



Measuring Shared Decision Making

A review of research evidence

A report for the Shared Decision Making programme
In partnership with Capita Group Plc

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1. About this report

This report has been commissioned by the Department of Health's national Shared Decision Making programme.

There is a wealth of research evidence around Shared Decision Making: its purpose, the need for it and evidence of its benefits and challenges. This report aims to complement existing literature and evidence, by focusing on measurement and evidence of implementation in England to date.

In doing so, our objective is to support those with an interest in developing Shared Decision Making within their organisations, to help them to understand:

- What elements of the decision making process should be measured, including for example, decision readiness and decision quality
- What measures exist and what research evidence supports their use
- What evidence is there of the implementation of these measures, and in what contexts?

This report provides a summary of the types of measures that are available, a recommendation of which measures might be appropriate for the national programme as well as a rationale for the suggested approach.

Definition: Shared Decision Making

Shared Decision Making is 'a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.'¹

As a concept, Shared Decision Making recognises that both the patient and the clinician bring different but equally valid experiences and expertise to the decision making process. Clinicians understand the treatments, their outcomes and prognosis based on population level data. The patient understands how the condition impacts upon their life and how they feel about risk (Coulter & Collins, 2011¹). Shared Decision Making is recommended in the majority of healthcare decisions where there is more than one feasible option and where the clinician does not have a clear preference as to which clinical option should be chosen.

The focus of this review is on evidence of implementation in England, however, much of the theoretical and scale/measure development work has been undertaken internationally (particularly in North America).



¹ Coulter, A. and Collins, A., 2011. Making shared decision-making a reality: no decision about me, without me. [pdf] London: The Kings Fund. Available at: http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html [Accessed 25 April 2012]

2. About the national Shared Decision Making programme

The Government has made a strong commitment to ensuring that the health service promotes the involvement of patients in decisions about their care and treatment². The mantra ‘no decision about me, without me’ has been widely adopted in Department of Health policy³.

The Shared Decision Making programme has previously supported the development of nine patient decision aids (PDAs), initially brought together and hosted on NHS Direct.

Definition: Patient Decision Aids (PDAs)

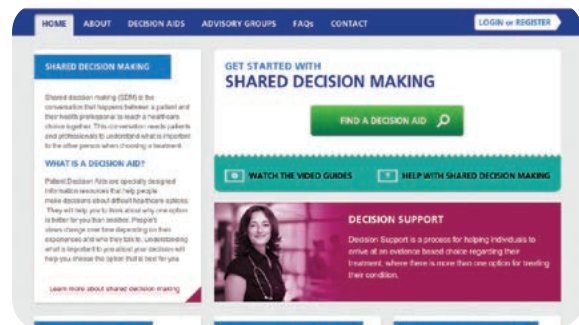
Decision support aids (decision support intervention, decision aid) can be simple, in the form of a treatment option table or more complex in the form of interactive questionnaire/tool, which are increasingly available online. Both interventions seek to offer patients an understanding of the range of options available to them and the implications of those options. These tools are designed to be used as a basis of support for that individual to make a decision. A decision aid can be used both as part of the patient consultation and by the individual before or after a consultation. A recent Cochrane review on the use of decision aids among people facing a treatment or screening decision found that they increase patients’ knowledge and realistic perception of outcomes, are likely to encourage decisions that are consistent with the patients’ values and improve communication between the clinician and patient, allowing greater participation in decision making (Cochrane Review, 2012)⁴.

This year further funding has been secured via the Department of Health’s QIPP programme⁵ to enable:

- The development and hosting of a total of 38 PDAs to cover a wider range of conditions and treatments; and decision coaching by telephone.

- Embedding PDAs into information systems and websites; developing capabilities for commissioning for Shared Decision Making; producing of guidance to support CCGs and the Commissioning Board to meet their statutory duty to involve patients in decisions about their care and treatment; and evaluation of the programme.
- Developing a culture for Shared Decision Making amongst clinicians, commissioners, patients and the public.

As part of the activity to evaluate the programme and to support wider programme activity, Capita has committed to carry out this review of the relevant evidence and literature.



A screenshot of the patient decision aids developed as part of the Shared Decision Making Programme. These are online at <http://sdm.rightcare.nhs.uk>.

2 Health and Social Care Act, 2012 – sections 23 and 26. London: HMSO
 3 The Department of Health 2010. Equity and excellence: Liberating the NHS. (Cm 7881). London: HMSO
 4 Stacey, D et al. Decision Aids for people facing health treatment or screening decisions (Review). The Cochrane Database of Systematic Reviews 2012, Issue 2. Art No.: CD001431. DOI: 10.1002/14651858.CD001431.pub3.
 5 Right Care, 2012. National Shared Decision Making Programme. [online] Available at: <http://www.rightcare.nhs.uk/index.php/shared-decision-making/about-the-sdm-programme/> [Accessed 11 July 2012]

3. The purpose and value of measuring Shared Decision Making

It will become increasingly important to measure the extent to which patients feel ready and able to take part in decisions regarding their health care, as well as measuring the quality of the decisions that are made.

Measurement of Shared Decision Making is necessary for a number of audiences and purposes, as table 1 illustrates. Different measurement approaches might be appropriate in relation to different purposes. For example, a measure that helps clinicians understand the extent of clinical improvement associated with Shared Decision Making might not be appropriate in measuring Shared Decision Making in terms of

commissioning services or indeed accountability. While the field of measurement is still relatively young, much of the work that has been undertaken so far has focussed on measurement for research and clinical improvement purposes. However, measurement for the purposes of accountability/ commissioning is currently less developed.

Table 1 - purposes of measurement

| Purpose | Audience | Interests in measuring SDM |
|--------------------------------------|---|---|
| Accountability and commissioning | Policy leaders (Commissioning Board, Department of Health and others) Commissioners (specialist commissioners and CCGs) | Measuring performance of the national programme Commissioning further support Supporting future policy development in related areas Ensuring that all communities are benefitting from Shared Decision Making and that inequalities are not increased Monitoring impact on the NHS Commissioning services which involve patients in decisions about their care and treatment Commissioning education (for professionals and patients) and other support services Holding services to account |
| Clinical performance and improvement | Clinicians and clinical teams | Developing a case for Shared Decision Making Supporting their own (localised) improvement and development – including appraisal Ensuring that patients are adequately informed and involved in decisions Helping to make Shared Decision Making work in practice |
| Research | Researchers and other stakeholders | Developing the Shared Decision Making evidence base Supporting evaluation of the programme and wider research into the impact of better decision making in England Evaluating the impact of Shared Decision Making in specific populations |

4. Methodology

This review looks at how Shared Decision Making (with a focus on the use of decision aids) has been evaluated both internationally and through smaller projects in England in order to inform the evaluation and measurement strategy of the programme going forward.

The findings in this report were developed following a review of evidence from a variety of sources, including:

- Randomised Controlled Trials (RCTs)
- The Cochrane Review of Decision Aids for people facing health treatment or screening decisions and systematic reviews of Shared Decision Making measures
- The MAGIC programme
- DH commissioned projects published via NHS Networks
- Work conducted by the Health Foundation, Decision Laboratory, King's Fund and Picker Institute

- Work conducted by the Informed Medical Decisions Foundation, Ottawa Health Research Institute, University of Cardiff and University of Newcastle

It is worth noting that this review was not systematic in nature and therefore some evidence may have been missed during its development. The review has focussed on evidence relating to the measurement of Shared Decision Making and, beyond a bias towards work conducted in the UK, there were no specific criteria for inclusion. As there is not a significant amount of UK based work published in this area, both published and unpublished work were included.



5. Findings

5.1 Evidence of progress towards Shared Decision Making in England to date

There is a growing body of evidence around the benefits of Shared Decision Making and strong political support, which is now reflected within some of the system levers in the NHS, such as the authorisation guidance for Clinical Commissioning Groups (CCGs)⁶. However, there is no evidence to suggest that Shared Decision Making is happening in a consistent or uniform way for the majority of patients.

A recent survey of patients showed that 52% felt that they were definitely involved in decisions regarding their care, while the remainder felt less involved (National Inpatient Survey, 2011)⁷. While patients would like to be more involved in decisions about their care, evidence suggests that there may be some challenges associated with clinician perceptions of the benefits of Shared Decision Making. Coulter (2009)⁸ therefore suggests that gaining clinician buy-in to Shared Decision Making may be one of the most significant challenges to its implementation. A systematic review of studies on professional barriers and facilitators to Shared Decision Making showed that time constraints were frequently identified as a barrier, along with the perception that Shared Decision Making is inappropriate for their patients or clinical speciality (Légaré et al, 2008 cited in Coulter 2009).

Other common barriers include the perception that Shared Decision Making is already happening, that patients don't want it, that it is ineffective and that there is no incentive to do it. The type of decision aid (or other support) is also likely to impact on the willingness of clinicians to see the benefits of Shared Decision Making. Elwyn's (2010)⁹ evaluation of the NHS Direct decision aids showed that clinicians (particularly doctors) were supportive of being able to refer patients to online decision aids but were less open to using the print out summaries that were generated by the decision aid. Concerns related to the perceived additional

time that reviewing the patient summaries may take and the perception that they would not be a helpful part of the consultation. This was in direct contrast to both the experience of the patients themselves (who found the patient summaries particularly useful) and the nurses involved in the pilot.

There have also been a number of localised research projects and pilot initiatives to implement Shared Decision Making. The most significant of these is the Health Foundation's MAGIC (Making Good Decisions in Collaboration)¹⁰ programme. The programme is working with a consortium of experts in Cardiff and Newcastle to explore the ways in which shared decision making can be embedded into mainstream clinical practice. The evaluation of its first phase of work is still underway with a report due in Autumn 2012. This literature review draws on some of its emerging findings.



5. Findings (continued)

A number of other initiatives were commissioned last year through the Department of Health, some of which have been evaluated¹¹, these include:

- Training GP trainees in health coaching techniques - London Deanery
- Piloting shared decision making and the use of Patient Decision Aids - South Norfolk Healthcare
- What does a “patient engaged organisation” look like and how do we get there: Clinical and staff perspectives in shared decision making - Herts Valley CCG
- Pilot Study into the Use of the NHS Direct Knee Arthritis Decision Aid - Nuffield Orthopaedic Centre
- Patient decision aid pilot of osteoarthritis of the knee - Solent NHS Trust
- Supporting Shared Decision Making - NHS North West and Picker Institute Europe
- Alzheimer’s call to action – NHS Institute for Improvement and Innovation
- Renal call to action - NHS Institute for Improvement and Innovation

Other organisations, such as pharmaceutical companies and health charities, are also becoming involved in this arena by integrating Shared Decision Making into their practices and approach to providing patient information. An example of this is the Year of Care programme which is a collaboration between the Department of Health, Diabetes UK, The Health Foundation and NHS Diabetes¹². The core principle of the programme is to encourage a collaborative approach to care planning and decision making.

While much of the work that is currently on going is not necessarily ‘joined up’ it is important to capture learning from these projects in order to inform the national programme’s activity to support the implementation of shared decision making and to develop an evaluation framework.

In discussing the evidence of implementation of Shared Decision Making in England it is important to consider the wealth of international evidence that is available. The majority of evidence available to date has been developed in the US and Canada

with The Informed Medical Decisions Foundation, Ottawa Health Research Institute, Harvard Medical School and Université Laval being among the many organisations which are leading the way in this field. The Informed Medical Decisions Foundation, for example, supports demonstration sites across the country in the implementation of Shared Decision Making in clinical settings (both primary and secondary care)¹³.

While the existence of widespread international evidence is recognised, the importance of demonstrating evidence of UK based implementation of Shared Decision Making is key to gaining clinician buy-in to the utility and applicability of Shared Decision Making in England.



- 6 Department of Health. 2012. CCG Authorisation: Draft guide for applicants. [online] Available at: <https://www.wp.dh.gov.uk/commissioningboard/files/2012/04/ccg-auth-app-guide.pdf> [Accessed 2 April 2012]
- 7 NHS Surveys [online] Available at: <http://www.nhssurveys.org/> [Accessed 15 May 2012]
- 8 Coulter, A., 2009. Implementing shared decision making in the UK. A report for the Health Foundation. [online] Available at: <http://www.health.org.uk/publications/implementing-shared-decision-making-in-the-uk/> [Accessed 24 April 2012]
- 9 Elwyn, G., 2010. NHS Direct as a platform for decision support for patients: evaluation of phase 1. [online] Available at: <http://www.nhsdirect.nhs.uk/News/NewsArchive/2010/NHSDirectPilotsANewApproachToPatientsTreatmentDecisions> [Accessed 4 April 2012]
- 10 The Health Foundation, 2012. MAGIC. [online] Available at <http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/> [Accessed 4 April 2012]
- 11 NHS Networks. 2012. Project outputs [online] Available at: <http://www.networks.nhs.uk/nhs-networks/sha-shared-decision-making-and-information-giving/news/sha-project-outputs-now-available> [Accessed 2 April 2012]
- 12 NHS Diabetes. 2012. Year of Care [online] Available at: http://www.diabetes.nhs.uk/year_of_care/ [Accessed 4 April 2012]
- 13 Informed Medical Decisions Foundation. 2011. [online] Available at: <http://informedmedicaldecisions.org/> [Accessed 4 April 2012]

5. Findings (continued)

5.2 The decision making process

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 (Lloyd, A, Joseph-Williams & Elwyn, G. 2011).

However, it is also clear that the following factors will have a significant impact:

- Understanding the treatment/management options available
- Understanding consequences, both in terms of the benefits and risks of each treatment/management option
- Feeling supported in the deliberation process
- Feeling supported in whichever decision they choose to make
- Having enough time to consider and digest the available options
- Appropriate timing of decision support intervention

(Coulter, A & Collins A, 2011)¹⁴

In terms of the process associated with making the decision, Elwyn and Charles (2009) have used the theoretical model of decision making developed by Charles et al (2007), as cited in Elwyn & Charles (2009), as a starting point to describe how a model of decision making could be applied to Shared Decision Making. The model¹⁵ encompasses three stages, which rely on both the patient and clinician playing a reciprocal role.

Information exchange

- The patient identifies their beliefs, values and preferences (with support from the clinician) that may impact on their choice of treatment/management approach
- The clinician informs the patient of their treatment/management options and explains the risks and benefits of each option

Deliberation

- The pros and cons of the available treatment options are discussed in light of the evidence and patient preferences

Implementation

- Both the patient and clinician work together to attempt to achieve a consensus and the clinician may offer a specific recommendation which contributes to the decision making

Elwyn & Charles (2009) point out that the implementation of each of these stages into mainstream clinical practice is likely to provide individual challenges and complexities, but that each stage is required in order to achieve the implementation of Shared Decision Making.

It is likely that some groups may need more specific or targeted support in the decision making process. In a survey conducted in 2005 by Picker Institute, it was found that, among those with a chronic condition, the elderly, those from lower social grades and those who are less educated, are generally less likely to be confident enough to become significantly involved in the management of their healthcare (Ellins, J & Coulter, A. 2005)¹⁶.



¹⁴ London: The Kings Fund. Available at: http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html [Accessed 25 April 2012]

¹⁵ Elwyn, G., & Charles 2009. Shared Decision Making in Healthcare. Achieving Evidence Based Patient Choice. Chapter 17

¹⁶ Ellins, J., & Coulter, A., 2005. How engaged are people in their healthcare? Findings of a National telephone survey. London. Picker Institute

5. Findings (continued)

5.3 What elements of this process should be measured?

There are a number of elements of the decision making process that can be measured as a means of evaluating Shared Decision Making. These include: outcome of decision, readiness to make a decision and decision quality.

The characteristics of a 'good' decision has in the past been debated (Elwyn & Miron-Shatz, 2009¹⁷), although it seems a consensus regarding the need to consider decision process as well as the decision outcome has been recognised as key to achieving a 'good' decision (Elwyn & Miron-Shatz 2009, Bekker, 2006¹⁸). Elwyn & Miron-Shatz (2009) argue that simply measuring decision outcome is not a meaningful indicator of quality, as the eventual outcome can be dependent upon many external factors. Bekker (2006) also discusses decision quality in terms of the expected utility theory (that decisions are made based on greatest expected utility) vs. reasoned choice (that decisions should be evaluated on how individuals make decisions). Bekker concludes that individuals are unlikely to have the cognitive ability to evaluate the likely utility resulting from a particular decision. It is therefore suggested that effective measurement of Shared Decision Making must separate the outcome of the decision from the process of making the decision.

With this in mind, consideration of a suitable measure of decision quality for the national programme 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 be considered alongside these qualitative measures.

Definition: decision quality

The consistency of the individual's decision with their values, satisfaction with decision, participation in decision-making and patient-clinician communication (Stacey et al, 2012)¹⁹.



17 Elwyn, G., & Miron-Shatz, T., 2009. Deliberation before determination: The definition and evaluation of good decision making. [online] Available at <http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2009.00572.x/abstract> [Accessed 4 May 2012]

18 Bekker, H., 2006. Genetic Screening: Facilitating Informed Choices. [online] Available at: Encyclopaedia of Life Sciences [Accessed 24 April 2012]

19 Stacey, D et al. Decision Aids for people facing health treatment or screening decisions (Review). The Cochrane Database of Systematic Reviews 2012, Issue 2. Art No.: CD001431. DOI: 10.1002/14651858.CD001431.pub3

5. Findings (continued)

5.4 Existing measures of shared decision making

In recent years a number of measures have been developed to evaluate decisions; these have been reviewed systematically elsewhere (Scholl et al, 2012)²⁰. The review conducted by Scholl organises existing and new measures into a framework separating measurement of feelings prior to the decision, decision process and decision outcomes.

See table 2 for their summary of published instruments relating to decision process and outcome.

Table 2 – published instruments relating to decision process/outcome

| Scale/Instrument | Details | Patient rating | Multi-faceted | Used in the UK |
|--|---|----------------|---------------|----------------|
| Decision Support Analysis Tool (Guimond et al., 2003) | Practitioners decision support, observer rating | ✗ | ✓ | ✗ |
| Decision Analysis System for Oncology (Brown et al., 2001) | SDM process, 70 items, 3-point scale, observer rating | ✗ | ✓ | ✗ |
| Dyadic OPTION Scale (Melbourne et al., 2010;2011) | SDM process, 12 items, 4-point scale, patients and physician rating, correlates to the OPTION scale | ✓ | ✓ | ✓ |
| Facilitation of Patient Involvement Scale (Martin et al., 2010) | Perceived physician encouragement for participation, 9 items, 6-point scale, patient rating | ✓ | ✓ | ✗ |
| 9-item Shared Decision-Making Questionnaire (Kriston et al., 2010) | SDM process, 9 items, 6-point scale, patient rating | ✓ | ✓ | ✗ |
| OPTION Scale (Elwyn et al., 2005) | SDM process, 12 items, 5-point scale, observer rating | ✗ | ✓ | ✓ |
| Perceived involvement in Care Scale (Lermann et al., 2005) | Degree of involvement in decision making, 13 items, yes/no scale, patient rating | ✗ | ✓ | ✓ |
| Rochester Participatory Decision Making Scale (Shields et al., 2009) | Physician behaviour encouraging participation, 9 items, 3-point scale, observer | ✗ | ✗ | ✗ |

²⁰ Scholl, I., et al 2012. Measurement of shared decision making – a review of instruments, [online] Available at: www.sciencedirect.com [Accessed 26 April 2012]

5. Findings (continued)

| Scale/Instrument | Details | Patient rating | Multi-faceted | Used in the UK |
|--|--|----------------|---------------|----------------|
| Scale on participation in nursing care (Smoliner et al., 2009) | Participation preferences and experiences in nursing care, 10 items, 6-point scale, patient rating | ✓ | ✗ | ✓ |
| Shared Decision Making Scale (Singh et al., 2010) | SDM process, 20 items, 2-point scale, observer rating | ✗ | ✓ | ✓ |
| The Health Care Empowerment Questionnaire (Gagnon et al., 2006) | Individual empowerment in relation to personal healthcare, 10 items, 4-point scale, patient rating | ✓ | ✗ | ✗ |
| Bereaved family regret scale (Shiozaki et al., 2008) | Decisional regret, 7 items, 5-point scale, rating by family members | ✗ | ✗ | ✗ |
| COMRADE (Combined Outcome Measure for Risk Communication and Treatment Decision-making Effectiveness) scale (Edwards et al., 2003) | Risk communication and confidence in decision, 20 items, 5-point scale, patient rating | ✓ | ✓ | ✓ |
| Decision Attitude Scale (Sainfort & Booske, 2000) | Satisfaction with decision/choice, usability of info, adequacy of info, 9 items, 5-point scale, patient rating | ✓ | ✓ | ✗ |
| Decision Evaluation Scales (Stalmeier et al., 2005) | Satisfaction-uncertainty, informed choice, decision control, 15 items, 5-point scale, patient rating | ✓ | ✓ | ✗ |
| Decision Regret Scale (Brehaut et al., 2003) | Decisional regret, 5 items, 5-point scale, patient rating | ✓ | ✓ | ✗ |
| Decisional Conflict Scale (O'Connor, 1995) | Uncertainty in decision making, informed values, clarity, support, effective decisions. 16 item scale, 5-point scale, patient rating | ✓ | ✓ | ✓ |
| Provider Decision Process Assessment Instrument (Dolan, 1999) | Degree of comfort with a treatment decision, 9 items, 5-point scale, physician rating | ✗ | ✗ | ✓ |
| Satisfaction with Decision Scale (Holmes-Rovner et al., 1996) | Satisfaction with decision, 6 items, 5-point scale, patient rating | ✓ | ✗ | ✗ |

5. Findings (continued)

The review points out that, as the field of measurement of Shared Decision Making is still relatively young, an abundance of research in which measures are developed and tested is available (Scholl et al, 2012). As a result, while there are many different measures available (many of which have demonstrated reliability) the degree to which the available measures are validated varies significantly. Many of the scales available have been validated in only a small number of studies (often by the scale author) and often have not undergone testing in a broader range of samples (Simon, D, Andreas L & Harter, 2007)²¹

As summarised on table 2, in evaluating the available measures, this review has considered the following attributes;

- Whether it is a patient rating
- Whether is multi-faceted or only covers one dimension of the decision
- Whether the scale has been used in the UK

Furthermore, many of the scales that have been developed are limited in dimension and do not take account of the various factors that contribute to a 'good' decision. The Decision Regret Scale (Brehaut et al., 2003, cited in Scholl et al, 2012), for example, looks only at distress or remorse following a decision. The satisfaction with decision scale (Holmes-Rovner et al., 1996, cited in Scholl et al, 2012) on satisfaction, and COMRADE, focuses on risk and confidence in decision.



²¹ Simon, D., Loh, A., Harter, M., 2007. Measuring (Shared Decision Making) – a review of psychometric instruments, [online] Available at: www.sciencedirect.com [Accessed 26 April 2012]

5. Findings (continued)

5.5 What measures have been most widely tested?

In comparison to many of the scales that have been developed, the decisional conflict scale (O'Connor, 1995)²², which is explained in more detail below, is multi-dimensional in its assessment of decision process and outcome, has been extensively validated and has been widely used both in the UK and internationally and across a broad range of treatment areas.

Definition: decisional conflict

The 16 item decisional conflict scale was developed to elicit information concerning the decision maker's: 1) uncertainty in making a choice; 2) modifiable factors contributing to the uncertainty, such as lack of information, unclear values, and inadequate social support; and 3) perceived effective decision making (O'Connor 1997).

In the recent Cochrane review (2012), it was found that of the 86 studies included, 39 used the decisional conflict scale and, of these, eight were conducted in the UK. The decisional conflict scale measures decision uncertainty that leads to decision delay, and quantifies modifiable factors which contribute to uncertainty, both during the process of deliberation and following the choice i.e. the outcome (O'Connor 1997)²³. It constitutes 16 items and can be displayed in a statement format (most used/tested) or in a question format. A lower literacy scale of 10 items is also available, along with a validated four item scale which is recommended for use in clinical practice.

The scale was developed in Canada and considers both the process (in terms of feeling informed, risks, benefits and support) and the outcome of the decision (in terms of uncertainty and satisfaction

with the decision). While the scale considers many of the dimensions of decision quality i.e. satisfaction with decision, participation in decision making and patient–clinician communication, it is important to note that the measure does not identify whether an individual's decision is in concordance with their values. The decisional conflict scale can act as both a means to evaluate the impact of decision support intervention at a local level and also provides a method of fine tuning them to patient need (O'Connor, 1997) as it helps clinicians to identify patients who are experiencing clinically significant decisional conflict. However, the decisional conflict scale may be less suitable for evaluating performance at a national level as it is yet to be tested in this context

The decisional conflict scale has been used in a broad range of treatment areas (Randomised Control Trials) including:

- Fetal screening for Down's syndrome (UK)
- HRT (UK)
- Colorectal cancer screening
- Prostate cancer screening
- Surgical intervention for breast cancer
- Breast cancer screening/testing
- Prenatal diagnostic testing
- Hypertension (UK)
- Menopause symptoms
- Birthing options after caesarian section (UK)
- Type 2 diabetes
- Benign prostatic hypertrophy
- Osteoporosis (UK)
- Menorrhagia (UK)
- Atrial fibrillation (UK)
- Ovarian cancer risk management
- Cystic fibrosis
- Termination of pregnancy (UK)

(Stacey et al, 2012)²⁴

5. Findings (continued)

In addition to the published studies of the decisional conflict scale, a number of unpublished studies in the UK have used the scale, including two projects which used the NHS Direct osteoarthritis of the knee decision aid.

In terms of implementation of measures into clinical practice, it is understood that a 16 item scale might be considered too long to become part of a regular patient consultation. In light of this, the 4-item SURE scale (Sure of myself, Understand information, Risk-benefit ratio, Encouragement) was developed for use in clinical practice from the decisional conflict scale. It was developed 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 (Légaré et al, 2010)²⁵. 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. During this study, the instrument was implemented using a patient self-completion questionnaire either after initial consultation or after watching the decision aid videos (depending on which of the study groups they fell into). The self-administered nature of the SURE instrument suggests that it will also lend itself to an online application (potentially as part of a decision aid) as well as a more traditional paper survey, which may be used when alternate decision support is used.



22 O'Connor, AM., 1995 [Abstract]. Validation of a decisional conflict scale, [online] Available at: <http://mdm.sagepub.com/content/15/1/25.short> [Accessed 2 May 2012]

23 O'Connor, AM., 1997. Decisional Conflict Scale [online] Available at: www.ohri.ca/decisionaid [Accessed 2 May 2012]

24 Stacey, D et al. Decision Aids for people facing health treatment or screening decisions (Review). The Cochrane Database of Systematic Reviews 2012, Issue 2. Art No.: CD001431. DOI: 10.1002/14651858.CD001431.pub3

25 Légaré, F., 2010 et al. Are you SURE? Assessing patient decisional conflict with a 4-item screening test, [online] Available at: <http://www.cfp.ca/content/56/8/e308.full> [Accessed 10 May 2012]

5. Findings (continued)

5.5 What measures have been most widely tested?

SURE Test - version for clinical practice

Yes equals 1 point, No equals 0 points.

If the total score is less than 4, the patient is experiencing decisional conflict.

| | | Yes [1] | No [0] |
|----------------------------------|--|--------------------------|--------------------------|
| Sure of myself | Do you feel SURE about the choice for you? | <input type="checkbox"/> | <input type="checkbox"/> |
| Understanding information | Do you know the benefits and risks of each option? | <input type="checkbox"/> | <input type="checkbox"/> |
| Risk-benefit ratio | Are you clear about which benefits and risks matter most to you? | <input type="checkbox"/> | <input type="checkbox"/> |
| Encouragement | Do you have enough support and advice to make a choice? | <input type="checkbox"/> | <input type="checkbox"/> |

The SURE scale is simple to analyse as it is possible to see, at a glance, whether the patient is experiencing decisional conflict i.e. if the patient says no to any of the four questions they are likely to be experiencing decisional conflict. The measure has utility in terms of providing clinicians with a mechanism for ensuring that patients are able to make a decision.

However, it does not evaluate satisfaction with the decision, specific knowledge of the condition and treatment options or indeed the consistency of the decision, with the patients values.

While the validation study conducted by Légaré et al indicates that the SURE scale provides an acceptable measure of decisional conflict which, due to speed and simplicity, is easy for clinicians to use, it is also worth noting that further usage in a broader range of patients and detailed testing of its validity and reliability is necessary.

As is evident from the broad range of treatment areas that the decisional conflict scale has been used in, one of the significant benefits of this

measure is its utility in a variety of conditions with no need to adjust to a specific condition. As an alternative to this approach, the decision quality instrument developed by Sepucha et al (2007)²⁶, measures the extent to which patients are making informed decisions and whether the decision made fits with their values specifically in the context of their condition.

Sepucha conducted a study, which explored the measurement of the quality of breast cancer decisions and concluded that measuring patients decision-specific knowledge as well as concordance of treatment options with their values are both important and necessary in measuring the quality of decisions. The implications of this work suggest that measures of decision quality should be developed for each condition specifically in order that decision specific knowledge can be adequately measured. Sepucha has led a number of other studies^{27 28 29 30} and reviews through the Harvard Medical School which explore the measurement of decision

5. Findings (continued)

quality across a range of conditions which have further illustrated the importance of evaluating concordance with the values and beliefs of the patient and the importance of decision-specific knowledge. A theme which runs through much of this work is the importance of recognising the differences between clinician and patient perspectives regarding the aspects of the decision in terms of available options, priorities of treatment and beliefs about the most appropriate course of action. In addition, a study conducted by Sepucha et al in 2011³¹, concludes that patients facing common medical decisions are not always able to



accurately assess how well informed they are. The study highlights the importance of both providing information to the patient and measuring the extent to which the patient has understood that information in order to facilitate and measure 'good' decision making.

The decision quality instrument has been adapted as part of the MAGIC programme (The Health Foundation)³² resulting in the decision quality measure (DQM). The DQM was used as part of the MAGIC programme to measure decisions relating to the treatment of breast cancer in the UK. During the programme the DQM was used to demonstrate a number of different aspects of the decision including improvement in knowledge, readiness

to make a decision and increased confidence in choice of treatment after consultations. In addition, the DQM was used by some teams to show that patients were informed about available options, ready to decide and confident in their choice of treatment. During the MAGIC programme the DQM was used alongside a shared decision making questionnaire, which sought to evaluate the patients perspective of involvement in their own care in order to provide feedback to clinicians.

While the benefits of using the DQI & DQM are clear, a number of practical implications require some consideration. Both measures particularly lend themselves to the measurement of decisions for improvement purposes, which may be appropriate in the context of the programme but may not be suitable when measuring performance of SDM more broadly. Furthermore, the need to adjust the decision quality measure according to the specific condition and the development work required in order to achieve a DQM for each clinical pathway covered by the PDAs developed as part of the programme, may also be considered a disadvantage when considering widespread usage in the short term. On a practical level, the length of the instrument (20+ questions) is also likely to be problematic in everyday clinical practice.

- 26 Sepucha, K et al., 2007. An approach to measuring the quality of breast cancer decisions. Patient Educ Couns. Epub 2006 Oct 4, Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17023138> [Accessed 17 July 2012]
- 27 Sepucha, K et al. 2008. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. Patient Education Counsel. Epub Aug 20. Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/18718734> [Accessed 17 July 2012]
- 28 Sepucha, K., Ozanne, E & Mulley, AG Jr., 2006. Doing the right thing: systems support for decision quality in cancer care. Annals of Behavioural Medicine [online] Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17107289> [Accessed 17. August 2012]
- 29 Sepucha, K., Ozanne, EM. 2009. How to define and measure concordance between patients' preferences and medical treatments: A systematic review of approaches and recommendations for standardization. Patient Education Counsel. Epub Jun 30. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/19570647> [Accessed 17 July 2012]
- 30 Lee, CN., Hultman CS., Sepucha, K., 2010. Do patients and providers agree about the most important facts and goals for breast reconstruction decisions? Annals of Plastic Surgery. Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20395809> [Accessed 17 July 2012]
- 31 Sepucha, K., et al 2011. How does feeling informed relate to being informed? The DECISIONS survey. Medical Decision Making. 2010 Sept-Oct. Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20881156> [Accessed 17 August 2012]
- 32 The Health Foundation, 2012. MAGIC. [online] Available at <http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/> [Accessed 4 April 2012]

5. Findings (continued)

5.6 Measuring decision readiness

Definition: decision readiness

The extent to which the patient understands the options available them and feels ready to make a decision.

As well as measurement of the decision process and outcome, some scales seek to measure the patient's feelings prior to making the decision in terms of decision readiness, willingness to take part in the decision and preparedness for making a decision.

During the evaluation of the decision aids developed by NHS Direct (Elwyn, G. 2010)³³ the DelibeRATE measure was used to assess decision readiness. DelibeRATE is a 10 item instrument which measures the extent to which the patient understands their options, along with their risks and benefits and feels able to make a decision. The scale can show whether patients need more support in their decision making and the study indicated that levels of deliberation varied, depending on the condition (osteoarthritis of the knee, localised prostate cancer and benign prostatic hyperplasia). The DelibeRATE measure has been used to evaluate the MAGIC programme, although limited evidence of its use elsewhere is available.

Alternative scales of decision readiness include the preparation for decision making scale (O'Connor, AM & Graham, ID 1995)³⁴ which evaluates the impact of patient decision support and the extent to which the support prepares the patient to make a decision. The scale consists of 11 items, each with five response categories, and a shorter version has been developed for clinical use. The preparation for decision making scale has been used in the two local unpublished NHS projects

which looked at the use of decision aids for osteoarthritis of the knee.

The Patient Activation Measure used by Ellins & Coulter (2005)³⁵, and developed by Hibbard et al (2004)³⁶, measures the extent of the patient's knowledge, confidence and skills for self-management of their health condition. The measure evaluates the patient's ability to become actively involved in their care and provides clinicians with information about their patient's capability to do so. However, the measure evaluates readiness for self-management specifically, rather than readiness to make a decision between alternate options, and may therefore be difficult to apply to the national programme.

Overall, there is less available evidence relating to scales of decision readiness, suggesting that further investigation is required. Recommending an approach for the national programme requires further consideration. However, the DelibeRATE measure and preparation for decision making scale could be trialled in support of local evaluation activity.

33 Elwyn, G., 2010. NHS Direct as a platform for decision support for patients: evaluation of phase 1. Cardiff University

34 Graham, ID., & O'Connor, AM., User Manual – Preparation for Decision Making. 1995 [updated 2010]. Available at: www.ohri.ca/decisionaid [Accessed 2 May 2012]

35 Ellins, J., Coulter, A., 2005. How engaged are people in their healthcare? Findings of a national telephone patient survey. London. Picker Institute.

36 Hibbard, J., et al, 2004. Developing the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. [online] Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361049/> [Accessed 24 April 2012]

6. Implications of implementing measurement of Shared Decision Making

What should measurement look like?

It is clear from reviewing the available evidence that in order for a measure to be integrated into clinical practice (and used for commissioning purposes) the measure must be;

- Easy to administer, preferably self-administered
- Flexible i.e. can be used with a decision aid or without
- Quick to administer i.e. not too many items in the instrument
- Easy to analyse, both for clinicians on a day to day basis and on an aggregated level

In light of the challenges in embedding and implementing Shared Decision Making (the most significant of which is gaining clinician buy-in) it is important that measurement supports the overall approach by achieving the criteria outlined above.

While there is limited evidence relating to the

implementation of the SURE scale specifically, what is available indicates that these criteria could be achieved. The case studies that are planned as part of the programme provide an excellent opportunity to conduct some initial testing of the application of the SURE score and the extent to which it meets the criteria set out above. Some initial usage of the SURE scale has already been undertaken as part of the programme. AQuA are responsible for developing a culture for SDM amongst clinicians, commissioners, patients and the public and as part of this strand of work have collected approximately 950 SURE scores among practices with the aim of evaluating improvement. The experience of AQuA thus far suggests continued usage of the SURE scale (for improvement purposes at least) although other instruments currently in development are also being considered for future use.



7. Conclusion

What approach should the programme and NHS organisations take to measure Shared Decision Making?



Research evidence in the area of the measurement of Shared Decision Making is a growing field. While there is currently no 'gold standard' in terms of measurement, the need to measure the process as well as the outcome is apparent. Furthermore, the need to balance the amount of time available during a patient consultation with the requirement to deliver a decision aid or other decision support materials, and evaluate decisions made during that consultation, presents a unique set of challenges in terms of implementation and gaining buy-in from clinicians.

With these challenges in mind, the review of evidence available suggests that the use of the decisional conflict scale (DCS) or the associated four item scale, SURE, would be most appropriate for use as part of the national programme initially. The decisional conflict scale, and to a much

lesser extent the SURE scale, has been widely used internationally and in a wealth of different conditions. Furthermore, the scale is general in nature and does not need to be adjusted for each condition. It can be used alongside a decision aid and in conjunction with alternative decision support materials, making it an adaptable measure.

At this point it is also worth noting the limitations of both the DCS and SURE scales. For example, neither evaluate the extent to which a decision is in concordance with the individual's values which has been identified by Sepucha (2007)³⁷ as being necessary for the effective measurement of decision making. In addition the SURE scale does not measure satisfaction with the decision or explore specific decision knowledge (which is only possible when using a scale which is specifically related to the clinical pathway, such as the DQI/DQM).

7. Conclusion (continued)

While it is possible to balance some of these limitations with the benefits in terms of speed and simplicity of using a 4-item instrument, the lack of data relating to general satisfaction with the decision, concordance with individual values and decision-specific knowledge must be acceptable to the programme if the SURE scale is to be used. A possible alternative would be to combine the SURE measure with one or two questions relating to satisfaction and efficacy of the decision taken from the DCS. For example: Do you expect to stick with your decision? Are you satisfied with your decision? However, as the SURE measure uses dichotomous questions and the DCS uses scaled responses it is recommended that this approach is explored with the developers of the SURE scale and DCS (Légaré, F & O'Connor, AM) before further consideration. Should any additional questions be used alongside the SURE measure it is recommended that they are piloted during the case study work as part of the programme.

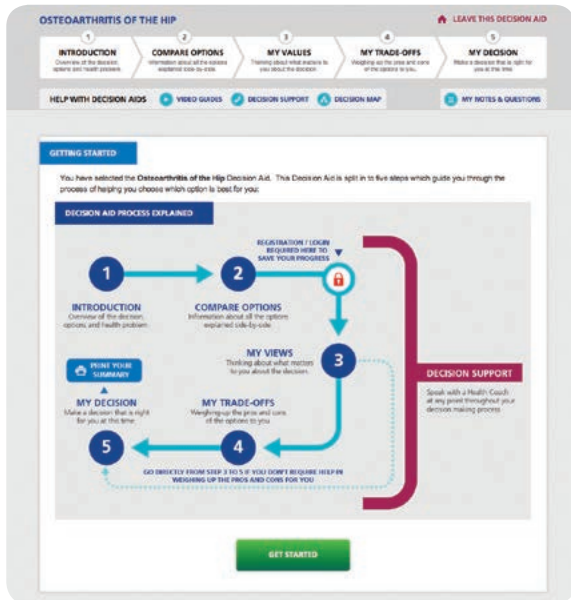
As the field of measuring decision quality is still very young and is continually evolving it is likely that other measures such as a DQM/DQI may become more feasible in the future. Although less

suitable from a practical point of view at present, both the DQM and DQI offer a comprehensive evaluation of decision quality in terms of evaluating patient knowledge, concordance with the patients values and beliefs and the involvement of the clinician in providing all of the necessary support and information. It is therefore recommended that their continuing development as well as the development of other measures are monitored by the programme as their adoption may be considered at a later date. It is also recommended that a DQM/DQI is used as part of the local case study evaluation if applicable (case study area and clinical pathway is still to be defined).

It remains to be seen whether the SURE scale will provide an effective measure to evaluate performance of Shared Decision Making/ Patient Decision Aids on a national level or for commissioning purposes as it has not been tested in either contexts. However, in the short term it is likely to be most suited to measurement for research purposes and to guide improvement locally. It is planned that the baselining activity will establish measures for the broader performance of Shared Decision Making and the Patient Decision



7. Conclusion (continued)



The 'Get Started' screen of a Patient Decision Aid

Aids, by taking a range of measures into account. In lieu of the ideal measure for decision quality at present, consideration should be paid to the national patient survey conducted on behalf of the Care Quality Commission (CQC) which has asked patients "Were you involved as much as you wanted to be in decisions about your care?" since 2002. While this alone does not provide an adequate measure of the quality of a decision it could provide an indication of the wider impact of the Shared Decision Making movement and the use of Patient Decision Aids (which could be particularly useful for commissioners). It is planned that the data collected during this survey will also be included in the evidence baseline, which forms part of the evaluation activity associated with the programme.

In terms of decision readiness, there is not enough available evidence to recommend a definitive approach to the programme. It is therefore recommended at this point in time that the DelibeRATE and preparation for decision-making scales are considered for usage in the future. Given the dynamic nature of the measures of Shared Decision Making it is important that future planning of the research strategy should take account the movement towards a dyadic

approach to the measurement of Shared Decision Making. The review conducted by Scholl (2011) et al found that while the majority of scales evaluate the patient perspective in respect of decision making there is a trend towards measuring the Shared Decision Making process from a dyadic perspective i.e. from the point of view of both the patient and clinician. As part of their work on creating a receptive culture for Shared Decision Making, AQuA are already starting to use this type of approach. They are gathering data from both clinicians and patients. Measures in this area have not yet been fully developed and tested and it is therefore recommended that the national programme should take this kind of approach into consideration as further research is conducted.



37 Sepucha, K et al., 2007. An approach to measuring the quality of breast cancer decisions. Patient Education Counsel. Epub 2006 Oct 4, Abstract only. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17023138> [Accessed 17 July 2012]

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