2017 HARC SCHOLARSHIP REPORT

What can we learn from international experiences to improve the uptake of shared decision making in NSW Health?

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1. Executive summary

This report outlines findings from a 2017 Hospital Alliance for Research Collaborative (HARC) Scholarship study that investigated approaches to advancing the uptake of shared decision making (SDM) in NSW Health.

SDM is a process of involving patients in making informed and preference based decisions about their care and treatment. SDM is an evidence-based decision making process that represents the crux of person-centred care.

Internationally, efforts to systematically implement SDM are considerable, with 22 countries contributing to the special issue of the *Journal of Evidence and Quality in Health Care, International Accomplishments in Shared Decision Making* (2017).

In Australia SDM is embedded in the *National Safety and Quality Health Service (NSQHS) Standards* and is identified as a key theme in the Australian Commission on Safety and Quality in Health Care (ACSQHC) *Investigating and Addressing Unwarranted Variation* paper. Despite these advances, Australia is considered to be lagging behind many other countries in the use of SDM processes and decision aids.

The aim of the 2017 HARC Scholarship was to identify effective implementation approaches to advance the uptake of SDM to enhance person-centred care, improve decision quality and reduce unwarranted variation in care across NSW Health.

A mixed method design was used to identify implementation approaches and inform a set of recommendations for the Agency for Clinical Innovation (ACI) and NSW Health:
- theoretical analysis of barriers for NSW Health using the Theoretical Domains Framework (TDF), COM-B ('capability', 'opportunity', motivation' and 'behaviour') model and Behaviour Change Wheel (BCW)
- rapid literature review using the 2017 special edition of the *Journal of Evidence and Quality in Healthcare: International Accomplishments in Shared* Decision *Making*
- participation in the international workshop, *National strategies for implementing shared decision making*
- attendance at the ninth International Shared Decision Making (ISDM) conference in July 2017
- consultations with international experts and site visits.

To facilitate sustainable implementation of SDM we need to understand and address the barriers in a systematic way. Results from the application of the TDF, COM-B and BCW indicated that education, training, enablement, modelling, incentivisation, persuasion and environmental restructuring would be effective in advancing SDM in NSW Health. Results

obtained from all other methods indicated that coordinated efforts, policy and legislation, clinical opinion leaders, access to high quality decision aids and evidence, training and education were success factors in the implementation of SDM.

Preliminary recommendations and suggested considerations are proposed in this paper. The following recommendations can be used to inform and prioritise strategies for advancing the uptake of SDM within NSW Health.

- Establish a Collaborative to encourage SDM and coordinated efforts in NSW Health.
- Build SDM awareness and system-wide capability.
- Implement and evaluate SDM through demonstration sites.
- Invest in decision aid development and dissemination.
- Identify suitable measures to understanding SDM performance.

The recommendations and considerations proposed should be considered as part of an ongoing investment to enhancing patient experience, person-centred care and reducing unwarranted variations in care.

Acknowledgements

2. Introduction

It has been argued that shared decision making (SDM) represents the crux of person-centred care and that, without SDM, optimal evidence-based practice cannot occur.[1]

SDM is defined as a process of involving patients in making informed and preference based decisions about their care and treatment. A 2014 systematic review [2] of SDM as a concept identified the following nine essential elements that can be translated into specific health professional behaviour:
1. The healthcare problem is defined and explained.
2. Alternative treatment options are presented.
3. Benefits, harms and costs of alternative treatment options are discussed.
4. Patient values and preferences are clarified.
5. Patient ability and self-efficacy is discussed and clarified.
6. What is known is presented and recommendations are made.
7. The patient's understanding is checked and clarified.
8. Decision is explicitly made or deferred.
9. Follow up is arranged.

Decision aids can be used in SDM to present easy to understand evidence based information and guide patients through the decision making process. Decision aids outline treatment options and the benefits and harms of each option, and help patients clarify their values and preferences for care and treatment.[3] They are particularly useful and effective when there is more than one treatment option and neither is clearly better, or when options have benefits and harms that may be valued differently by the patient making the decision.[2]

A 2017 Cochrane review of 105 studies reviewed the effects of decision aids for health treatment and screening decisions compared to usual care. Results showed that patients who used decision aids had increased knowledge and were better informed, had more accurate risk perceptions and were more involved in the decision making process. There was no consistent effect on cost, adherence or health outcomes.[1, 3, 4]

A *British Medical Journal* Clinical Evidence review of 3,000 treatments found that only 11% were clearly beneficial.[5] This finding reinforces the need for health professionals to translate the probabilistic nature of evidence and support patients to make informed and preference based decisions about treatment. SDM has also been shown to reduce overuse of treatment options that are not associated with benefits.[2]

Measuring SDM continues to be a challenge internationally. While a recent systematic review found more than 40 instruments available to assess the process of SDM, the quality of measurement is lacking because validation is missing or the methods are poor.[9]

The Bureau of Health Information (BHI) routinely collects measures of SDM performance in NSW Health including:

- whether the patient was involved in decisions about treatment and care
- the provision of information and clarity of communication with patients and their families.[10]

Recent data show that 60% of 23,929 adult admitted non-Aboriginal patients and 58% of 2,467 Aboriginal patients were involved, as much as they wanted to be, in decisions about their care and treatment.[10] Further, 85% of 21,440 non-Aboriginal patients and 78% of 2,507 Aboriginal patients said they received the right amount of information about their condition or treatment.[10]

The ACSQHC has identified SDM as a strategy for reducing unwarranted variations in care and has firmly established SDM in the *NSQHS Standards* (2017).[6,7] The ACSQHC *Investigating and addressing unwarranted variation* paper states:

> *Shared decision making is therefore widely seen as a strategy for promoting patient-centred care and reducing unwarranted variation. If shared decision making is to occur, patients and clinicians need to have ready access to evidence about treatment options, understandable information about the probability of risk and benefit, and guidance on weighing the pros and cons of different options. The clinical culture must support patient engagement.* [6]

Despite the growing interest and emerging evidence base, the adoption of SDM (including the use of decision aids) in Australia has been slow. Barriers to using SDM in Australia include a lack of coordinated national effort, policy, advocacy, research funding, training, resources and implementation.[8]

To facilitate sustainable implementation of SDM in NSW Health, we need to understand and address the barriers to its use in a systematic way. The aim of this 2017 HARC scholarship was to identify effective implementation approaches to advance the uptake of SDM to enhance person-centred care, improve decision quality and reduce unwarranted variation in care across NSW Health.

3. Rapid literature review

3.1 Review strategy

A rapid literature review was conducted to identify and examine the different implementation approaches being used to advance SDM internationally. The review was conducted using the 2017 special edition of the *Journal of Evidence and Quality in Health Care: International Accomplishments in Shared Decision Making.*

The papers included in the review were from the following 22 countries: Africa, Argentina, Australia, Brazil, Canada, Chile, China, Denmark, France, Germany, Iran, Israel, Italy, Malaysia, Netherlands, Norway, Peru, Spain, Switzerland, Taiwan, the United Kingdom (UK) and the United States of America (USA).

The results were themed and categorised using the following barriers identified in the 2014 Hoffman et al paper[8] on SDM in Australia:
- lack of coordinated effort
- policy
- advocacy
- research funding
- training
- resources and implementation.

3.2 Results

3.2.1 Coordinated efforts

Implementation of SDM has been most systematically approached and coordinated in Canada, Denmark, the USA, Netherlands, Taiwan, the UK and Germany.[9, 10, 11, 12, 13, 14, 15, 16, 17]

The UK established a SDM Collaborative in 2015 to coordinate efforts to support the wider healthcare system to embed SDM into routine clinical practice.[16] Similarly, the German Network for Evidence-Based Medicine was established to promote concepts of evidence-based medicine and SDM in practice, teaching and research.[17]

Most recently, Taiwan has implemented a systematic plan to integrate SDM into clinical practice including decision aid development, a SDM campaign and integration into policy.[15]

3.2.2 Policy

SDM is firmly on the policy agenda in the UK. The NHS strategic plan states, '*when people do need health services, patients will gain far greater control over their own care*'. SDM has also become a legal imperative in the UK following the 2015 Supreme Court ruling on Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland). The practical

implication of this ruling is that people of full mental capacity must be advised about their treatment options, including the risks, so they can make informed choice and consent for treatment.[16]

In the USA, SDM is recognised as a strategy to support value-based healthcare and financial incentives are being used to encourage the adoption into clinical practice. At a federal level there are two procedures that are incentive based and SDM is necessary for reimbursement coverage through Medicare: lung cancer screening with low-dose CT scan and left atrial appendage occlusion. The state of Washington has a preference for SDM as an alternative to informed consent and is also enforcing decision aid certification through law.[13]

3.2.3 Advocacy

Clinical opinion leaders have been instrumental in making the case for SDM implementation in the Netherlands. SDM is firmly on the agenda among patient representative groups, policy makers and professional bodies. The national campaign, *Betere zorg begint met een goed gesprek* (*Better care starts with a good conversation*)*,* has been implemented to improve SDM awareness and utilisation of the 'Ask Share Know' questions to enhance SDM in practice.[14]

In Denmark a national patient survey conducted in 2016 found 50% of 250,000 patients experienced poor communication with health professionals about the risks and benefits of different options for treatment.[12] This was a driver for Danish patient organisations to lobby for greater involvement in making decisions about treatment and advancing SDM.

In Germany a number of organisations are advocating for SDM, including:
- the Institute for Quality and Efficiency in Health Care
- the Commissioner for Patients
- the Agency for Quality in Medicine
- the Institute for Quality and Transparency in Health Care
- the German Network for Evidence-Based Medicine.[17]

3.2.4 Research funding

Canadian funders require patient engagement in research and the University of Montreal has appointed a Research Chair in Patient and Public Partnership. The University of Calgary has also established a training program for patient and community engagement in research.[11]

Internationally, there have been limited studies on the cost-effectiveness of patient decision aids and SDM. However, Canada conducted a cost-effectiveness analysis with a randomised controlled trial (RCT) for the use of decision aids for patients considering a total joint

replacement. Results showed that using patient decision aids produced similar health outcomes and reduced healthcare costs.[11]

In Germany more than €20 million (approximately $31,306,000 AUD) was invested to fund over 70 research projects between 2008-2014 to investigate a diverse range of SDM research questions and interventions.[17]

In the USA 17% of all projects funded by the Patient-Centered Outcomes Research Institute (PCORI) included a decision aid component.[13] PCORI was established to fund research that can help patients make better informed decisions about their healthcare.

3.2.6 Training

The National Competence-Based Catalogue of Learning Objectives in Medicine of the German Medical Faculty Association (MFT) and the German Medical Association has embedded SDM and patient-centred care topics into the curriculum in Germany. The German national curriculum on communication in medicine has been delivered to all 36 medical faculties. Germany is also leading a RCT on e-learning for SDM.[17]

In 2015 the Swiss Medical Association released a directive outlining SDM as the 'ideal model' and that patient preferences should be incorporated into clinical guidelines. In the last five years all Swiss medical schools have formally integrated SDM into pre- and post-graduate training programs.[18]

3.2.7 Resources

The Ottawa Hospital Research Institute in Canada leads and updates the Cochrane review on decision aids and maintains the *A to Z inventory of decision aids*. In addition, the Canadian provinces of Saskatchewan, British Columbia and Alberta purchased access to the Healthwise Knowledgebase, which includes access to over 180 online decision aids adapted for the Canadian context. Laval University in Quebec also created Decision Box, which is a collection of validated printable decision aids on prenatal care, dementia and haematology.[11]

Germany has also invested significantly in decision support technologies that have been developed and implemented for the current National Clinical Practice Guidelines Program. This includes decision aids for asthma, chronic obstructive pulmonary disease, coronary heart disease, diabetes and depression.[17]

In 2016 the Danish government allocated 40 million Danish krone (approximately $830,000 AUD) from the national budget to support decision aid development. This is in addition to the 22 million Danish krone allocated to the development and implementation of specific decision aids for cancer treatment.[12]

Norway has developed a national online portal called DAfactory, which includes access to decision aids and implementation support strategies including guidelines and training resources.[19]

The Netherlands have invested in SDM measurement including the validation of Dutch language versions of instruments including Option 5, SDM-Q9 and CollaboRATE. In addition, generic quality indicators for patient involvement are being validated and integrated into patient reported experience measurements.[14]

Similarly, the USA invested in the evaluation of two patient-reported measures: a measure of decisional quality (Healthwise) and a measure of patient engagement (CollaboRATE). Results showed that sometimes patient reported experiences did not correlate with direct observation of quality. A recommendation was to measure the quality of informed consent.[13]

3.2.8 Implementation

A number of demonstration initiatives have been implemented in the UK to explore the feasibility of integrating SDM into routine clinical practice. This includes MAGIC: Making Good Decisions in Collaboration (exploring how to overcome barriers to SDM implementation) and the Year of Care program (using the House of Care Model to support personalised care planning based on the principles of SDM).[16]

The Netherlands are implementing SDM in 24 clinical pathways in 12 hospitals for stroke care. Its Ministry of Health also implemented a specific registration code on 1 January 2018 to finance the extra time that is needed for SDM during consultation.[14]

In Germany decisions aids are routinely used in single clinical areas, including back pain, antibiotics, anxiety, depression, breast cancer screening, prostate cancer screening, caesarean births, knee pain, tonsil surgery, heavy menstrual bleeding and palliative care. [17]

Canada has developed a model of inter-professional SDM that is being used to guide programs to implement decision coaching. Decision coaching is non-directive and supports patients to develop skills in thinking about treatment options, preparing for discussions about the decisions and implementing the decision.[1]

4. Methods

A mixed method design was used to identify implementation approaches and inform recommendations to advance SDM in NSW Health:
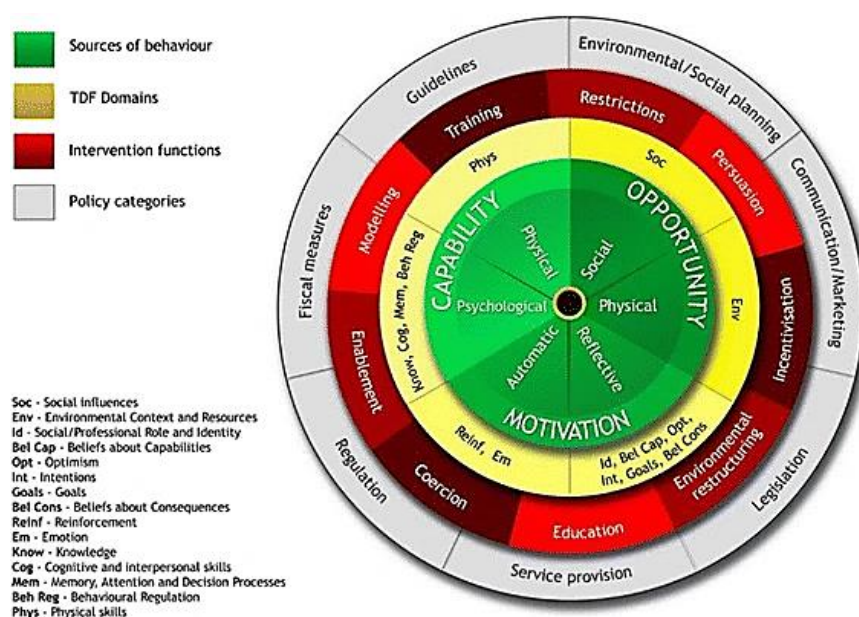
- theoretical analysis of barriers for NSW Health using the Theoretical Domains Framework (TDF), COM-B ('capability', 'opportunity', motivation' and 'behaviour') model and Behaviour Change Wheel (BCW)
- rapid literature review using the 2017 special edition of *Evidence and Quality in Healthcare: International Accomplishments in Shared Decision Making*
- participation in the international workshop: National strategies for implementing shared decision making
- attendance at the ninth International Shared Decision Making (ISDM) conference in July 2017
- consultations with international experts and site visits.

4.1 Theoretical analysis of barriers for NSW Health

The TDF, COM-B and BCW[20, 21] were used to conduct a behavioural analysis of barriers and identify suitable intervention functions for the implementation of SDM (see Figure 1).

Figure 1. Theoretical Domains Framework (TDF), COM-B ('capability', 'opportunity', motivation' and 'behaviour') model and Behaviour Change Wheel (BCW)

The TDF and COM-B were applied retrospectively to the barriers identified by participants at the 2017 NSW *Health Shared Decision Making Masterclass: Making health decisions together*. An open-ended questionnaire was used to explore the experiences and perspectives of participants towards implementing SDM in NSW Health.

The participant responses were classified according to the TDF. Coded statements within the domains were reviewed to generate barrier descriptions representing common themes for implementing SDM. Responses from the questionnaire were classified according to the domains with the TDF and sources of behaviour using COM-B. The BCW was then applied to identify the intervention functions and policy categories that would be most effective in addressing the barriers and advancing the implementation of SDM.

The appropriateness of the intervention functions and policy categories was evaluated using the APEASE criterion (Acceptability, Practicality, Effectiveness/cost-effectiveness, Affordability, Safety/side effects and Equity)[21] with mentors co-chair of the Chronic Care Network and a member of the ACI Consumer Council.

Domain	Construct	Barrier Description	Explanation	COM-B Model	Intervention Functions (Evaluated using APEASE)	Policy Categories
Knowledge	Knowledge	Clinicians don't know what shared decision making is	"Lack of team awareness about what shared decision making is"	Psychological capability	Education	Communication / Marketing; Guide
					Training	
					Enablement	Guidelines; Fiscal measures; Regu
	Knowledge	Consumers don't know what shared decision making is	"There is a lack of community awareness and education"	Psychological capability	Education	Communication / Marketing; Guide
					Training	
					Enablement	Guidelines; Fiscal measures; Regu
	Knowledge	Clinicians don't know the evidence or treatment options	"Staff not **knowing** the evidence or not knowing how to explain it in everyday language"	Psychological capability	Education	Communication / Marketing; Guide
					Training	
					Enablement	Guidelines; Fiscal measures; Regu
Skills	Practice	Clinicians aren't experienced in shared decision making	"Clinicians need to get use to delivering it – practice!"	Physical capability	Enablement	Guidelines; Fiscal measures; Regu
					Training	Guidelines; Fiscal measures; Regu

Figure 2. Example application of the Theoretical Domains Framework (TDF), COM-B ('capability', 'opportunity', motivation' and 'behaviour') model and Behaviour Change Wheel (BCW)

4.2 Rapid literature review

A rapid review of the literature was conducted using the 2017 special edition of the *Journal of Evidence and Quality in Health Care: International Accomplishments in Shared Decision Making*, which included papers from 22 countries. The results were themed and categorised using the following barriers identified in the 2014 Hoffman et al paper[8] on SDM in Australia:

- lack of coordinated effort
- policy
- advocacy
- research funding
- training
- resources and implementation.

4.3 International workshop: National strategies for implementing shared decision making

An international discussion on implementing SDM was facilitated by international experts from Germany and the UK in June 2017. Workshop participants came from Argentina, Australia, Canada, China, Denmark, Germany, Israel, Netherlands, Norway, Spain, the UK and the USA.

4.4 International shared decision making conference

The ninth International Shared Decision Making (ISDM) conference was held in France on 2-5 July 2017. The conference provided an opportunity to network for future collaborations and access current findings and developments in SDM.[22]

4.5 International consultations and site visits

Consultations occurred with international experts from Australia, England, the USA, Canada and the Netherlands to explore in detail effective implementation approaches for advancing SDM. Site visits included Oxford University, the Kings Fund and the Health Foundation in England.

5. Summary of results

5.1 Theoretical analysis of barriers for NSW Health

A total of 53 participants completed an open-ended questionnaire to identify barriers to implementing SDM in a NSW Health context at the *2017 NSW Health Shared Decision Making Masterclass: Making health decisions together* (see Figure 3).
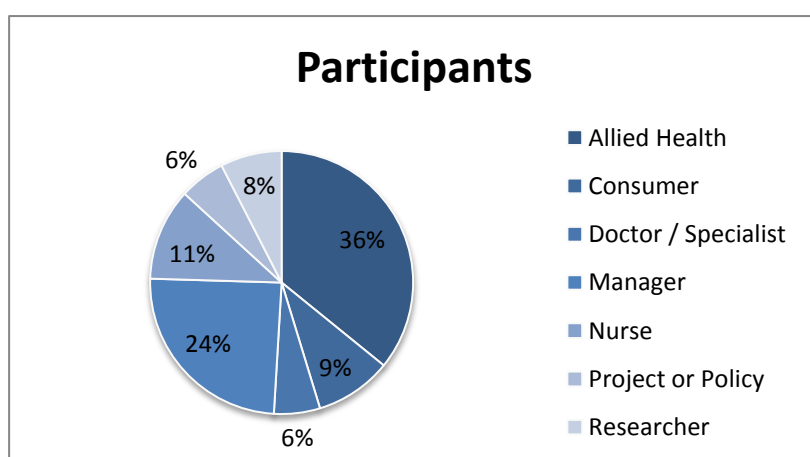
Figure 3. Overview of participants who completed open-ended questionnaire

Nine of the 14 theoretical domains were considered to be relevant to implementing SDM. The predominant domains identified by participants were:

- knowledge
- skills
- professional role and identity
- beliefs about capabilities
- beliefs about consequences
- reinforcement
- environmental context and resources
- social influences
- emotion.

The highest number of participant responses was coded to resources and environmental context. This could suggest a lack of organisational culture, implementation intention and resources to support SDM implementation in NSW Health. Time constraints and multiple competing priorities were also identified as barriers. One participant stated:

> *'There is a perception among clinicians that shared decision making is very time consuming.'*

Responses indicated that barriers included access to resources, including information on SDM, decision aids and high quality synthesised evidence.

> *'We need simple resources, for both clinicians and patients, which are readily available'.* (Participant)

Ensuring a high level of knowledge and skills was considered a vital step in implementing SDM in NSW Health. A lack of awareness of what SDM is was reported as a barrier for health professionals, consumers and communities. The following comments from participants provide important insight into how social influences could be potential barriers to advancing the uptake of SDM:

> *'This will challenge practice. Especially the doctors.'* (Participant)

> *'Options are discussed by the doctor with the patient, but I am not confident they give all the pros and cons.'* (Participant)

Participants reported that self-confidence, professional identity and organisational commitment were barriers to implementation of SDM in NSW Health. One participant stated:

'The medical model dominates the relationship between the clinician and consumer'.

Results from the application of the TDF, COM-B and BCW indicated that education, training, enablement, modelling, incentivisation, persuasion and environmental restructuring would be effective in advancing SDM in NSW Health. Intervention functions that could be used in NSW Health include:

- strategies to increase knowledge and understanding of SDM
- skill development opportunities with health professionals receiving feedback on their practice and behaviour
- multi-method communication approach to stimulate action
- localised examples that model and demonstrate SDM in practice
- guidelines on SDM and access to resources
- opportunities to implement SDM into practice.

5.2 International workshop: National strategies for implementing shared decision making

The international workshop examined two key topics in SDM implementation: education and policy. This was a four-hour workshop facilitated by experts in SDM from England and Germany. Participation enabled connection with international experts in SDM and international shared learning about implementation barriers and enablers.

The following table summarises the discussion and informed the recommendations for advancing SDM in NSW Health.

Table 1. Advancing SDM in NSW Health

Topic	Discussion points
Education	- Health professionals and consumers need specific knowledge and skills to facilitate a SDM process. - Internationally there is no agreement about the core capabilities for SDM and this is a barrier when designing education and training. - There is a move towards web-based training modules and video-based interactive training. - There is no experience or strong evidence that e-learning is effective and the results are ambivalent.
Policy	- The following countries are in the process of developing system-wide strategies for implementing SDM with the support of statutory agencies: Canada, Denmark, France, Germany, Italy, Netherlands, Norway, Spain, Taiwan, the UK and the USA. - No country has adopted a systematic approach. - It is unclear the extent to which SDM is occurring in practice. - Most countries have patient rights, including the right to information

| | and to informed consent. |
| | • One of the barriers to implementing SDM is that there is no single or shared definition of SDM. SDM is an English term and doesn't always fit with global language and terminology. Not a lot of time was invested at the start in regards to cultural adaptations of the term SDM. |

5.3 International shared decision making conference

The July 2017 International Shared Decision Making (ISDM) conference was themed *Time to reflect on shared decision – where are we now and where do we want to be*. More than 200 delegates attended the conference, with representation from most countries.[22]

5.3.1 Opening plenary

Amiram Gafni, Professor in the Department of Clinical Epidemiology and Biostatistics, and member of the Centre for Health Economics and Policy Analysis (CHEPA) at McMaster University (Canada), provided the opening plenary.

The plenary was a reflection on the past, present and future of SDM. Professor Gafni posed a thought-provoking and controversial question: *If SDM is so good, what is the problem?*

He stated that SDM is more complex than first expected and we need to continue to challenge our thinking and practice. He presented the TRIO Approach (see Picture 1) to extend researchers' and health professionals' understanding of the diverse and varying scope of carer involvement and influence in decision making.
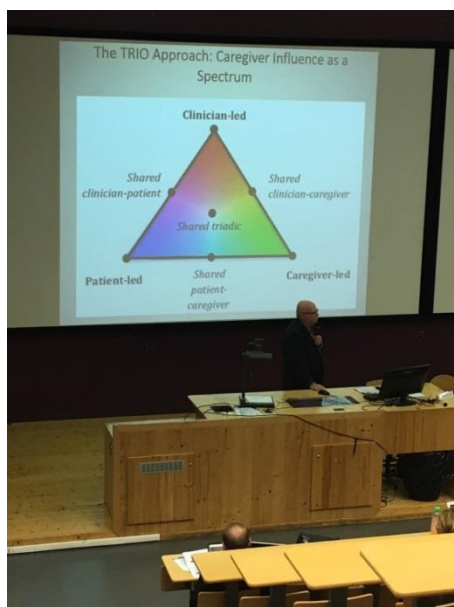
Picture 1. The TRIO approach: Caregiver influence as a spectrum

Professor Gafni stated that SDM is still not clearly defined and he questioned the promise of SDM (see Picture 2). He stated that we need to move away from absolute statements that SDM will reduce costs and reiterated that patients should always have the choice to be involved in making decisions about their healthcare.
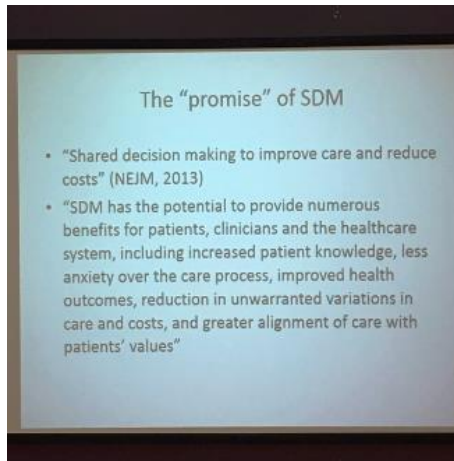
Picture 2. The 'promise' of SDM

5.3.2 Presentations
Most of the studies presented at the ISDM conference were on decision making processes, decision aid development and efficacy, implementation and measurement. The main clinical context for the studies was mental health, cardiovascular disease, diabetes and cancer.

While there was a consumer plenary, a key theme identified by delegates was the need for more patient involvement at the conference.

Presentations reiterated that most efforts to implement SDM are isolated and often focused on the implementation of decision aids, rather than SDM as a process. Internationally there is a gap between aspiration and sustainable implementation of SDM in clinical practice. Consistent barriers identified and discussed included a lack of:
- systematic implementation and coordination of SDM
- awareness of SDM
- access to quality decision aids
- suitable measures and measurement instruments
- access to education, training and assessment.

Experts argued that that SDM needs to move past being theoretical and focus more on changing attitudes and building skills in applying SDM.

5.4 International consultations and site visits

Eight consultations were conducted to explore international examples of good practice and identify approaches to SDM implementation that could be applied in the NSW Health context.

Consultations occurred with international experts from the UK, the US, Canada and the Netherlands. Site visits included the Nuffield Department of Population Health at the University of Oxford, The Kings Fund and the Health Foundation in England.

Two international experts in SDM from Laval University (Canada) and Oxford University (UK) provided feedback and advice on the recommendations and considerations included in the report.

5.4.1 United States
Consultation with SDM expert from the Mayo Clinic Shared Decision Making National Resource Centre

The Mayo Clinic Shared Decision Making National Resource Center promotes patient-centered medical care by progressing SDM through the development, implementation, and assessment of patient decision aids and SDM techniques.[23]

Decision aid development has occurred in the following clinical areas:
- cardiovascular primary prevention choice
- depression medication choice
- diabetes medication choice
- osteoporosis decision aid
- smoking cessation around the time of surgery
- rheumatoid arthritis medication choice
- statin choice (electronic decision aid).[23]

The Centre uses a human-centered design approach for decision aid development. This is a highly iterative approach for optimising the user experience and subsequently the effectiveness of a system, service or product.[3] All decision aids are evaluated through a RCT before being implemented into clinical practice.

The Instrument for Patient Capacity Assessment (ICAN) was developed to help patients and health professionals discuss areas of the patient's life and issues in treatment. It promotes consideration of the ways in which life, health and healthcare interact.[24] ICAN was developed using a human-centred design approach that included synthesising the evidence and conducting clinical observations to develop an initial prototype; field testing including

additional clinical observations; iterative prototyping with incremental changes to finalise the decision aid; and evaluation through a RCT before implementation into clinical practice.

The design process included 15 clinical observations sessions and nine prototype iterations tested in 59 clinical encounters (Pictures 3, 4, 5 and 6).
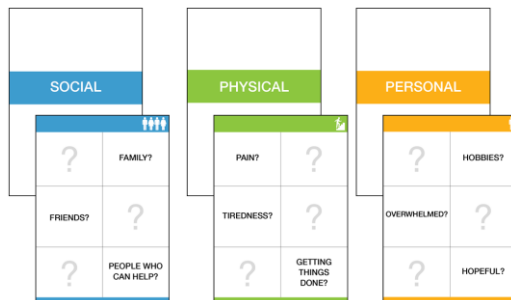
Picture 3. Initial ICAN prototypes
Source: Shared with permission from *Mayo Clinic Shared Decision Making National Resource Centre*
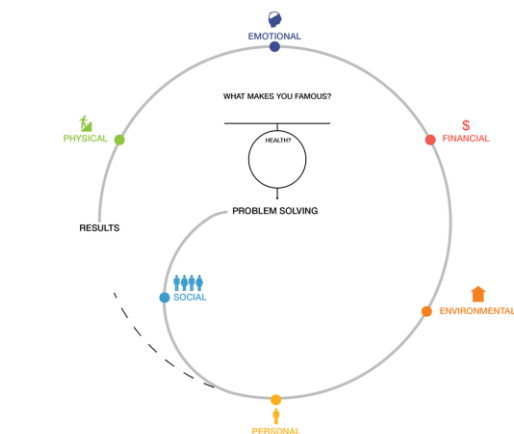
Picture 4. Iteration of the ICAN prototype
Source: Shared with permission from *Mayo Clinic Shared Decision Making National Resource Centre*

Picture 5. Iteration of the ICAN prototype
Source: Shared with permission from *Mayo Clinic Shared Decision Making National Resource Centre*

Picture 6: Final Mayo Clinic ICAN decision aid

5.4.2 United Kingdom (England and Wales)

- *Consultations with SDM experts from Newcastle University and the National Institute for Health and Care Excellence*
- *Site visits and consultations with SDM experts from the Nuffield Department of Population Health, University of Oxford; the Kings Fund; and the Health Foundation*

The Health Foundation is a London-based charity that funded and supported the implementation of the MAGIC (Making Good Decisions in Collaboration) program in two demonstration sites in England and Wales. MAGIC aimed to support clinical teams in primary and secondary care to embed SDM with patients in clinical practice between 2010 and 2013.[24, 25]

A consortium of experts from Newcastle University and Cardiff University worked with health professionals in seven different clinical settings from Newcastle upon Tyne NHS Foundation Trust, Northumbria Healthcare NHS Foundation Trust and Cardiff and Vale University Health Board. The following approaches to overcome barriers to implementation

were tested in different clinical settings: clinical skill development and training, patient decision aids, patient activation, clinical and organisational leadership and support for commissioning.

MAGIC identified a number of key barriers to implementing SDM:
- patients not ready for SDM
- adding to workload and increasing consultation time
- space to practice SDM skills and receive feedback
- managing competing priorities
- patients not having the confidence or health literacy to participate in SDM
- patients not engaging with SDM
- lack of financial incentives to practice SDM
- lack of knowledge about SDM
- difficultly measuring SDM impact
- changing work practices and culture.

MAGIC identified a number of recommendations for progressing SDM implementation:
- gaining staff commitment and buy-in
- using short, simple and user-friendly decision aids
- employing action learning strategies to ensure clinicians have the time and space to practice SDM skills and get feedback
- ensuring decision aids are available and easy to access
- providing training on SDM tailored to the needs of clinicians and local context
- aligning SDM to wider objectives and priorities
- engaging clinical and non-clinical champions
- using human-centred design when developing decision aids
- collecting pre and post data to demonstrate impact.[25]

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. At present, NICE is coordinating a Collaborative to ensure a shared and coordinated approach to implementing SDM in the UK. Established in 2015, the Collaborative is a group of organisations and individuals committed to thinking collectively about the role of SDM in the UK. The Collaborative membership includes organisations from statutory and charitable sectors, patient and voluntary sector organisations and academia. The group meets face-to-face on an annual basis.

The Collaborative has a set of recommendations to encourage a culture of SDM and approaches in healthcare, including leadership and culture change; local leadership; education and training; decision aids; guidance development and evidence reviews; measurement; and research[2, 28] (see Appendix).

Canada

Consultation with SDM expert from Ottawa Hospital Research Institute

The Ottawa Hospital Research Institute (OHRI) leads the Cochrane review on decision aids and maintains the *A to Z inventory of decision aids*.[4, 29] For decision aids to be included in the inventory, they must meet the following minimum criteria:

- satisfy the definition of a decision aid
- publish last updated date (no more than five years old)
- include references to scientific evidence
- be publically available.

The OHRI is also in the process of identifying and testing specific SDM interventions that support Indigenous people in making health decisions. This includes culturally appropriate decision aids and decision coaching that is shared between health professionals, patients and communities.[30, 31, 32]

Following a review of 300 decision aids that found none were culturally appropriate, the OHRI adapted and tested the Ottawa Personal Decision Guide (OPDG) in partnership with 19 First Nations women from Inuit and Metis. The OPDG is the only validated generic decision aid available internationally (Picture 7).

Picture 7. Ottawa Personal Decision Guide

The study design for the adaptation and testing of the OPDG was an interpretive descriptive qualitative design, structured by the Ottawa Decision Support Framework and a postcolonial theoretical lens. Focus groups were used to discuss the decision aid followed by individual

usability testing through interviews and coaching.[29] The following themes were identified and informed the adaption of the OPDG (see Picture 8):

- 'This paper makes it hard for me to show that I am capable of making decisions'
- 'I am responsible for my decisions'
- 'My past and current experiences affect the way I make decisions'
- 'People need to talk with people'
- 'I need to fully participate in making decisions'
- 'I need to explore my decision in a meaningful way'
- 'I need respect for my traditional learning and communication style'.

Picture 8. Adapted Ottawa Personal Decision Guide

When testing the decision aid, participants identified that coaching was needed to support the SDM process. Decision coaches are trained to be non-directive and to provide evidence and support. Results showed that decision coaching and use of the decision aid increased knowledge and involvement in treatment and care.[29]

6. Analysis and implications for the Agency for Clinical Innovation

SDM is a defined as a process where patients and health professionals make informed and preference-based decisions together. The evidence-based decision making process is considered the crux of person-centred care and positions patient involvement in their healthcare as an accepted right. [1]

SDM can benefit patients, health professionals and the health system, including increased patient knowledge and alignment to their values and preferences, improved outcomes and reductions in unwarranted variation in care.

Despite being an evidence-based decision making process, SDM is not embedded within the culture of NSW Health or the ACI. Results outlined in this report showed that the barriers identified for implementing SDM in NSW Health are consistent with the barriers identified and experienced internationally.[6, 33, 34, 35, 36]

It is expected that the demand for SDM will exponentially grow in Australia, given the explicit focus on sharing decisions and planning outlined in the NSQHS Standard 2: Partnering with Consumers.[7]

The ACSQHC *Australian Atlas of Healthcare Variation* also emphasised that SDM is an important strategy for reducing unwarranted variation and for promoting person-centred care. It recommended SDM to reduce variation in surgical interventions:

> *Ensuring that patients understand the evidence about the likelihood of risks and benefits is particularly important if the degree of benefit from surgical treatment is not clear. Accessible information, improved health literacy and high-quality tools for shared decision making would support patients to make better informed choices about care.*[6]

7. Recommendations

The following preliminary recommendations and considerations should be considered as part of an ongoing investment to enhancing patient experience, person-centred care and reducing unwarranted variations in care.

There are a number of areas where investments could be made to progress and build a culture of SDM in NSW Health:
- Establish a Collaborative to encourage SDM and coordinated efforts in NSW Health.
- Build SDM awareness and system-wide capability.
- Implement and evaluate SDM through demonstration sites.
- Invest in decision aid development and dissemination.
- Identify suitable measures to understanding SDM performance.

A comprehensive business case would need to be developed to explore the feasibility of all recommendations, including the benefits, risks, costs, organisational capability and potential timelines. This will ensure the ACI and other organisations are enabled to select and support recommendations that strategically align to state and federal health priorities and continue to enhance person-centred care in NSW.

Experts in SDM from Laval University (Canada), Oxford University (UK), Bond University (Australia), and the University of Sydney (Australia) reviewed and provided feedback and

advice on the recommendations and considerations included in the report. The recommendations were also reviewed by the ACI:

- Chronic Care Network Co-chair
- Specialist Consultant
- Consumer Council
- Primary Care and Chronic Services Program Manager
- Director of Primary and Chronic Care Services.

Recommendations	Considerations
Set up a Collaborative* to encourage SDM and coordinated efforts in NSW Health. **In this context a Collaborative denotes a group of people coming together, not a collaborative methodology for quality improvement.*	- Explore the feasibility of replicating the UK SDM Collaborative, which is coordinated by the National Institute for Health and Care Excellence. This would include a consensus statement, action plan, success criteria, timelines and designated roles and responsibilities. - Explore opportunities to partner with The University of Sydney and Bond University through the Ask Share Know Centre for Research Excellence, Clinical Excellence Commission, the BHI; ACSQHC, NPS MedicineWise: Choosing Wisely, Health Consumers NSW and/or the Consumer Health Forum**.** - Integrate SDM into the ACI consumer engagement priorities, with alignment to the strategic plan to build a culture of SDM at the ACI.
Build SDM awareness and share knowledge within NSW Health.	- Publication and active dissemination of the SDM resources aligned to the *Consumer Enablement Guide* promote practical and evidence-based recommendations to clinicians in NSW Health. - Establish a web-based community of practice for NSW Health to develop shared practices and learn together. - Develop and implement a structured social media strategy to disseminate knowledge about SDM (e.g. weekly tweets about SDM and a monthly tweet chat) in partnership with experts in SDM. - Co-produce a promotional campaign for NSW Health with consumers, families and communities. Explore opportunities to do this in partnership with Consumer Health Forum and/or Health Consumers NSW and the feasibility of using the 'Ask Share Know' questions.

	• Develop case studies to illustrate the benefit of SDM relevant to the NSW health and Primary Health context.
Support system-wide capability.	• Identify clinician-based and consumer-based core capabilities for SDM in partnership with the University of Sydney and Bond University. • Develop training material for SDM capability, including knowledge and skill development (which is integrated into core communication training). • Embed SDM all capability programs at the ACI. • Advocate for and seek consensus from the Senior Executive Forum to include SDM as a core training package with the Health Education and Training Institute (HETI). • Establish performance indicators for SDM inclusion into all ACI products as an evidence-based decision making process. • Identify influential clinicians and consumers to provide effective leadership of SDM within NSW Health.
Explore the feasibility of SDM implementation through demonstration sites.	• Develop a business case to support demonstration sites to implement SDM using behaviour change interventions and techniques in different health settings in NSW. • Identify and apply for suitable research grants. • Pilot cultural adaptions of SDM and align to the ACI Cultural Competency Strategy. • Use the TDF and COM-B barriers analysis to inform behaviour change techniques for demonstration sites relevant for the local context. • Commission the development of an inter-professional capability model for demonstration sites. • Assess scalability of tools, resources and behaviour change techniques from demonstration sites and implement a scaling up process in NSW Health.
Invest in decision aid develop and dissemination in NSW Health.	• Develop a generic decision aid for health-related or social care decisions and/or evidence-based decision aids for high priority topics (with consideration to Leading Better Value Care, Unwarranted Clinical Variation or Integrated Care). • Explore the feasibility including a cost-benefit analysis of purchasing a library of decision aids from a private company and/or adapting existing decision aids for the NSW Health context.

	• Ensure all decision aids align to the International Patient Decision Aid Standards (IPDAS) Collaboration.
	• Explore future opportunities to integrate decisions aids into electronic medical records (EMR) in partnership with eHealth.
	• Provide easy access to SDM tools and resources through the ACI website or Innovation Exchange.
Identify suitable measures to understand SDM performance at different levels in NSW.	• Partner with BHI and international experts in SDM to identify suitable measures (process and decision quality) at the clinical and system level.
	• Partner with BHI to identify, analyse and/or implement suitable measures to further enhance understanding and benchmarking of SDM performance in NSW Health.

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9. Appendix

Shared Decision Making Collaborative
A consensus statement

Shared Decision Making

1. 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]

2. Shared decision making between healthcare professionals and patients improves decision quality and patient satisfaction and, in some cases, results in more cost-effective care. Embedding shared decision making in practice is a key factor in realising the new models of care in the Five Year Forward View.

The Collaborative

3. The Shared Decision Making Collaborative is a group of organisations and individuals committed to thinking collectively about the role of shared decision making in UK health systems, drawing on international experience. It comprises a range of organisations from the statutory and charitable sector, patient and voluntary sector organisations, and academia.

Recommendations

4. The following recommendations are endorsed by the Collaborative members listed below. The recommendations describe a multi-component approach that, taken together, will encourage a shared decision making culture and approaches to healthcare.

Leadership and culture change

5. All NHS bodies and patient organisations should actively support a culture of shared decision making so it becomes a routine expectation of patients and clinicians. To support this, a single organisation should be identified to promote and support all elements of shared decision making, and to track progress.

Local leadership

6. Local Trusts should make shared decision making a Board level responsibility, forming part of its quality and patient experience obligations.

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[1] Coulter, A. and Collins, A., 2011. Making shared decision-making a reality: no decision about me, without me