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Editorial

Shared Decision Making: Vision to Reality

What is the shared international vision for shared decision making (SDM), and how do we make it a reality? The theme of the 2009 International Shared Decision Making (ISDM) conference arose out of a desire to explore the theoretical underpinnings of engaging patients and providers to ensure that all medical decisions are well informed and take each patient's goals and concerns into consideration. We identified four core issues that need to be addressed to move the vision into practice. The organizing committee felt there was a great need within the community for more clarity on what is meant by SDM, how it is implemented in day-to-day care, as well as a greater understanding of how the impact of SDM can and should be measured. Finally, it is critical that we increase our understanding of how the principles and practice of SDM can be taught to health professionals and patients. The ISDM 2009 conference was designed around these four areas, and this special edition of Health Expectations includes papers that expand our understanding of these issues.

Increasingly, patients are faced with fateful health decisions that have many options, uncertain outcomes and benefits and harms that are valued differently by each individual. There is no one right answer about how to proceed. Shared decision making recognizes the importance of having patients and providers work together to select tests and treatments. Patients and providers bring different expertise to the decision. Providers are mainly responsible for assimilating and appropriately applying evidence-based information, and patients are responsible for sharing their preferences. Using SDM, well-informed patients and providers can determine which choice matches what is most important to patients – delivering high-quality care that is both evidence-based and patient-centred.

In 2009, the 5th ISDM conference was held in the United States for the first time. This conference brought leading scientists, clinicians, policy makers and payers together to learn, discuss and debate key issues about the ways in which to best translate SDM research into clinical practice. The ultimate purpose was to strengthen the role of the patient in medical decision making and to foster evidence-based, informed, patient-centred medical care. The conference was designed to cover four core questions about SDM, with each answer moving the concept further from vision to reality:

1. *What is it?* These sessions and papers highlighted the most promising conceptual frameworks and context for defining shared decision making and evidence-based medicine as well as exploring the theoretical underpinnings behind shared decision making and evidence-based medicine.
2. *How do we implement it?* The system requirements, methodological strategies and outcome measures required for implementing SDM and patient decision aids (pDAs) into clinical practice. Particular emphasis was placed on: (i) underserved populations (low literacy, low numeracy, low income, non-native language speaking, rural patients and

inner-city patients); (ii) patients with chronic conditions; and (iii) cross-cultural adaptation and dissemination of pDAs and SDM.

3. *How do we measure its impact?* The best ways to measure the effect of SDM on the quality of decisions and the implications for the quality and costs of care.
4. *How do we teach it?* How to help patients and providers engage in effective SDM.

Based on the growing debate around health-care reform that was happening in the United States at the time, the organizers added a plenary session to examine the role of SDM in health-care reform across different countries. *What is required for payment reform, standards and accreditation of decision support and decision support tools?* The regulatory, legal and payment policies required to accelerate the widespread adoption of SDM and pDAs into clinical practice.

The conference built on the accomplishments of the four previous ISDM conferences held in Oxford, UK (2001), Swansea, UK (2003), Ottawa, CA (2005) and Freiburg, GR (2007). The conference was attended by more than 260 people from 13 countries (Australia, Canada, Denmark, England, France, Germany, Japan, Netherlands, Norway, South Korea, Switzerland, USA and Wales). The programme included five plenary sessions, four pre-conference workshops, 54 oral presentations, 12 workshops/symposia and 130 poster presentations showcasing the latest shared decision making research and decision support tools. This special edition of *Health Expectations* presents eight original papers, highlighting results presented during the most highly ranked sessions at ISDM 2009.

What is it?

The opening plenary session, *What is Shared Decision Making and Why We Care* set the stage for the conference. Glyn Elwyn's talk outlined the history of SDM for important medical decisions about tests and treatments. He highlighted the features of the SDM process that include the following: equipoise, option representation, deliberation and determination. Dr. Elwyn concluded his presentation by inviting all attendees to think about three questions over the course of the conference: (i) When to do SDM? (never, sometimes, always?) If always, should we insist that patients take part in making the decisions? (ii) When there is disagreement, how should it be resolved? and (iii) Should we worry about health outcomes? Is a good decision independent of outcome?

In this edition, we include three papers that help advance our understanding of what SDM is. The first, by Sivell *et al.* [1], contributes a theory-based approach to guide the selection of content for decision aids. Sivell *et al.* used the Theory of Planned Behaviour (TPB) and the Common Sense Model of Illness Representations (CSM) to describe the evidence about factors that influence breast cancer patients' surgery choices. The investigators reviewed 26 studies to determine the factors that influence women's decisions about treatment for breast cancer. The paper illustrates how these two theories, TPB and CSM, can be used to inform the design and development of decision support interventions.

A core component of many decision aids is helping patients understand risk or chances of good and bad health outcomes. Rocio Garcia-Retamero and Mandeep Dhami [2] investigated risk communication using numbers and pictures in a sample of immigrants and non-native language speakers to determine whether there is a difference in understanding treatment risk reduction if it is expressed as a ratio in their native language vs. non-native language, and also whether this population can be aided by using visual displays to enhance their comprehension. The investigators conclude that it is important to go beyond direct translation when communicating risks to non-native patients. Using visual aids can help to more effectively communicate health risk information.

Lindy Behrend *et al.* [3] examined the degree of patient–physician agreement on content and outcomes of coronary heart disease prevention discussions in primary care. They found fairly good agreement about whether discussions had taken place, physician recommendations and final treatment decisions (i.e. either to take medicine or to change lifestyle), yet there was poor agreement between patients and their physicians regarding discussion content (e.g. whether pros and cons of treatment choices and patients' preferences were discussed).

How do we implement it?

In the second plenary session, Angela Coulter, Jack Wennberg and Albert Mulley presented, some lessons from *Large Scale Implementation of SDM*. Jack Wennberg provided an historical context for moving from practice variation research, to outcomes research, to research on SDM. He concluded that clinical appropriateness should be based on sound evaluation of treatment options (outcomes research), and medical necessity should be based on informed patients' choice among clinically appropriate options (high-quality SDM). Albert Mulley described a successful business model for providing decision support via health coaching and decision aid distribution to health plan clients in the United States. There is a small but growing research agenda around implementation of patient decision aids. Two papers address this topic from different areas in the US health care system, primary and specialty care.

Dominick Frosch *et al.* [4] report on a qualitative study to examine the feasibility of implementing cancer screening decision aids in twelve community-based primary care practices. Implementation worked best in practices where physician(s) and staff were dedicated to patient care, and the practices had adequate clinic infrastructure, as well as positive work and patient care environments. Working decision aids into the practice flow immediately prior to the consultation was the most successful implementation model. The biggest challenge to this community-based implementation was the original buy-in of the physicians, as a very low number of providers indicated interest in participation.

Sandra Feibelmann *et al.* [5] report an evaluation of the Breast Cancer Initiative, a programme designed to promote the implementation of patient decision aids into community-based breast cancer centres throughout the United States. In contrast to the Frosch study, they found tremendous professional interest (from both physician and non-physician providers) in providing pDAs to patients to better inform them and help them make better decisions. The interest, however, did not always translate into successful implementation. Their structured approach to disseminating breast cancer pDAs to community breast cancer sites is discussed in the article as well as the factors that are associated with sustained implementation of pDAs at these sites.

How do we measure its impact?

Karen Sepucha, Richard Thomson and Gerd Gigerenzer gave the third plenary session, *How Do We Recognize Good Medical Decisions*? Karen Sepucha introduced the session on measurement by asking attendees to think about a question, "How do we know if a good decision has been made?" She stressed that we are at a point as a field of SDM researchers that we need reliable, valid measures for knowing whether or not a good decision has been made. Richard Thomson and Gerd Gigerenzer both presented talks dealing with how to measure the quality of decisions. Richard Thomson described the imperatives and tensions in measuring decision quality, emphasizing that a good decision should be measurable at the individual, provider and population levels. Measures should also be valid and reliable. Good shared decisions have common components – they are informed (knowledge) and are consistent with patients' values. Gerd Gigerenzer presented data that suggested that more information does not always lead to better decisions. Thus, challenging the field to examine how much and what type of information is really needed to ensure good decisions. Also, Gigerenzer emphasized the need for a balance between intuitive and calculative decision-making (few people select a spouse by listing their beloved's "pros" and "cons"). Two papers that discuss values clarification techniques are included in this special edition and are described later.

Purva Abhyankar *et al.* [6] assessed whether values clarification techniques, the part of decision aids that help patients assimilate the factual information with their personal values, enhance informed decision making and discuss how and why values clarification techniques work. The authors conclude that explicit values clarification techniques enable patients to deliberate about the decision information using their own personal values and ultimately lead to better decision-making experiences.

R. Trafford Crump and Hilary Llewellyn Thomas [7] studied the effect of two different values elicitation techniques (the non-engaging Leaning Scale vs. the engaging Threshold Technique) to see whether patients' strength-of-preference scores for elective care interventions at the end of life were affected by the order of the technique used. They sought to determine whether patients' preference scores change if their preferences were elicited using an engaging technique prior to using a non-engaging technique. The investigators found that interposing an engaging threshold technique exercise did not have an effect on patients' strength-of-preference scores.

How do we teach it?

In the final plenary session, *Where is the Patient Perspective in Practice Guidelines?* Hal Sox, Victor Montori, Marcia Kelson and Trudy van der Weijden served as panelists. In his introduction to the session, Dr. Sox suggested three potential methods for incorporating patient variability into guidelines: (i) to use the decision support system and document inputs (probabilities and utilities); (ii) allot clinicians a certain number of "free passes" to bypass guidelines (what is a reasonable allotment?); and (iii) patients should be allowed to verify their preferences for non-guideline-adherent care. Victor Montori stressed that evidence alone is never sufficient to make a clinical decision (or practice guideline), it is vital that patients' values and preferences be included as well. Dr Montori concludes that evidence-based medicine considers patients' preferences in formulating guidelines (and clinical decisions); variation in preferences should lead to a downgrade in recommendations; weak recommendations may signal the need to tailor to patients' preferences (and context); and decision aids may help translate guidelines into practice. Marcia Kelson presented the NICE (National Institute for Health and Clinical Excellence) approach to including the patient perspective in practice guidelines. She stressed that patients have their own unique perspectives on: their condition; what constitutes good and poor care; the outcomes they want from treatment and care; risks, benefits and acceptability of treatment; preferences for treatment and management options; and information and support needs. This is why guideline recommendations need to address and integrate these to produce patient-centred guidance for both clinicians and patients. Trudy van der Weijden's talk focused on the integration of implementation of practice guidelines with implementation of SDM. She described the challenges in implementation of clinical practice guidelines as the need to translate population-based data to the individual patient who has his or her own individual preferences. Also, it is necessary to recognize 'weak' guideline recommendations (for preference-sensitive decisions) and emphasize that these decisions should be shared between patient and provider based on the patient's preferences.

As guidelines evolve and increasingly call for the incorporation of patients' preferences, goals and concerns, it is critical to ensure that providers have the skills to do this well. In this special edition, France Légaré *et al.* [8] report on a programme to train family physicians in SDM to optimize the use of antibiotics for acute respiratory infections. The training programme consisted of DECISION+ which is a multiple component, continuing professional development programme in SDM that includes interactive workshops and related materials, reminders of expected behaviours and feedback to physicians on the agreement between their decisional conflict and that of their patients.

Conclusions

This special edition contains eight papers representing the proceedings of the ISDM, 2009. The ISDM Scientific Committee rated all presentations at the conference, and investigators with the highest ratings were asked to submit papers summarizing their presentations at the conference. Once papers were submitted, they underwent the standard *Health Expectations* peer-review process.

We want to thank the ISDM Executive Committee for all of their help in putting such an excellent scientific programme together, the Scientific Committee for their time reviewing abstracts, and the investigators for sharing their results with the international SDM community. Special thanks to Vikki Entwistle and Rosanne Bell from *Health Expectations*, without whose guidance and persistence, this special issue would not have been possible.

Based on the success of the 5th ISDM Conference as evidenced by the results presented at the conference and in this special edition of HEX, we look forward to the next chapter in the story of involving patients as more active partners in their health care that will be presented at the 6th International Shared Decision Making conference in Maastricht, the Netherlands from June 19–22, 2011 (see http://www.ISDM2011.org for more details).

Conflict of interest

Drs. Barry and Levin and Morgan MacCuaig receive salary support as President, Research Director, and Evaluation Coordinator respectively, for the Foundation for Informed Medical Decision Making, a not-for-profit (501 (c)3) private foundation (http://www.informedmedicaldecisions.org). The Foundation develops content for patient education programs. The Foundation has an arrangement with a for-profit company, Health Dialog, to co-produce these programs. The programs are used as part of the decision support and disease management services Health Dialog provides to consumers through health care organizations and employers.

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