

9TH INTERNATIONAL SHARED
DECISION MAKING CONFERENCE



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BOOK OF ABSTRACT
Workshops

How e-health can help to improve Shared Decision-Making training to healthcare professionals and patients?

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**to be confirmed*

Background.

The FREeDOM “think tank (French collaboration group for SDM)” was born in 2014 on account of the gap between the reflection and practice in many countries, such as USA, Australia, Northern Europe and also French-speaking countries (Canada, Switzerland, Belgium, France), the growing demand of patients and more generally citizens, and the very limited diffusion of SDM practices in France. The international environmental scan (Légaré et al. 2012) and its update (Diouf et al. 2016) confirm that the production of SDM training programs is growing fast worldwide, and indicates that SDM training programs still vary widely. Most still focus on the single provider/patient dyad and few are evaluated. It highlights the need to adapt training programs to interprofessional practice and to evaluate them. Since then e-health and SDM has risen further towards the health policy agenda and is being actively promoted by various multidisciplinary researchers universities, international bodies, health organisations and hospitals, particularly in France, which is catching up in this area. So the question raised in this workshop is at the heart of the challenges of SDM training to healthcare professionals and patients. The ISDM conference offers an excellent opportunity to gather good-quality information on the current state of progress and share experiences across a wider group of countries.

Learning objectives.

To share information and experiences at different level of the health system in France and worldwide about practical strategies for developing e-health tools, why these materials are developed and for who? And how these materials could help SDM, focusing on what has worked and what hasn't.

Methods.

We propose an interactive workshop to share information, including four brief presentations of main issues on development and implementation of French e-health projects and tools, results and cross-cutting perspectives of stakeholders, and a facilitated discussion with a view to integrate together expectations and preferences of patient association and users, healthcare professionals and developers of e-health technologies. A report will be produced after the conference for circulation to participants.

Audience.

All participants with an interest in the topic; e-health developers; human and social science researchers, public health researchers, methodologists, patient representatives. Numbers need not be limited.

Keywords.

#shared-decisionmaking #ehealth #esante #training #healthpolicy #epatient #chronicdisease #cancer #physicalactivity #empowerment #healthinformation #healthliteracy #evidence-basedmedicine

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National strategies for implementing shared decision making – what has worked and what hasn't?

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Background: Shared decision making (SDM) has been enthusiastically embraced by patient groups, policy makers, clinicians, researchers and professional societies, but it has been slow to filter into mainstream clinical practice. Experience in various demonstration projects in North America and Europe suggests that the following factors need to be in place to create the conditions for more widespread adoption:

- 1) Policy initiatives and support from governments or public authorities
- 2) Incentives for clinicians to change their practice – professional, ethical, legal, financial
- 3) Leadership – clinicians, patients, other
- 4) Skills and capacity – training courses, organisational development
- 5) Tools – patient decision aids, question prompts, quality assurance processes
- 6) Performance measures – decision quality, health outcomes
- 7) Proof of concept – demonstration sites, local evidence.

In a previous study of approaches to implementing SDM in five European countries (France, Germany, Spain, Netherlands and United Kingdom), we found that while all these countries had research groups working on SDM, patient groups calling for its wider use, and ethical and professional standards indicating its desirability, but there was no evidence of a systematic approach to implementation (1).

Since then SDM has risen further towards the top of the health policy agenda and is being actively promoted by various international bodies. The ISDM conference offers an excellent opportunity to gather information on the current state of progress in respect of SDM implementation across a wider group of countries. We therefore propose an interactive workshop to share information on what is happening with a view to mapping progress around the world.

Learning objectives: To share information about practical strategies for implementing SDM, focusing on what has worked and what hasn't.

Methods: An interactive workshop, including brief presentations and a facilitated discussion. A report will be produced after the conference for circulation to participants.

Audience: Invited participants drawn from those preparing papers for the special issue of ZEFQ, plus others with an interest in the topic. Numbers need not be limited.

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The Challenge of Shared Decision Making for Chronic Conditions: Lessons Learned from the ICAN Discussion Aid

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Background and aims

Care of patients with chronic conditions is not only medically complex, it is communicatively challenging. Shared Decision Making approaches for this patient population requires additional strategies to move from specific decision points (e.g., the choice to take a statin or which diabetes medication to take) to a point of understanding how individual decisions impact the way in which the patient's total plan of care fits within their life context.

For each person cared for it is unclear what might and should be talked about; how chronically interacting issues of life, illness, and treatment are best discussed by patients and clinicians; and how patient-valued care is shaped in conversation.

This workshop will consider the development of tools and approaches to support patients and their healthcare teams in discussing issues in living with and treating chronic conditions through user-centered design methodology. This workshop is based upon our research group's decade of experience creating and testing decision aids for chronic care that are used in 150,000 encounters per year, as well as our recent development of a longitudinal discussion aid, the ICAN Discussion Aid, for a wide range of health professionals to use with patients with chronic conditions.

Participants will:

- 1) Distinguish communicative from protocol-driven approaches to chronic care.
- 2) Understand conceptual foundations for discussing chronic conditions.
- 3) Gain experience in using the ICAN Discussion Aid and consider how it applies to future research in SDM for Chronic Disease.

Methods

Content	Method	Time
Introduction and workshop overview	Self-introduction of participants and facilitators.	10 minutes
Appreciating the communicative challenges of chronic care	Small group discovery exercise to surface the complex and perspective dependent issues of chronic care.	15 minutes
Concepts in discussing problems and issues	Presentation on conceptual foundations	10 minutes
Introduction to the ICAN Discussion Aid	Presentation	10 minutes
ICAN Discussion Aid Activity	Small groups: Designing a discussion aid	20 minutes
Activity Reflection	Group discussion of activity	20 minutes

Summary/conclusion

At the conclusion of this workshop, participants will have a rich understanding of the challenges facing patients and their health professionals as they discuss treatment of and living with chronic conditions. This foundation will prepare participants to further consider how to apply these concepts to enrich the field of shared decision making for chronic conditions.

Reaching for Patient-Centered High Value Care: Working Toward the State of the Science in a Toolkit

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Background: Models of health system change offer a powerful tool for high value care (i.e. sustainable care in which the benefits outweigh the harms and costs to patients, providers, and systems). To optimize change, efforts need to begin with high quality evidence and acknowledge patients as the final arbiters of care. Further, all levels of system leaders need readily available evidence, tools, and resources to facilitate patient-centered high value care.

Workshop Learning Objectives: In this workshop, participants will:

- 1) Explore concepts of value and their intersection with patient-centeredness,
- 2) Reflect on the pathway to patient-centered high value care and how the evidence and toolkit support that pathway,
- 3) Use the toolkit to assess the resources, attitudes, and habits in their own settings and how those compare to best evidence, and
- 4) Provide their opinions on needed additional resources, and the dissemination, implementation, and testing of the toolkit.

Description of Toolkit Methods, Results, and Conclusions: To facilitate patient-centered high value care, the Reaching for High Value Care team undertook a scoping review of patient-centered care (PCC) and its relationship to a high value care change model, translated findings to a toolkit of evidence briefs and resources for all levels of system leaders, and sought input on these briefs from key stakeholders, including leaders of the International Shared Decision Making Society and other key leaders in shared decision making and high value care, until no additional feedback was solicited.

In this review, we found insufficient evidence to determine the effects of interventions designed to promote the overall process of PCC. However, we found multiple interventions to support the individual sub-processes of PCC for patients, providers, and systems. When we translated our findings into a toolkit of evidence briefs, stakeholders noted that the toolkit was clear, simple, thorough, timely, and likely to be useful globally. They also suggested additions and revisions that improved the shared purpose and quality of this work. This toolkit now needs broader stakeholder input, dissemination, implementation, and further testing to determine its usefulness in promoting health, wellbeing, patient satisfaction, and sustainable systems.

Pre-requisites: none

Maximum number of participants: 60

Conducting Shared Decision-Making for Mental Health Concerns: Strategies for Adults and Youth

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Background: Despite the moral imperative to engage in shared decision-making (SDM) for mental health, doing so presents significant, unique challenges. These include: 1) service users often presenting with co-morbid mental health difficulties, and the complexity of treatment options (pharmacological, psychological and social) for mental health; 2) perceived or actual lack of decisional capacity or capacity to be involved in SDM process; and challenges specific to youth mental health, such as 3) youths' varying developmental levels and cognitive abilities; and that 4) caregivers and guardians are often involved in decision-making, and they may disagree with youth perspectives. Although these challenges will be discussed in the context of mental health treatment, the issues they raise (e.g., understanding of treatment options, competence to participate in treatment planning, navigating SDM with multiple stakeholders) can be extended to the implementation of SDM in a variety of settings.

Learning Objectives: 1) To recognize the importance of incorporating service user perspectives in the treatment planning process for mental health concerns; 2) To identify likely challenges when conducting SDM for mental health with adults and youth; and 3) To gain familiarity with specific techniques and approaches that may facilitate SDM with adults and youth.

Methods: This workshop will integrate didactic and interactive approaches. The first part of the workshop will focus on the rationale for SDM in mental health treatment (and psychosocial treatment in particular), the latest evidence in this area, and common challenges in conducting SDM for mental health concerns. The second part of the workshop will focus on current efforts in the field to design and test SDM for mental health concerns (including the presenters' work). Interactive activities will emphasize the practical application of this work and teach specific skills and approaches to address common challenges. Each presenter has been engaged in the theoretical development and practical application of SDM for mental health, with a special emphasis in youth mental health. Participants will engage in practical exercises to develop basic skills in undertaking SDM discussions in these populations using the techniques that were discussed and demonstrated earlier in the workshop.

Audience: Audience members should have a basic understanding of what SDM is.

Maximum Number of Participants: 25 participants

“Express Rather than Impress”: Discussing Challenges in a Peer-group of Early Career Researchers

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Background and Aims

Early career researchers face many challenges—such as securing funding, establishing peer collaborations, confronting doubts and uncertainty concerning research, and identifying career trajectories—and may benefit from discussing these issues with peers. Since 2011, the early career network (yEACH) has coordinated workshops that bring together early career researchers to discuss these challenges and provide constructive advice. Based on literature on early career challenges and feedback from previous attendees, we propose conducting a workshop at ISDM 2017 that focuses on methodological challenges, career development, and networking issues. This workshop's content builds upon previous delivery at the ISDM 2013 conference and several International Conferences for Communication in Healthcare (ICCH), refining content to best meet participants' various expressed needs.

Our workshop aims to meet the following learning objectives:

- 1) Master the principles of peer-to-peer support in research and career development.
- 2) Share and receive constructive feedback on research and career challenges.
- 3) Develop networking skills and build international support networks.

Methods to support these aims:

Participants will select attendance in advance, and those who wish to gain the most support from the workshop will submit a short description of their current challenges to facilitators in advance of the workshop. We will ask participants to select a focus area, and we will use these areas to organize participants into small groups. Small groups will engage in facilitated activities to address their needs. Ideally, this workshop will be delivered early in the conference agenda, either as a pre-conference, or during the first day, such that participants have the opportunity to continue networking throughout the remaining time in Lyon.

During the 90 minute workshop, small group focus areas may include:

- 1) Research/Methods: Challenges related to ongoing research projects and methodology.
- 2) Career Development: Challenges related to career (e.g., mentorship, personal-professional balance, job seeking/transitions).
- 3) Networking: Challenges related to networking with others (e.g., developing “elevator speech,” identifying collaborators).

Summary/Conclusion: At the end of this workshop, early career participants interested in shared decision making research will be better positioned to “pitch” their research to senior scientists, engage in networking at this conference and beyond, and find alternative solutions for areas in which they feel challenged in their current projects. Moreover, the workshop will serve as a starting point for accessible peer-to-peer networking with other participants both during and after the conference.

Whose Leg Is It Anyway? When engaging with a limb just doesn't get the right response ...

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Background

Involving people in their care is a major trend in contemporary healthcare practice. A number of initiatives that encourage patients to ask key questions of their doctors or nurses are already in use. For example in the UK, a wide variety of organisations, including the National Institute for Health and Care Excellence (NICE), promote several initiatives to support 'shared decision-making' [1], and an initiative recently developed within the UK, 'ThinkSAFE', prompts similar patient behaviours in relation to helping them to stay safe [2, 3]. Evidence suggests that people want to be involved in decision making about their care and that they are willing and able to intervene to prevent harm. There also is growing evidence that encouraging patient involvement can improve the quality and safety of healthcare. However, there are many potential barriers to patients asking healthcare professionals questions, including healthcare professionals' unwillingness to engage with patients in this way. Patients may worry about appearing rude or demanding so can often adopt a passive role rather than one of collaboration (2)

Learning Objectives

To understand the relational barriers and facilitators to effective patient/provider communication

To reflect on behaviours that promote or inhibit patient involvement in practice

To discuss and debate the role of humour and dramatization in enhancing understanding and influencing behaviour

To feed back on the sketches and supporting materials as an educational resource and an innovative means of enhancing research impact

Methods

In this workshop, participants will view a series of offbeat and humorous video sketches that are based on real issues raised in qualitative research carried out by the authors which aimed to explore the perceptions of patients and clinicians on promoting patient involvement (2). Video sketches were developed collaboratively with Operating Theatre, a UK-based film and drama company. Whilst the context of the underpinning research was improving patient safety, patients have reported similar perceptions or experience in relation to their attempts to engage in shared decision making with a care provider (4). The sketches have been designed to be deliberately surreal and thought provoking, and their purpose is to encourage reflection and discussion of the attitudes and feelings invoked by the situations depicted in the sketches. Small and large group work will engage participants in supported discussions that encourage exploration on the issues and problems in more depth.

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3. Hrisos S, Thomson R. (2016) Chapter 9 Direct engagement: developing and piloting the *ThinkSAFE* intervention. <https://dx.doi.org/10.3310/pgfar04150>
4. Joseph-Williams, N, Elwyn, G, Edwards, A. (2014) Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. PEC 94.3: 291-309. <http://www.sciencedirect.com/science/article/pii/S0738399113004722>

Audience – no pre-requisites. This workshop has broad relevance to both professional and lay delegates.

Maximum number of participants – Maximum 60 delegates in an area/space with cabaret style layout

Duration: 1.5 hours

Improving patient decision aid manuscripts using the new SUND AE Checklist from IPDAS

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Overall aims: The two goals of the workshop are (1) to introduce the recently completed reporting guidelines, Standards for UNiversal reporting of patient Decision Aid Evaluations (SUND AE), designed to improve the quality and transparency of reporting of studies evaluating patient decision aids and (2) to engage the shared decision making community in designing strategies for implementation and dissemination of the guideline.

Description: An international group of experts from the International Patient Decision Aid Standards (IPDAS) collaboration, with input from the international shared decision making community, developed the SUND AE guidelines. The guidelines are an evidence- and consensus-based set of recommendations that are summarized in a 26-item checklist. In addition, the developers created an Explanation and Elaboration (E&E) document that provides detailed examples of how to address each of the checklist items within a manuscript.

During this workshop, the faculty will briefly present the results of the development process and will discuss the relationship between SUND AE and other reporting guidelines (e.g. CONSORT). The development process followed well-established reporting guidelines development methodology. Feedback from more than 100 international stakeholders indicated a high level of consensus on the importance of the items, as well as a strong willingness to use the items when preparing manuscripts.

The workshop participants will break into small groups and have the opportunity to examine the extent to which selected published papers incorporate SUND AE checklist items. The groups will critically examine the quality of reporting of the items, and the role of the Checklist and E&E to support better reporting.

Finally, the small groups will make recommendations for strategies to promote implementation and dissemination of the guidelines. The SUND AE guidelines have been developed for use by a wide variety of patient decision aid researchers, and may also be useful for informing study design and supporting peer-review of manuscripts.

Learning objectives:

After this interactive workshop, attendees will be able to:

- Describe the development and appropriate use of the SUNDAE guidelines, checklist and E&E document when designing and reporting studies
- Critically review published studies to identify reporting of checklist items
- Discuss the feasibility of using the checklist and E&E
- Identify strategies for implementing and disseminating the SUNDAE guideline

Pre-requisites: None, but familiarity with decision aid evaluation studies will be helpful.

Size: 30-50

Duration: 60-90 minutes

NOTE: In prior discussions with Nora, we prefer this workshop to occur during the conference (possibly during a lunch period or parallel session) and NOT on Sunday.

Implementing decision support for colorectal cancer screening in vulnerable populations

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Background: Colorectal cancer (CRC) is an important cause of morbidity and mortality. Screening can reduce CRC incidence and mortality in adults ages 50-75. Several methods of screening are available, each with specific advantages and disadvantages. Surveys suggest that knowledge of the benefits and downsides of screening remain low, and that many adults have not had the opportunity to discuss screening with their provider. These barriers are even greater among those from vulnerable populations. Patient decision aids have been shown to be effective in increasing knowledge and interest in CRC screening in controlled trials. However, implementing decision support in vulnerable populations is challenging, and even when decision support is provided, many patients face additional barriers in carrying out their preferred decision. Better implementation of decision support for CRC screening has the potential to improve decision-making and reduce health disparities.

Methods: In this workshop, we will review different options for implementing decision support for CRC in vulnerable patients, drawing from over 20 years of experience in designing and testing such interventions, including current multi-site trials funded by the American Cancer Society and National Cancer Institute. Topics include:

- 1) Introduction to decision support tools for CRC screening
- 2) Case study: clinic-based decision support for patients with low literacy, with audience discussion of strategies to overcome digital divide
- 3) Case study: mailed decision support for Medicaid beneficiaries
- 4) Options for enhancing the effect of decision support: patient navigation and the use of text message reminders
- 5) Summary: consideration of the advantages and disadvantages of different methods for reaching vulnerable populations- group activity, followed by questions and answers

Results: At the conclusion of the workshop, participants will be able to:

- 1) Recognize the effects of decision support on CRC decision making outcomes
- 2) State the advantages and disadvantages of different methods for implementing decision support in vulnerable populations, in both clinical and non-clinical settings
- 3) Identify other colleagues who are actively implementing or planning to implement efforts to increase CRC decision support

Conclusions: This workshop will provide participants with practical, evidence-based recommendations for decision support for CRC screening in vulnerable populations.