who will be the Executive Lead for Shared Decision Making within the Organisation?
- Who will be the Clinical lead for Shared Decision Making across the Organisation and within each Directorate, Department or Team?
- Who will co-ordinate the implementation plan?
- What are your timescales
- Which areas will you focus on?
- Who are the key stakeholders and how do you plan to work/communicate with them?
Module 3 (continued)

3.3 Engaging Staff in Shared Decision Making

Shared Decision Making is about cultural change and it cannot be achieved in isolation. Therefore it is really important to bring the whole team and colleagues with you. It is worth considering the following:

- Which staff will be directly or indirectly affected by implementing Shared Decision Making? Think about those staff that perform corporate functions or those members of staff who work across more than one team/department.
- What key roles and responsibilities will you need people to fulfil (see section 3.6)?
- How will you plan to communicate Shared Decision Making to staff, both locally and organisationally?
- Will there be differing approaches for different groups e.g. clinicians, nurses, allied health professionals and administrative staff?

3.4 Engaging Patients and Carers

Shared Decision Making cannot be successfully implemented without patient engagement.
This is always the most challenging aspect of the programme as both patients and clinicians are unsure about their roles in this potentially ‘new world order’. It is really important to try and get some patients involved early in the process not only to encourage other patients, but also to encourage health professionals.

- How will you provide information and resources to service users and carers re: Shared Decision Making?
- Do you have any patient engagement groups who could contribute to your Shared Decision Making implementation?
- What communication strategy will you have for sharing Shared Decision Making successes within your organisation?

3.5 Engaging with the Executive Team

Support from the organisation’s Executive team is vital to the successful embedding of Shared Decision Making. An Executive lead should be identified who will need to demonstrate on-going commitment to embedding, sustaining and spreading the programme at a board level.

The Clinical and Project Lead should schedule monthly meetings with the Executive Lead to update them on successes to date as well as barriers the team is facing. Removing barriers and facilitating change are key roles that the Executive Lead can assist in; demonstrating the priority of Shared Decision Making to the organisation and those within it.
The Chief Executive should also be aware of when the team meets and be encouraged to participate or be briefed. There may also be a Non-Executive Director who may be interested in getting involved and supporting the Shared Decision Making Programme, as a powerful champion.

3.6 Roles and Responsibilities

It is a tripartite approach that has been adopted to aid AQuA’s implementation of Shared Decision Making to try to ensure that there is maximum leverage of power and influence across the organisation and to overcome the limitations of any one individual, as change and improvement cannot be made by one person in isolation. The team should consist of a core group of individuals who form the nucleus of improvement work, as well as other team members who are integrally involved in current processes within each focus area at your organisation.

Your core team should have representation and skills in three different dimensions:

- Day-to-day team leadership
- System/clinical leadership
- Data collection expertise
- Skills in report writing for monthly/quarterly reports.
There may be one or more individuals on the team that represent each dimension, and one individual may fulfill more than one role. All three components should be represented in order to support and drive the change needed to deliver on Shared Decision Making goals and objectives. Examples of who could be included in the support teams include:

- Medical team members
- Allied Health Professional team members
- Nursing team members
- Front-line staff
- Patient leaders
- Support staff
- Executive support.

All of whom will:

- Have a working knowledge of the areas selected
- Work together as a team that functions at an accelerated pace
- Have time to work on this project, be motivated and excited about this change and be able to attend team meetings
- Be willing to share their experience and expertise with the rest of the organisation.
Module 3 (continued)

Asking staff to complete the Shared Decision Making Pre-implementation Questionnaire (RESOURCE 4) may help in assessing individual’s views in relation to Shared Decision Making prior to implementing the project. To determine if your organisation/directorate/team is ready to implement Shared Decision Making, complete the Readiness Diagnostic Tool (RESOURCE 5).

3.6.1 Organisational Lead / Executive Lead

Defining who will take responsibility at executive level within the organisation allows those individuals tasked with working on the programme to understand the key drivers and clear organisational objectives for Shared Decision Making within both their work areas and the organisation as a whole. Clear reporting structures to board level via defined lines of responsibility and work streams will enable individuals to understand the importance that their organisation places on the programme. This clarity also enables future implementation and spread of Shared Decision Making to be more easily defined, and delivered.

3.6.2 Programme Lead

The Programme Lead is critical to driving the Shared Decision Making programme for the organisation. They are responsible for:

- Ensuring that changes are tested and implemented
- Challenges are identified/addressed
Module 3 (continued)

- Results are reported
- Information/skills/knowledge learnt is shared
- Data collection is facilitated.

Completing self assessment of project progress (e.g. Self Assessment Scale For Collaboratives, RESOURCE 6) might be helpful. It is important that this individual understands not only the details of Shared Decision Making in each clinical area identified, but also the various effects of making change(s) in the system.

This individual will need to carry a level of authority and influence to ensure suitable credibility with both senior clinical colleagues and technical experts, and also a confidence to report out to the Executive leadership as well as representing front line teams at the focus area events. Most importantly, they should have enthusiasm to help their multidisciplinary teams to implement change.

The Executive Leadership should be aware that dedicated time will be required for the day-to-day management of Shared Decision Making by the project lead for this role.

The Programme Lead should:

- Have a working knowledge of the clinical area(s) selected
- Have managerial and facilitation skills
Module 3 (continued)

- Be able to organise and co-ordinate a team that works at an accelerated pace
- Be able to set clear deadlines, convey and enforce these to their team to enable delivery of objectives
- Be motivated and excited about change creating new service and implementation designs
- Ensure smooth communication between the organisation and the improvement teams within it
- Develop a report on activity monthly/quarterly for circulation within Directorate/Team/other committees as well as externally.

An overview of Shared Decision Making using a booklet is available (SEE RESOURCE 7).

3.6.3 Clinical Lead

The Clinical Lead needs to not only embrace the concept of Share Decision Making, but also to understand the implications of Shared Decision Making within each clinical area identified, and the clinical impact of making change(s) in the system.

This individual will need to carry a level of authority and influence to ensure clinical credibility with colleagues both within the clinical area in question, but also within the wider organisation/health community. Most importantly, like the Programme Leads, they should have an enthusiasm to help their multidisciplinary team embed Shared Decision Making within their clinical areas.
Module 3 (continued)

The Clinical Lead should:

- Have time to interact regularly with the participating team
- Have clinical credibility with colleagues
- Have the authority to eliminate barriers which may affect the aims of the team
- Be willing to spread the changes throughout the organisation / health economy
- Be a member of the team and participate in meetings and activities
- Be able to work in multidisciplinary teams and across department lines
- Be used to working to deadlines and co-ordinating others to do so (see also Shared Decision Making overview booklet RESOURCE 7).

Consider:

- Are you going to provide regular updates for staff?
- Will it be part of induction training - face to face (Shared Decision Making Overview Presentation) or e-learning resources?
- How will you resource the implementation of Shared Decision Making e.g. staff back-fill, time release for training?
- Will there be any unintended consequences of implementing Shared Decision Making i.e. what impact will Shared Decision Making potentially have on pathways if there is a change of treatment option chosen?
3.8 Spread

“A key factor in closing the gap between best practice and common practice is the ability of health care providers and their organizations to rapidly spread innovations and new ideas. Pockets of excellence exist in our health care systems, but knowledge of these better ideas and practices often remains isolated and unknown to others” (Massoud et al 2006).

The long term ambition is that Shared Decision Making will become integrated into the way all teams work so that it becomes the norm. However, this will only happen if organisations embrace the challenge of changing the culture to ensure that Shared Decision Making becomes the norm.

A Framework for Spread developed by the (Massoud et al 2006) suggests that there are four key components that are required to enable the spread to be successful:

- Widespread acknowledgement by leadership that the improvement project is a key strategic initiative of the organisation
- The designation of both executive sponsorship and day-to-day leadership
- The existence of successful sites that are the source of the specific ideas to be spread
- Evidence that the ideas result in the desired outcomes.
The IHI further suggest that answering the following 5 questions helps in determining a plan of action for organisational spread:

1. Can the organisation or community structure be used to facilitate spread?
2. How are decisions about the adoption of improvements made?
3. What infrastructure/enhancements will assist in achieving the spread aim?
4. What transition issues need to be addressed?
5. How will the spread efforts be transitioned to operational responsibilities?

In response to more detailed guidance on sustainability and spread a questionnaire has been developed to help teams think about areas where they could work to effectively spread Shared Decision Making across their organisation (SEE RESOURCE 8). This can then be developed into an action plan.

There is a general introduction to Shared Decision Making Overview Booklet (SEE RESOURCE 7) and supporting presentation for wider organisational information and education requirements for staff or groups who want to know more about Shared Decision Making (Shared Decision Making Overview Presentation).
4.1 Introduction

Now you know what Shared Decision Making is and how to embed it within your teams, the next step is wider adoption and spread amongst your colleagues and patients across your organisation (see section 3.8) and wider health community. In this module you will find a selection of tools and resources you can utilise to engage clinicians and patients with the concepts of Shared Decision Making.

4.2 Patient Engagement

What do we mean by “patient engagement”?

It means talking to people about their health and care needs and those they care for, as well as listening to what they have to say about the services they access. It provides an opportunity for the Service to hear what patients have to say, to get patients involved in the design and delivery of services and to enable them to get involved in the development of their own health and social care based on their personal preferences and cultural beliefs.
As can be seen below, only 21% of patients are satisfied with their involvement in their care. Shared Decision Making in itself, as well as the involvement of patients in the embedding of Shared Decision Making across a department or an organisation, is a perfect opportunity to involve and engage patients in their care.

“We have decided to engage our patients in email feedback on SDM as this seems to be their preferred route. It’s also a lot quicker and more responsive than the post.”

“We have recruited a cohort of patients as a user forum for us to email our questions out to, so that they can respond quickly to us.” — Maternity Team, Pennine Acute Hospitals NHS Trust
Module 4 (continued)

4.3 Tools for Patient Engagement

Research shows that encouraging patients to ask three simple questions leads clinicians to provide higher quality information about options, their benefits and harms.

‘Ask 3 Questions’

Ask 3 Questions is based on research by Shepherd et al (2011) at the University of Sydney.

The purpose of this tool is to introduce patients to Shared Decision Making and to give them an opportunity to play a more active role in the decisions about their health care, based on their personal preferences and beliefs.

Ask 3 Questions encourages patients to get answers to three simple questions when they are asked to make a healthcare decision.

The Ask Three Questions are:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?
Jean said; “I really liked the Ask 3 Question leaflet and although the questions did not feel natural at first, they were a good prompt for me to keep focussed on what I wanted to discuss with my GP. The result was that my normal 10 minute consultation only took 5 minutes, I got all the answers that I wanted and we agreed on a plan.”

Adrian said; “Using Ask 3 Questions meant that my GP appointment was structured and I got much more information from my GP than I think I would have normally, which was very helpful. I have also used the questions since then for my appointments with the specialist and the nurse and it seems to be a better way of dealing with a consultation.”

“I thought discussing things in depth and giving choices was going to be time consuming but now think this will reduce time in consultations as focussing on what the lady wants to discuss will save time. I was worried re: time/work load, but the pilot has demonstrated that investing time saves time as the women talk about what matters to them, rather than us lecturing at them about a lot of subjects they aren’t bothered about.”

Maternity team, Blackpool Teaching Hospital NHS Foundation Trust

AQuA has developed films, posters and other materials that can be displayed in patient areas, consultation rooms and other public places. The resources also include information leaflets which can be included in appointment letters. All resources are available to download and reproduce from www.advancingqualityalliance.nhs.uk/SDM/
4.4 Patient Leaders

As Shared Decision Making is a partnership approach between patients and health professionals, it is important to try and engage patient leaders and advocates as early as possible in the process. This is a real and tangible opportunity for patients to play an active part in improving quality within the Health Service, but it is not necessarily easy.

As a Shared Decision Making Patient Leader, they can be ambassadors for improvement and have a unique chance to influence both health care providers and fellow patients, family and friends by being part of a new and innovative programme of change within the NHS.

There are many opportunities available to a Shared Decision Making Patient Leader and they can adapt and customise this role to suit their lifestyle, technological abilities and personal preferences, availability and time.

See RESOURCE 8 Sustainability and Spread Questionnaire and RESOURCE 9, which provides an initial engagement letter to help you to recruit patients. The patient engagement booklet (RESOURCE 10) explains Shared Decision Making and the role of a patient leader.
4.5 Resources for Health Professionals

In addition to engaging with patients, you will need to engage with clinicians as partners to ensure all your clinical staff are on board and prepared to learn about and embed Shared Decision Making in their practice.

You may well meet opposition from some clinicians to Shared Decision Making. Many will say they are doing it already when in fact they don’t fully understand the concepts and the benefit not only to patients but to clinicians themselves. Below are many reasons that will help explain to clinicians why Shared Decision Making is beneficial.

In terms of using with patients: “I recently had a discussion with a patient about a very difficult and complicated decision regarding the possible use of a second course of strong immunosuppression for a long term condition. The choice/option/decision structure was very helpful as a way both to approach the consultation and to reflect on the discussion in my letter to the patient afterwards.” Renal Consultant, King’s Health Partners

“The women have been really receptive to it. I feel that they have responded well to being involved in Shared Decision Making. I feel this is particularly positive with the vulnerable women we work with in Blackpool Maternity Team.” Maternity team, Blackpool Teaching Hospital NHS Foundation Trust
Its use can be justified by several means:

- A belief that patients’ views are important and that doctor and patient have equality in the consultation
- An ethical stance emphasizing patient autonomy and the legal principle of consent
- Studies show improved clinical outcomes and better compliance with treatment

The rewards for health professionals include as follows:

- More structured consultations
- Clearer risk communication with patients (Gigerenzer et al 2008 and 2010, Akl et al 2011, Carling et al 2009)
- Deeper understanding of patient values/motivators for treatment
- Improved patient health literacy (Kim 2001, Price-Haywood et al 2009)
- Improved treatment commitment and compliance
- Reduced unwarranted variation (Glover 1938, Wennberg et al 2010)
- Improved confidence and self-efficacy by patients (Loh et al 2007)
- Safer care (Elwyn 2003)
- Greater compliance with ethical standards
- Reduced likelihood of litigation and complaints (Barry et al 2008)
- Better health outcomes
Why should Health Professionals bother with Shared Decision Making?

- Better compliance with treatment decisions related to their healthcare
- Improved knowledge and understanding both of the patient (by the clinician) and by the patient (in regards to their healthcare decisions)
- More accurate risk perceptions by patients
- Greater comfort and commitment to decisions by patients
- More active participation in their healthcare by patients
- Fewer patients choosing major surgery as a ‘default’
- Likely reduction in risk of litigation when things go wrong

**4.6 Organisational Awareness of Shared Decision Making**

As you begin to embed Shared Decision Making, it is useful to consider how you plan to generate awareness throughout the whole organisation and wider health community. You may have already identified clinical leads and clinical areas to start work in, but you will also need to generate awareness across the whole organisation at different levels as well as planning how to raise awareness with patients and the wider public.
It is useful to consider who you may involve and the different levels of information/education/training that will be required. To organise your planning of this work stream, you may wish to complete a Stakeholder Map to identify all the different groups and organisations. A sample is included (RESOURCE 11) to help you to identify who needs to be involved and what level of information they will require. Whilst clinicians involved in consultations with patients will require specific skills training, for others, such as non-clinical staff, general awareness training will be sufficient.

Below are just a few examples of the avenues you can use to promote Shared Decision Making:

- Intranet
- Staff newsletter (See RESOURCE 12 for an example draft)
- Team brief
- Senior nurse/clinician meetings
- Directorate meetings
- Involvement of the patient liaison teams
- Patient focus groups
- Patient education sessions
- Patient newsletters
- Patient link – TV system with a rolling message promoting both Shared Decision Making and Ask 3 Questions
- Posters and displays
Social media is a fantastic and free resource for engaging with a wide audience. You can start a SDM group on your Hospital/FT/PCT’s LinkedIn page.

To set up a LinkedIn page go to: http://learn.linkedin.com/new-users/

Here is an example of AQUA’s Shared Decision Making group on the AQUA LinkedIn Page.

You can also utilise Twitter to start a conversation (www.twitter.com).

The AQUA Programme has worked with Patient Opinion to try to harness patient and health professional voices to promote the spread of Shared Decision Making. Patient Opinion was founded in 2005 and is the UK’s leading independent non-profit feedback platform for health services. Patient Opinion is about honest and meaningful conversations between patients and health services.
Shared Decision Making
Train the Trainer Online Resource

Module 4 (continued)

Patient Opinion works because healthcare organisations are able to easily hear this feedback and it helps busy organisations to use real time feedback to have a genuine impact on their services.
https://www.patientopinion.org.uk

Using social media can keep your audience regularly updated with your Shared Decision Making progress, share patient stories and clinician feedback and can start to create a ‘voice of the crowds’ to help promote Shared Decision Making.

4.8 Shared Decision Making Films

There is an animated film for the Ask 3 Questions Campaign which can be used with or without sound for use in waiting rooms or clinic areas.

To show Shared Decision Making in action AQuA has also produced a series of short films. The filmed scenarios demonstrate health professionals and patients engaged in consultations and Shared Decision Making for a variety of conditions including maternity (Jane), musculoskeletal (Penny) and BPH (benign prostatic hyperplasia, the most common prostate disorder) (Bernie).

To view these clips please visit:
www.advancingqualityalliance.nhs.uk/SDM/
Module 5

Systems and Processes to Support Shared Decision Making

5.1 Introduction

This section discusses in detail different ways to measure Shared Decision Making – decisional conflict, decisional quality and patient satisfaction. SURE, the measurement tool used by the collaborative, and the more detailed and recently launched SHARED tool are outlined. Recording Shared Decision Making decisions in patient notes, IM&T systems and commissioning for SDM are also included in this module.

5.2 Measurement

There is currently no definitive tool for measuring the success, degree or outcomes of Shared Decision Making in practice, and there is on-going debate as to how to effectively measure ‘good’ decision making (Scholl et al 2011). It is important that you are able to measure the use of Shared Decision Making within your organisation.

Embedding Shared Decision Making into practice is only part of the process and the measurement of Shared Decision Making is useful for a number of purposes. The following pages illustrate the variety of measurement uses (CAPITA literature review 2012 RESOURCE 13).
Module 5 (continued)

5.2.1 Interests in Measuring Shared Decision Making

Clinicians and Clinical Teams

- Developing a case for Shared Decision Making
- Supporting Shared Decision Making implementation and assessing that service delivery and patient impact i.e. are adequately informed and involved
- Supporting their own improvement, development and performance – including appraisal providers
- Engaging with commissioners
- Targeting improvement
- Supporting teams and individuals with access to education and training commissioners
- Developing mechanisms of commissioning services which deliver or support Shared Decision Making implementation
- Commissioning education and other required support
- Holding services to account.
Shared Decision Making
Train the Trainer Online Resource

Policy leaders (Commissioning Board, Department of Health and others)

- Monitoring and evaluating implementation of national policies
- Commissioning further support for Shared Decision Making implementation
- Supporting future policy development in related areas (such as commissioning)
- Holding local organisations to account
- Ensuring that all communities are benefitting from Shared Decision Making.

Researchers

- Developing further the evidence base around Shared Decision Making
- Supporting wider research into the impact of better decision making in England
- Evaluating existing programmes and methods of Shared Decision Making implementation
- Evaluating existing Shared Decision Making for specific groups of patients.

In addition, there is also the perception of the patient or health professional on Shared Decision Making’s outcome and the observer perspective of the competence and performance of health professionals or patients in coming to a decision. A great number of factors will impact on an individual’s readiness to make a decision and the quality of the decision achieved, including the type of decision that the patient faces and where they are in the clinical pathway.
5.2.2 Different Types of Measures

Consideration of a suitable measure of Shared Decision Making must take into account the need to measure both the process of making the decision and the outcome of that decision. Impact on decision outcome from a clinical perspective should also be considered alongside these qualitative measures.

In general, there are three broad schools of thought – Patient Satisfaction with a Decision Measures, Decision Quality Measures and Decision Conflict Measures detailed below.

5.2.3 Patient Satisfaction with a Decision

The Patient Satisfaction with a Decision scale (SWD) (Holmes-Rovner et al 1996) builds on O’Connor and O’Brien-Pallas’ (1989) conceptual model of an effective decision i.e. one that is informed, consistent with the decision maker’s values, and behaviourally implemented. The purposes of the SWD scale are:

- To measure global satisfaction with the decision and the three attributes of an effective decision (O’Connor and O’Brien-Pallas’ model)
- To differentiate satisfaction with the decision from related aspects of satisfaction (satisfaction with provider, desire to participate in decision)
- To be short and easy to use.
5.2.4 Decision Quality Measures

Decision Quality Measures refer to the extent to which treatment or management decisions reflect the considered preferences of well-informed patients and are implemented. The key questions are:

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

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

The challenge with this measurement is that the questionnaire has to be tailored for each clinical pathway and so is not practical for wide scale adoption.
5.2.5 Decisional Conflict Scales

In comparison to many of the scales that have been developed, the Decisional Conflict Scale (O’Connor et al, 1995) is multi-dimensional in its assessment of decision process and outcome and has consistently demonstrated validity both in the UK and internationally across a broad range of treatment areas. The 16 item scale was developed to elicit information concerning the decision maker’s:

- Uncertainty in making a choice
- Modifiable factors contributing to the uncertainty, such as lack of information, unclear values, and inadequate social support
- Perceived effective decision making (O’Connor 1995).

A lower literacy scale of 10 items is also available along with a 4 item scale which is recommended for use in clinical practice.
The 3 measures above all have various advantages and disadvantages, which are outlined below:

<table>
<thead>
<tr>
<th></th>
<th>Decisional Conflict Scale</th>
<th>Decisional Quality Measure</th>
<th>Patient Satisfaction with a Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it a patient rating</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Is it multi-faceted</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Applicability across all clinical specialities</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Ease of use</td>
<td>Yes (short form requires limited time commitment from patient and data collector, small number of questions, yes/no responses)</td>
<td>No (significant number of questions, not available for all clinical specialities/decision points)</td>
<td>Yes (short form, requires limited time commitment from patient and data collector)</td>
</tr>
<tr>
<td>Association with meeting anticipated clinical outcome</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Whether the scale has been used in the UK</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

CAPITA Literature Review 2012 (RESOURCE 13)
5.2.7 SURE Score

In terms of implementation of measures into clinical practice, it is understood that the 16 item Decisional Conflict Scale might be considered too long to become part of a regular patient consultation. In light of this the 4-item SURE (Sure of myself: Understand information; Risk-benefit ratio; Encouragement) scale was developed for use in clinical practice based on the Decisional Conflict Scale.

It was developed in order to encourage clinicians who may be put off by the length of time required to complete the 16-item measure to use a measurement tool in clinical practice (Legare et al 2010). The developers of the scale have shown a negative correlation with the Decisional Conflict Scale. This is in line with the hypothesis that a perfect SURE score indicates no decisional conflict.

Practically speaking the SURE tool is a short, generic tool with simple to evaluate results, which is important for wide scale integration. The self-administered nature of the SURE instrument means that it also lends itself to an online application (potentially as part of a decision aid) as well as a more traditional paper survey. In addition, the decisional conflict approach is useful where there is not a decision aid available. However, where there is an aid, a Decision Quality Measure is sometimes better, although more resource intensive (Sepucha 2008). See also the Capita Literature Search 2012 (RESOURCE 13).

The SURE tool is included within the Resources section as RESOURCE 14.
5.2.8 SHARED Tool (Bekker, Nye, Walker and Legare 2012)

As part of the National Shared Decision Making programme, the clinical teams were asked to use the SURE tool to determine the levels of decisional conflict experienced by the patients taking part in the Collaborative Programme to measure improvement. Following completion of over 1500 SURE tools and analysis, there was discussion that the SURE tool was not sensitive for use in a clinical setting or specific enough across all specialties, despite the academic research that did not necessarily support this.

Following discussion between Dr Hilary Bekker at the University of Leeds and the AQuA Shared Decision Making Team a new tool, SHARED has been developed to address some of these concerns. This tool incorporates the SURE Tool along with 4 additional questions which address the process of Shared Decision Making. The tool is currently being piloted across a number of sites and is in the process of validation.

The SHARED tool can be found in the Resources section as RESOURCE 15.
5.2.9 Care Quality Commission (CQC) National Patient Surveys

The NHS patient survey systematically gathers patient views about the care and treatment they have received in hospital and primary care. Co-ordinated and managed centrally by the Picker Institute on behalf of the Care Quality Commission, all hospitals take part annually. Picker work with information departments to provide patient data against set criteria. Patients are then randomised to take part and are sent a postal questionnaire to complete. Comparisons can then be made between hospitals. Importantly hospitals are able to monitor their results each year and action plan areas of weakness.

Since 2002 the question “Were you involved as much as you wanted to be in decisions about your care?” has been included in the patient questionnaire. This question provides an indicator that can be used to assess progress on Shared Decision Making. It would be helpful therefore to contact your Head of Patient Experience to find out the results for your hospital since 2002-2011. For Primary Care please contact your commissioning lead.
5.3 Recording Shared Decision Making / Documentation

Documentation and coding of Shared Decision Making is key to recording the Shared Decision Making discussions that have taken place to evidence patient engagement and involvement with their treatment decision, and also reflecting the patient’s values and preferences. Including Shared Decision Making within your patient documentation doesn’t require a complete overhaul of the clinical records; it can be as simple as the health professional documenting the patient preferences and reasons for their choice.

“I simply record in the patient notes that the following options were discussed then list the options.” Dr Alan Nye, General Practitioner, Oldham

5.3.1 Examples of how to Record Shared Decision Making

University Hospital of South Manchester and South Manchester CCG MSK interface (tier 2) service has reviewed their clinical assessment documentation to include the SURE tool as a way of encouraging a Shared Decision Making approach. The new documentation incorporates the SURE tool as a prompt to ensure Shared Decision Making takes place and the patient is engaged with the consultation. It also assesses the level of involvement that each patient has with their decisions at every point in their healthcare journey, not just at that particular clinic. An example of the South Manchester Assessment documentation can be found in the Resources section as RESOURCE 16.
Mid Cheshire Hospitals NHS Foundation Trusts’ maternity department has produced a consent form for women undergoing the 20 week anomaly scan. Historically consent was informal and implied, and analysis of the SURE data during the project indicated that women were often unaware that the main purpose of the scan was to detect for foetal abnormalities. Women often think that the main purpose was to determine the sex of their baby.

The consent form was therefore devised as a method of ensuring that all women are fully informed regarding their options. The anomaly scan is discussed during a consultation with the midwife and the consent form is used as a tool to ensure all information is discussed with the woman and that the woman is fully involved with the decision-making process and also as a way of ensuring consent is obtained. The consent form can then be filed in the patient’s clinical records to evidence Shared Decision Making.

5 Boroughs Partnership NHS Foundation Trusts have reviewed their Musculoskeletal Clinical Assessment and Treatment Service (CATS) documentation to include Ask 3 Questions. It provides another way of reminding staff and encouraging use of Ask 3 Questions (RESOURCE 17).
To embed and utilise existing systems rather than create further work for clinical teams there are a number of codes already in existence in relation to Shared Decision Making:

Read v2
- 8C1 Shared decision making
- 8C10 Shared decision making with patient decision aid
- 8C11 Shared decision making without patient decision aid
- 8C12 Shared decision making with decision support
- 8C13 Shared decision making without decision support

Read v3
- XaYjg Shared decision making
- XaYjh Shared decision making with patient decision aid
- XaYji Shared decision making without patient decision aid
- XaYjj Shared decision making with decision support
- XaYjm Shared decision making without decision support

SNOMED
- 815691000000107 Shared decision making (procedure)
- 815711000000109 Shared decision making with patient decision aid (procedure)
- 815731000000101 Shared decision making without patient decision aid (procedure)
815751000000108  Shared decision making with decision support (procedure)
815791000000100  Shared decision making without decision support (procedure)

To find out more about the codes used within your own organisation it may be useful to consult with your Informatics and Coding teams to identify the most effective way of coding consultations and patient outcomes to evidence Shared Decision Making. For example, NHS Trafford has written a template for both EMIS and VISION clinical systems. This provides a great example of a way to provide both guidance through the process and support documentation of Shared Decision Making in practice.

The template can easily be set up on any EMIS or VISION system or for individuals working on different clinical systems; the example template shows what component parts are required so that an equivalent template can be established.
Module 5 (continued)

5.4 Commissioning

Being able to evidence that Shared Decision Making is taking place is key for a number of reasons. Primarily, Shared Decision Making is ethically the right thing to do as it ensures that the patients are fully engaged with making decisions regarding their care. In addition, Shared Decision Making is being incorporated into a number of performance and outcome systems, for example NICE quality standards, Commissioning Outcomes Framework (COF), and CQUINs (see RESOURCE 18 for sample Shared Decision Making CQUIN). For further information refer to the Levers and Incentives document included in the Resources section as RESOURCE 19.

Some questions to consider from a commissioning perspective:
1. How can you demonstrate that staff are employing a Shared Decision Making approach during their clinical consultations?
2. How will you know whether Shared Decision Making is making a difference?
3. What are the important measures and data to gather?
4. How will you gather and collate this information?
5. What do you think are key patient-derived measures?
6. Have you asked patients what is important to them?
7. Who in your organisation has skills in evaluation or measurement for improvement? How can you connect with them to help measure progress and impact of Shared Decision Making?
8. Who do you need to be sharing this data with in your organisation to ensure there is continued support for Shared Decision Making?
6.1 Embedding Shared Decision Making into Your Organisation

In order to support the embedding of Shared Decision Making within your organisation it is useful to consider how Shared Decision Making can be incorporated into the governance processes and procedures so that it runs through the organisation like a stripe in toothpaste. This does not have to be an overnight process, but as documents are reviewed as part of the organisation’s governance processes, it is good to use this opportunity to add any additional fields in reporting systems to record or measure Shared Decision Making and to think about including Shared Decision Making language into patient correspondence. E.g. were you involved in making decisions about your care?

6.2 Training

Training is another way to embed Shared Decision Making within the culture of the organisation. There are several ways of achieving this and there are resources and links within this programme that can assist you.
Induction Training – Shared Decision Making can be incorporated in the induction programme for all new staff. This could be delivered face to face or online, the face to face session should take no more than 30 minutes and enables staff to gain an overview of the concepts of Shared Decision Making. See Shared Decision Making Overview Presentation.

Mandatory Training – Some organisations have decided to make Shared Decision Making training mandatory for certain groups of staff. This could be delivered face to face using the attached training resource or the E-Learning Modules found on the AQUA website.

At yearly staff reviews clinical teams can use patient stories to demonstrate the practice of Shared Decision Making in their area.
Module 7

Frequently Asked Questions

1. **What is Shared Decision Making?**

   Shared Decision Making (SDM) is a process in which patients are encouraged by their health professional to participate in selecting their appropriate health treatments or care management options. Not being properly informed about their illness and the options for treatment/management is the most common cause of patient dissatisfaction (Coulter and Cleary 2001). Most patients want more information and a greater say in decisions about how they will be treated.

   In Shared Decision Making patients are involved as active partners with their health professional in clarifying acceptable clinical options and choosing a preferred course of care (O’Connor et al 2007). Shared Decision Making is appropriate in any situation where there is more than one reasonable course of action and no one option is self-evidently best. This situation is common as there are many ‘preference-sensitive’ decisions about treatment and care. In these cases the patient’s attitude to the likely benefits and risks should be a key factor in the decision.

2. **What are the three questions I should ask?**

   1. What are my options?
   2. What are the pros and cons of each option?
   3. How do I get support to help me make a decision that is right for me?
Module 7 (continued)

3. What if the clinician doesn’t let me ask three questions or isn’t receptive to Shared Decision Making?

For Shared Decision Making to be truly effective both the health professional and the patient need to be jointly engaged with the consultation. By being prepared and asking the three questions you will hopefully receive all of the information and support that you require to enable you to make a decision regarding the best treatment option for you. However, if you feel that your health care professional is not supporting the process you could contact the Patient Liaison Service. You are also entitled to ask for a second opinion.

4. Where can I get more information?

http://www.advancingqualityalliance.nhs.uk

Option Grids website http://www.optiongrid.co.uk/
Totally Website www.totallyplc.com
Right Care www.rightcare.nhs/SDM
Health Foundation site www.health.org
University of Ottowa, Ontario Decision Aid site http://decisionaid.ohri.ca/
Mayo Clinic Decision Aids http://dev.shareddecisions.mayoclinic.org/
5. What are Option Grids?

Work on Option Grids started in 2009 at the Decision Laboratory, Cardiff University. Option grids are produced using scientific evidence and where possible following guidance produced by NICE in collaboration with both clinicians and patients. They have been designed to be used during a consultation with your health professional. Grids will help you to compare reasonable important options looking at both the pros and cons of each option. For more information go to [http://www.optiongrid.co.uk/](http://www.optiongrid.co.uk/)

6. How can I include Shared Decision Making in CQC reviews?

The two key standards which are explicit to Shared Decision Making are “Standard 1: you can expect to be involved and told what is happening at every stage in your care” and “Standard 2: you can expect care, treatment and support which meets your needs”.

Your review can incorporate the following:

1. Documented evidence in care plans
2. Yearly documentation audits
3. Marketing Shared Decision Making and patient surveys seeking patient views on the above standards
4. Mandatory training of staff to understand and adhere to the principles of Shared Decision Making in practice.
Module 7 (continued)

7. How can I include Shared Decision Making in my Quality Accounts?

Shared Decision Making is an integral part of delivering quality care and is linked to the QIPP agenda; you can incorporate this under patient experience surveys indicating Shared Decision Making and patient complaints.

8. What are the key ingredients to making Shared Decision Making a success?

1. Senior Executive support within your organization to support the adoption and spread of Shared Decision Making
2. Clinical leadership and engagement
3. Reliable information and communicating risks and benefits in a non biased and understandable format
4. Embedding Shared Decision Making into existing clinical systems for recording and documentation
5. Engaging your patients so that they have the confidence to Ask 3 Questions.
Module 7 (continued)

9. How do we show patients it is not about “fobbing them off” with the cheapest option?

Explain that there are a range of options and it is up to the patient to decide on the choice, based upon what is important to them. If you are offering all options in a balanced and unbiased way, the patient should feel that they are being helped to make a decision about the most appropriate option for them, rather than feeling pushed towards a particular option.

10. What do we do with patients who have already made up their minds?

You can still check that the patient has made a decision based on balanced, unbiased information and was aware of the different options available. If they have made a decision based on good, reliable evidence and having considered their preferences, this is fine.

11. I don’t know all the risks of each treatment. How can I have that discussion with patients?

See if there is a decision aid, or research the risks and benefits. As a team you may wish to produce a proforma, based upon NICE guidance to ensure all key facts are being communicated with your patients.
12. My patient doesn’t want to be involved. Can I make the decision for them?

There are different stages to any decision, the first two being pre-contemplation (not even thinking about making a decision) and contemplation (aware that a decision may need to be made but not yet intending to make one). There may be many reasons why someone is not yet ready or intending to make a decision. Using a technique such as motivational interviewing (see page 32) could help you to engage with the patient and understand why they do not want to be involved. This will then help you discuss options with the patient and perhaps encourage them to get involved and share in the decision-making process.

You could also send out a decision grid prior to the consultation or give them a decision grid to take away so they can think more about their options.

13. My patients can’t read the decision grids. Does this mean I can’t do Shared Decision Making?

No. You do not have to have a decision grid to do Shared Decision Making and by the same token you can do Shared Decision Making with a patient even if they cannot read the grid. You could read the information to them or ask if they have a carer/friend/relative who would be able to help them consider their options. You should be aware that it is possible that an element of bias may creep in, often unconsciously if a third party is involved.
14. How can I ensure that the patient has understood the information?

You can ask the patient to repeat what you have told them or ask them questions to check their understanding; “Let me just check that I have explained this well enough – can you tell me what you have picked up from what I’ve told you?”

15. What do I do if the patient asks me “what would you do?”

Ask them “What further information do you need to make this choice?”, and point out that the final decision is up to the patient but you will support them in making it.

16. What if the patient’s choice is for the clinician to choose?

This is OK as long as the offer for Shared Decision Making is made and that as a health professional you explore the patients’ preferences and values and reflect these back to the patient when making the decision.
Module 7 (continued)

17. How do I allow patients time to reflect on which option is best for them, when we do not have capacity to invite them back?

It often helps to have systems in place to signpost patients to sources of information prior to the appointment, such as decision aids. Most patients will make a decision in the consultation, but a few others will need more time. This is their right and we have to accommodate this in how we plan our clinics.

18. What about competing targets?

Evidence from three Cochrane reviews is that Shared Decision Making does not add time to the patient’s journey and indeed often reduces time consuming invasive interventions, promotes concordance and self care. There are indications to suggest that it also reduces complaints (see also national policy drivers section 1.2.7).

19. What is the impact of Shared Decision Making on public health / population health?

It improves patient understanding of their health and any associated problems, and there is evidence to suggest that it improves compliance and associated health related behaviours.
20. What is the difference between informed consent and Shared Decision Making?

They are similar, but informed consent is a legal requirement prior to any invasive treatment. Shared Decision Making can be used for any preference sensitive decision and should be done in advance and in addition to informed consent. Shared Decision Making is NOT informed consent.

21. This approach is going to make my consultations longer, meaning I see less patients, how is it a good thing?

The evidence is that it does not take longer. Three Cochrane reviews have suggested that often Shared Decision Making does not take any longer and in fact reduces the number of contacts a patient has with their Health Professionals along the patient pathway, as it promotes a greater understanding of their condition and in turn greater concordance and self management support/self care.

22. What are the benefits to me as a clinician of incorporating Shared Decision Making into my practice?

You have more informed patients making clinical consultations more focused, this in turn improves treatment adherence which provides greater satisfaction for clinicians and improved patient outcomes. You can be confident that the patient is fully informed regarding their treatment and less likely to experience decisional conflict.
23. Patients want us to make the decision, how do we support them in changing this behaviour?

Ask them “What further information do you need to make this choice?”, and point out that the final decision is up to the patient but you will support them in making it. Motivational interviewing skills will also help with this.

24. We are getting 100% in our SURE scores so we are doing Shared Decision Making aren’t we?

SURE is a proxy for Shared Decision Making. A high SURE score of over 95% is good and this shows there is little decisional conflict. However, it does not confirm that patients are being offered all relevant options.

25. Still need more convincing?

Below are a series of quotes from patients and staff involved in the piloting of Shared Decision Making:

“Doing Shared Decision Making with women was a bit of an eye-opener to me, a lot of the women were far more concerned with risks we don’t normally discuss that much in VBAC i.e. laceration of the baby’s head during c-section. I was surprised at some of the reasons why they had decided to try for a normal vaginal birth next time. Having the decision grid made me go through these other options, risks and benefits with the women.”
“We also found that putting a definite structure on our engagement with the women helped to reduce the amount of writing we were doing in consultations. The decision grid has focussed the information shared, and the new documentation has reduced the writing we were doing to record the conversations we had with our women.”

“We have decided to engage our patients in email feedback on SDM as this seems to be their preferred route. It’s also a lot quicker and more responsive than the post.”

“We have recruited a cohort of patients as a user forum for us to email our questions out to, so that they can respond quickly to us.” Maternity team, Pennine Acute Hospitals NHS Trust

“Shared Decision Making has provided some structure to the decision-making process. When I’ve implemented Shared Decision Making it allowed me to impose some structure on the consultation and I just needed to remember to issue forms to patients. Most patients were happy to do it, though some felt it was unnecessary and added nothing. A few of them saw it to be especially advantageous.” Mr Philip Wykes, Clinical Lead Orthopaedic Surgery, Bolton NHS Foundation Trust

Angie (Patient);
“I felt really positive about using Ask 3 Questions. It meant I got more information out of my appointment with my consultant, and I felt more satisfied at the end of the appointment, even though I still had no real answers – it was a more rounded consultation and the dynamic felt very different, but in a good way.”
Adrian (Patient):
“Using Ask 3 Questions meant that my GP appointment was structured and I got much more information from my GP than I think I would have normally, which was very helpful. I have also used the questions since then for my appointments with the specialist and the nurse and it seems to be a better way of dealing with a consultation.”

Jean (Patient):
“I really liked the Ask 3 Question leaflet and although the questions did not feel natural at first, they were a good prompt for me to keep focussed on what I wanted to discuss with my GP. The result was that my normal 10 minute consultation only took 5 minutes and I got all the answers that I wanted and we agreed on a plan.”

“My personal view is that prevention of Serious Untoward Incidences (SUIs) is multifaceted. Whilst the clinical professionals have a duty of care to ensure clinical guidelines are followed and any intervention is delivered in a safe and caring way, I do feel that by encouraging patients to question the care/treatment they are receiving it may help pick up errors such as wrong site surgery. This could, for example, include where the opposite side is marked up during pre-op the patient may question this knowing where they were due to receive surgery etc…”
Simon Jarvis, Head of Patient Engagement, Heart of England NHS Foundation Trust
“A challenge faced by practitioners can be that they can see more potential for recovery than the patient wishes to achieve. Often a patient would not go home unless they could mobilise the “length of the ward”. However, at home the patient only wanted, and needed, to be able to walk a few yards from living room to kitchen! Shared Decision Making will put the patient in the driving seat and practitioners will learn to understand that ‘relevant’ is more important than ‘possible’,” Norah Flood, Professional Lead for Allied Health Professionals, 5 Boroughs Partnership NHS Foundation Trust

“Using Shared Decision Making has changed my practice. I have always suggested what is best for my patients but now I give them the options and we discuss to come to a decision suited to the patient.” Mr Shahid, Consultant Obstetrician, Wrightington, Wigan and Leigh NHS Foundation Trust

“In terms of using with patients: I recently had a discussion with a patient about a very difficult and complicated decision regarding the possible use of a second course of strong immunosuppression for a long term condition. The choice/option/decision structure was very helpful as a way both to approach the consultation and to reflect on the discussion in my letter to the patient afterwards.” Renal Consultant, King’s Health Partners
“I feel Shared Decision Making is something we think we have always done, but when considering Shared Decision Making probably never have shared choices fully. I think this gives a good template to guide discussions.”

“It has improved working together with the vulnerable team. It has improved discussion with the women who have engaged with the Shared Decision Making Project.”

“The women have been really receptive to it. I feel that they have responded well to being involved in decision making. I feel this is particularly positive with the vulnerable women that we work with.”

“I thought discussing things in depth and giving choices is going to be time consuming but now think this will reduce time in consultations as focussing on what the lady wants to discuss will save time.”

“I was worried re: time/work load, but the pilot has demonstrated that investing time saves time as the women talk about what matters to them. Rather than us lecturing at them about a lot of subjects they aren’t bothered about.”

“I think patients feel valued if they are consulted about care, especially in the vulnerable group we work with in maternity.”

“Women feel that they have been able to make better choices and also feel ‘special’ to be involved.”
“Shared Decision Making could be used in many areas and I would look at ways it could be used in the community.” Maternity team working with vulnerable groups e.g. substance misuse, deprived communities, Blackpool Teaching Hospital NHS Foundation Trust

“We have to listen to our patients and make them decide for themselves when there is more than one option; this will increase patient satisfaction and adherence to treatment.” Attarbashi Shatha, Consultant Obstetrician and Gynaecologist, Wrightington, Wigan and Leigh NHS Foundation Trust

“I love Shared Decision Making. In the past I felt like I was persuading people and if they opted for a home birth I was worried, because if something went wrong you feel responsible that you persuaded them to take that option. Now I feel much more that it is the patient’s choice and I’m happy with that. It’s informed choice.” Diane Davis, Midwife, Central Manchester University Hospitals NHS Foundation Trust

“It’s about clinicians “letting go” and allowing patients to make a different choice to the one they may have made.” Dr Christopher Goldsmith, Renal Consultant, Aintree University Hospital NHS Foundation Trust
“In the past we would often have known the patient’s preferences, circumstances or values because we had worked with them over a long period of time as their GP. Nowadays however, patients do not always see the same clinician because the practices are so large or because there are trainee GPs in the practice, so perhaps we do need to be asking them what their preferences and values are.” General Practitioner, NHS Trafford

“One of the really good things that is coming out of this work for us is that all the nurses are finding it is changing the way they work generally. I think you can find that you are just repeating the same ‘patter’ that you say to every patient and it is good to have to make changes to this. I can tell in my home visits that I am consciously changing the way I talk to my patients to avoid that usual patter.” Kidney Specialist Nurse, Salford Royal NHS Foundation Trust


http://www.advancingqualityalliance.nhs.uk/SDM/
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