



# ISDM 2019

# 10<sup>th</sup> International Shared Decision Making Conference

Book of Abstracts

Workshops

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## ISDM 2019 Abstracts for Workshops

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# 1 - 20th Anniversary Update of the Ottawa Decision Support Framework: A Workshop to Discuss Evidence, Lessons Learned, and Future Research

Dawn Stacey<sup>1,2</sup>, Laura Boland<sup>2,3</sup>, , Mirjam Garvelink<sup>4</sup>, Lauren Hoefel<sup>1</sup>, France Legare<sup>5</sup>, Krystina Lewis<sup>1</sup>, Marie-Chantal Loiseau<sup>6</sup>, Annette O'Connor<sup>1</sup>

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## **Background:**

For 20 years, the Ottawa Decision Support Framework (ODSF) has been used to guide clinicians and patients facing difficult health or social decisions. The premise is that unresolved decisional needs adversely affect informed values congruent decision making. The quality of decision making improves if needs are addressed with theory informed decision support interventions (e.g. clinical counseling, patient decision aids, decision coaching). The ODSF is being updated using systematic reviews of patients' decisional needs, Decisional Conflict Scale, and trials of patient decision aids developed using the ODSF.

## **Overall aim:**

To bring patients, clinicians, policy makers, educators and researchers together with ODSF experts for: a) a series of skill-building and informative conversations about the updated evidence and implications for the ODSF and b) identifying future research questions.

## **Learning objectives:**

Participants will have the opportunity to: 1) Review the history of and the evidence behind the ODSF; 2) Reflect on the different ways the ODSF can be used to enhance the quality of patients' decisions; 3) Share experiences of using the ODSF; 4) Reflect on challenges and successes with using the ODSF; and 5) Identify future research questions.

## **Description of the workshop (2 hours):**

We propose an interactive workshop to stimulate creative thinking, discussions, and inform future directions. First, we will provide an overview of 20 years of ODSF use. Second, we will hold small group discussions facilitated by recognized ODSF experts who will act as table hosts. Participants will spend about 15 minutes at each expert's table (e.g. decisional needs, Decisional Conflict Scale, patient decision aids, decision coaching) before shifting tables, for a total of 60 minutes. Participants will have opportunities to share their own experiences with using the ODSF, reflect on the challenges and successes of its use, and generate ideas for future research. Third, the small group discussions will be summarized and shared in the larger group. Overall, participants will benefit from the opportunity to learn from the experts and discuss the theoretical underpinnings, methodological issues, and practical challenges that have been encountered in using the ODSF tools and outcome measures.

## 2 - Developing and Implementing Decision Aids for Cancer Screening in Primary Care

Michael Pignone<sup>1</sup>, David Miller<sup>2</sup>, Alison Brenner<sup>3</sup>, Daniel Reuland<sup>3</sup>

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### **Background:**

Cancer screening offers important opportunities for shared decision-making in primary care practice. Decision aids can improve decision-making processes and outcomes; however, they have not been widely implemented. Further, even once decision aids are offered, limited attention is paid to how informed patient preferences are implemented in practice.

Our multi-center research team has extensive experience developing, testing, and implementing decision aids for cancer screening in primary care. We have organized a workshop that is both didactic and interactive. We will present findings and experiences from our decision aid testing and implementation research in primary care. We will focus on colorectal and lung cancer screening as exemplars in our presentation; however, other cancer screening decisions will be addressed during the session. Participants will engage in individual and small group activities to identify and “workshop” their own ideas and challenges related to design and implementation of decision aids for cancer screening.

### **Aim:**

To enhance collective knowledge and skills regarding both the design and implementation of decision support for cancer screening in primary care

### **Target audience:**

Decision aid developers, SDM advocates and researchers, primary care providers, and policymakers

### **Organization (120 minutes):**

1. Introductions
2. Brief background and problem description, including
3. Group discussion (participants)
4. Presentation (leaders)

Developing and implementing decision aids for the primary care context: examples of colorectal and lung cancer screening

### **3 - La conception d'outils d'aide à la prise de décision partagée en santé**

Anik MC Giguère<sup>1,2,3,4</sup>, Caroline Larose<sup>3</sup>, Hervé Tchala Vignon Zomahoun<sup>5</sup>, France Légaré<sup>1,3,4,5</sup>, Patrick Archambault<sup>1,3</sup>, Krystina B Lewis<sup>6</sup>, Marie-Eve Poitras<sup>7</sup>, Nicolas Dugré<sup>8</sup>

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#### **Introduction :**

Les outils d'aide à la décision (OaDs) permettent de connaître les options disponibles face à un problème de santé, et de peser les avantages et désavantages de chacune. Par rapport aux soins habituels, les OaDs permettent aux personnes d'être mieux informées, d'avoir une meilleure idée de ce qu'elles préfèrent, de jouer un rôle plus actif dans la prise de décision clinique, et d'avoir une meilleure perception des avantages/désavantages d'un traitement ou d'un changement aux habitudes de vie. La conception des OaDs demeure toutefois largement confinée aux travaux de recherche. En conséquence, les possibilités de mise à l'échelle des OaDs dans toutes les situations cliniques où la prise de décision partagée serait requise sont limitées. Pour combler cette lacune, nous avons développé une formation en ligne pour soutenir toutes les parties prenantes dans le développement et la mise en œuvre d'OaDs.

#### **Objectif de l'atelier :**

À la fin de cette formation, les participants seront capables d'évaluer ce qui est requis pour concevoir un OaD, juger la qualité des OaDs, et implanter un OaD en pratique courante.

#### **Audience cible :**

Chercheur-e-s et étudiant-e-s gradué-e-s, professeur-e-s et enseignant-e-s, décideur-e-s et professionnel-le-s des organisations de soins et services de santé, Patient-e-s ou citoyen-ne-s partenaires de projets de recherche faisant la promotion de la prise de décision partagée, ou partenaire dans l'élaboration d'OaDs.

#### **Description de l'atelier :**

Dans cet atelier interactif, les participants seront invités à partager leurs expériences, leurs types de pratiques et leurs besoins pour concevoir un OaD. L'atelier comprendra de brèves présentations magistrales, intercalées d'études de cas et d'exercices pratiques en petits groupes animés par des expert-e-s. Les présentations couvriront entre autres (1) les caractéristiques des OaDs, (2) les stratégies de conception, notamment comment trouver l'information, comment aider les personnes à clarifier leurs valeurs, et comment limiter la complexité de l'OaD et améliorer l'expérience de l'utilisateur, (3) l'évaluation des OaD, et (4) les stratégies d'implantation. Les participants seront invités à appliquer les enseignements reçus à un projet de conception d'OaD de leur choix, soit pour leurs milieux cliniques ou pour la recherche.

<https://health.uottawa.ca/nursing/student-life/student-resources>

## 4 - Shared Decision Making in Rehabilitation

Simon Décary<sup>1,2</sup>, Allyson Jones<sup>3</sup>, Marie-France Coutu<sup>4</sup>, Yannick Tousignant-Laflamme<sup>4</sup>, Élodie Chénard<sup>1,2</sup>, France Légaré<sup>1,2</sup>

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### **Background:**

The grave consequences of disabilities related to musculoskeletal, neurological and cardiorespiratory disorders result in frequent healthcare system reorganization as governments seek sustainable rehabilitation models. Engaging patients and families with physical impairments and disabilities in shared decision making (SDM) may promote adherence and ultimately improve quality of life. Yet SDM training programs and tools are still rare in rehabilitation contexts.

### **Overall aim:**

To equip health professionals providing rehabilitation care with the knowledge, skills and tools to integrate SDM into their practices.

### **Target audience:**

Health professionals who provide rehabilitation care such as physiotherapists, occupational therapists, psychologists, physicians or nurses. We also highly encourage all other stakeholders (managers, policy makers, patient-partners with disabilities) to participate.

### **Conclusion:**

This workshop will provide participants with a rich understanding of concepts and tools for applying SDM to rehabilitation. The ISDM conference offers a unique networking opportunity to gather a community interested in integrating SDM into rehabilitation.

## 5 - Patient and Public Involvement in Research: Why and How?

Ann Bradley<sup>1</sup>, Myrtle Mitchell<sup>2</sup>, Kristin L. Carman<sup>3</sup>, Danielle Schubbe<sup>1</sup>, Renata W. Yen<sup>1</sup>, Glyn Elwyn<sup>1</sup>, Marie-Anne Durand<sup>1</sup>

<sup>1</sup>The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, Lebanon, NH, USA, <sup>2</sup>Montefiore Medical Center, Bronx, NY, <sup>3</sup>Department of Public and Patient Engagement, Patient Centered Outcomes Research Institute, Washington, DC

### **Background:**

Patient and public involvement in research (PPIR) is increasingly advocated to improve the quality, validity, generalizability, dissemination and implementation of research studies. Appearing over 20 years ago, PPIR is becoming a requirement in most aspects of the research cycle: from planning studies and obtaining research funding to managing projects, publishing and disseminating findings. Patient and public involvement in data collection and analysis remains rare. PPIR seems particularly relevant in the context of research studies aiming to promote patient engagement in healthcare.

### **The aim of the workshop:**

This workshop aims to: 1) outline the true benefits of PPIR, 2) establish guiding principles for the successful involvement of patients and the public, 3) avoid common pitfalls and barriers to successful collaboration, 4) provide examples from successful PPIR, and 5) understand how best to plan and design patient and public involvement for your project (including data collection and analysis).

### **Target audience:**

All researchers and other stakeholders (patients, caregivers, health professionals) with an interest in:

- Patient and public involvement in research;
- Involving patient and the public in research for the first time;
- Increasing the extent to which they engage patients and the public;
- Maximizing the impact of patient and public involvement.

### **Learning objectives and methods:**

Objective 1: Understand how to maximize the impact and success of patient and public involvement in research (including data collection and analysis)

Objective 2: Explore multiple ways to operationalize patient and public involvement in research through examples provided by patient associates (actively involved in data collection) and the Director of Public and Patient Engagement at PCORI

Objective 3: Determine how best to plan and design appropriate patient and public involvement for your project.

This workshop will be led by two patient associates (patients who are actively engaged in conducting research). They are currently involved in recruitment and data collection for a randomized controlled trial of breast cancer patient decision aids. Facilitation and support will be provided by the Director of Public and Patient Engagement at PCORI, and health services researchers. Short didactic sessions will be combined with small group discussions.

## 6 - Understanding as the Core Process of Developing Share-Decision Making (SDM) Tools for Obesity

Guillermina Noël<sup>1,2,3</sup>, Thea Luig<sup>1,4,5,6</sup>, Denise Campbell-Scherer<sup>1,7,8,9</sup>

<sup>1</sup>University of Alberta, <sup>2</sup>Physician Learning Program, <sup>3</sup>Human-centred designer, <sup>4</sup>Medical anthropologist, <sup>5</sup>Research Associate, <sup>6</sup>Department of Family Medicine, <sup>7</sup>Professor Department of Family Medicine, <sup>8</sup>Associate Dean Lifelong Learning & Physician Learning Program, <sup>9</sup>Alberta Diabetes Institute

### Background:

People living with obesity suffer from multiple health conditions, including diabetes and mental health. Managing obesity is affected by misinformation about its complexity and chronicity, resulting in unrealistic expectations by healthcare providers and patients. Effective obesity management has to be individually tailored for each patient.

Obesity management is challenging due to the medical complexity of patients, the socio-economic factors affecting their health, and the need to understand the connection between all these aspects. Obesity management demands personalized care planning to provide support tailored to the uniqueness of each patient.

### Aim:

This workshop will outline the multidisciplinary approach the 5As Team Program used to improve the efficacy and suitability of the 5As SDM tools through a collaboration between patients, care providers, and researchers.

### Audience:

Clinicians interested in SDM in obesity and other chronic conditions

### Learning objectives and methods for organizing the workshop:

Methods

Introduction

Getting to know each other	Interpersonal interaction	10 min
The challenges of obesity management	Exercise	15 min
Understanding through anthropology	Exercise	15 min
Improving the SDM tool	Group exercise	20 min
Wrapping up	Reflection exercise	20 min



## 7 - How to Motivate Physicians to Train in Shared Decision-Making: Exchange on Success Factors und Useful Strategies

Christine Kuch<sup>1,2</sup>, Pola Hahlweg<sup>3</sup>, Kai Wehkamp<sup>1,2,4</sup>, Anja Lindig<sup>3</sup>, Isabelle Scholl<sup>3</sup>, Friedemann Geiger<sup>1,2</sup>

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<sup>3</sup>Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany, <sup>4</sup>University Medical Center Schleswig-Holstein, Department of Internal Medicine I, Kiel, Germany

### **Background:**

One strategy to implement shared decision-making (SDM) in routine clinical practice is to train physicians and other health care professionals (HCPs) in communication skills needed for making shared decisions with their patients. Among others, this strategy is used in two large-scale SDM implementation studies in Germany. The studies take place at the University Hospital of Kiel (850 physicians, every department of the entire hospital, and about 100 nurses of the entire hospital) and the University Medical Center Hamburg-Eppendorf (about 140 physicians and about 200 nurses, 3 departments). The motivation of HCPs to attend training is particularly crucial with regard to the aim of comprehensive implementation.

### **Aim of the workshop:**

To detect success factors and useful strategies to foster HCP's attendance at SDM training. These could relate for example to the training itself (content, duration, methods, setting, etc.), to its organization (scheduling, participants, communication, marketing, project management, multimethod approach etc.), and to the health care organization and the health care system (leadership, resources, cultural factors, incentives, community factors, etc.).

### **Target audience:**

Researchers, trainers, hospital representatives, health care professionals, leaders of implementation projects.

### **Learning objectives and methods for organizing the workshop:**

Methods:

After a short input on success factors from the implementation studies in Kiel and Hamburg, we will collect success stories and good examples within small groups. Afterwards, results will be exchanged in a "facilitated marketplace". Using a "strategy walk", a method incorporating all participants, new approaches to implement these success factors in participants' own health care organization or research project will be developed. We will sum up the workshop by looking at the numerous possibilities we collected and developed.

## 8 - Exploring Opportunities to Advance SDM Research and Care with AHRQ's Care and Learn Model

Alaina K. Fournier<sup>1</sup>, Mary Nix<sup>1</sup>, Jan Genevro<sup>1</sup>, Victor M. Montori<sup>1,2</sup>, Arlene Bierman<sup>1</sup>

<sup>1</sup>Agency for Healthcare Research and Quality, Maryland, United States of America, <sup>2</sup>Mayo Clinic Knowledge and Evaluation Research Unit, Minnesota, United States of America

### **Background:**

AHRQ's Care and Learn model describes the two key functions – caring and learning – of a healthcare system that responds to the health needs of patients and families, while taking into consideration their values, preferences, and life circumstances. Learning is a continuous function of the system and its stakeholders during the processes of caring. AHRQ uses the model to identify functions of the healthcare system that its work and research investment can inform and improve. Shared decision making (SDM) aims to bring patients, their families, and their healthcare teams together to provide appropriate and effective care, but SDM is still not widely adopted in clinical practice as a component of care for a variety of reasons. AHRQ is interested in advancing SDM research to improve its practice and use, and ultimately, the care of patients.

### **Aim of the Workshop:**

The aim of the workshop is to advance SDM research and care by using AHRQ's Care and Learn model to explore opportunities to improve how SDM is understood, taught, practically applied, implemented, and measured throughout the healthcare system.

### **Target audience:**

SDM researchers, clinicians, patients, other funding agencies

### **Learning objectives and methods for organizing the workshop:**

Participants will learn about AHRQ's Care and Learn model and how it may be applied to various aspects of SDM research. Small discussion groups of participants will be presented with different scenarios that reflect the various purposes of SDM in various care settings and contexts. The participants will also be given a standard list of questions to explore if and how best the Care and Learn model applies to each scenario. Faculty will be available to the small groups to further explain the activity and purpose, answer questions about the model, and guide the group to the endpoint, as needed. Following small group discussions, each group will share their results and the larger group will add to the discussion, facilitated by the faculty.

# 9 - Cracking the Code: A Practical Application for Shared Decision Making in Patient-Oriented Research

Chloe Guinaudie<sup>1</sup>, Sara Jalali<sup>1</sup>, Chantelle Mireault<sup>1</sup>, Yvonne Pelling<sup>1</sup>, Jimmy Tan<sup>1</sup>

<sup>1</sup>ACCESS Open Minds, Canada

## **Background:**

ACCESS Open Minds (ACCESS OM) is a pan-Canadian youth mental health patient-oriented research network comprised of 14 services sites, with over 300 members including youth, families/carers, researchers, service providers, and policy makers. It is transforming youth mental health services through the provision of high quality and accessible youth mental health care and by using innovative research to evaluate how services are provided. Funded by CIHR as Canada's first SPOR, ACCESS OM has implemented patient-oriented strategies across various contexts, including urban, rural and Indigenous communities. For example, youth and family/carers have contributed to the design of clinical services, research protocol/methodology, and strategic planning. Shared decision making has resulted in new knowledge reflective of youth and family/carers' knowledge, priorities and needs, ultimately improving youth mental health care across the country. These insights are applicable to various patient-oriented research settings.

## **Aim of workshop:**

The aim of this workshop is to share insights, to discuss challenges, and to facilitate discussion on techniques to implement and sustain opportunities for shared decision making between stakeholder in health research and evaluation.

## **Target audience:**

Patients, patient partners, community members, researchers, policy makers, service providers, funders, proponents of shared decision making in health research contexts.

## **Learning objective and method:**

Promote knowledge exchange of strategies which can be used to implement and sustain shared decision making. The discussion will be structured around three themes:

- 1) Clinical service design and implementation;
- 2) Research protocol design and implementation
- 3) Organizational

Participants will be divided into small discussion groups. An effort will be made to create diversity within each group. Each group will discuss strategies to foster shared decision-making opportunities through a given theme. Methods will be shared with the larger group. Exchanges of ideas will be visually represented and recorded through a word cloud generator to provide an interactive forum for large group discuss while documenting workshop outcomes. Facilitators will share insights from the ACCESS OM pan-Canadian youth mental research project (from various standpoints: lived experience, research and clinical services).

# **10 - A National Heart, Lung, and Blood Institute (NHLBI) Workshop: Understanding and Preparing for the NIH Grants Process**

Susan T. Shero<sup>1</sup>, Jennifer Curry<sup>1</sup>

<sup>1</sup>National Heart, Lung, and Blood Institute, National Institutes of Health, Maryland, USA

## **Background:**

The NIH grant application process can be challenging, especially for those applying for the first time.

## **The aim of the workshop:**

The primary aim of this workshop is increase participants' overall knowledge of the NIH grant application process and available resources; and to discuss a current SDM funding opportunity announcement PA-19-166 "Implementation of shared decision making for HLBS diseases and conditions (R01 Clinical Trial Optional)."

## **Target audience:**

The target audience for this workshop is early stage investigators, mid-career investigators, and anyone interested in NIH grant processes and funding opportunity announcements.

## **Learning objectives and methods for organizing the workshop:**

After a brief presentation on topic areas such as general tips for preparing to submit an application; avoiding pitfalls; and identifying types of funding opportunity announcements that could be used for SDM research (Parent program announcements, requests for applications, ancillary studies, supplements), participants will take a closer look at the current funding opportunity announcement "Implementation of shared decision making for HLBS diseases and conditions (R01 Clinical Trial Optional)" to identify FOA-specific requirements and discuss the research areas of interest and selected examples sections.

The remaining portion of the workshop will be used for informal discussion and questions and answers relative to the presentation topics, FOAs, and the participants' own research projects/applications.

# 11 - Using Mind Mapping to Support Shared-Decision Making with Pediatric and Geriatric Patients

Kathleen Kieran<sup>1,2</sup>, Matthew L. Russell<sup>3</sup>

<sup>1</sup>Seattle Children's Hospital, Seattle, WA, USA, <sup>2</sup>University of Washington, Seattle, WA, USA,

<sup>3</sup>Boston Veteran's Affairs Medical Center, Boston, MA, USA

Divergent objectives and narratives between members of a healthcare team may lead to suffering, underscoring the need to align patient care with the patient's self-identified goals. Shared decision making (SDM) with patients who may not be able to make healthcare decisions for themselves presents a unique challenge to healthcare providers, caregivers, and patients. Children and the elderly are two such groups. Previous research on SDM in pediatric and geriatric patients has found that caregiver involvement, regulations and policies, and communication skills training for providers are several of the key factors perceived as barriers to effective SDM. Thus, there is a clear need for a technique in which all facets of the patient's story can be told, within the context of the biopsychosocial model. Mind mapping is a highly effective way of getting information in and out of the brain, and a creative and logical means of note-taking and note-making that literally "maps out" ideas in a visual, artful style. Linear, rote, mnemonic-based strategies for patient/caregiver engagement may not promote the organic identification of stakeholder priorities. In contrast, mind maps create a natural organizational structure that radiates from the center and use lines, symbols, words, color and images according to simple, brain-friendly concepts, revealing connections and raising additional questions. Understanding the "topography" of relationships and priorities focuses team discussions, finds shared interests in seemingly divergent objectives, and identifies which team member may best lead a discussion on a particular topic. In this two-hour workshop, learners will become familiar with and will practice mind-mapping. Using several clinical vignettes, learners will make, share, and reflect upon their own maps. Learners will also have the opportunity to map their own clinical vignettes.

## **Target audience:**

Stakeholders in the care of geriatric and/or pediatric patients.

## **Brief agenda:**

Introduction to and explanation of mind mapping (30 minutes), practice/discussion with provided vignettes (35 minutes), practice/discussion with own vignettes (35 minutes), questions/ group discussion (20 minutes).

## 12 - Role of Artificial Intelligence in Patient-centred care and Shared Decision Making

Samira Abbasgholizadeh-Rahimi<sup>1</sup>

<sup>1</sup>Faculty of Medicine, Department of Family Medicine, McGill University

### **Background:**

Research into artificial intelligence has drastically increased around the world and artificial intelligence tools are increasingly being applied in different fields and industries including health care. Artificial intelligence is being used to harness and analyze big data to improve efficiency and personalization in health care. It is already being used for image analysis in radiology, pathology, and dermatology, with a diagnostic speed exceeding that of medical experts and equaling and even excelling their accuracy (1). Artificial intelligence could improve equality of access to care; increase the speed of care; increase the quality of care; enable more patient-centered care, and so more undiscovered potentials and benefits. Patient-centered care and Shared Decision Making (SDM) as an essential aspect of patient-centered care can benefit enormously from artificial intelligence. However, little is known on the use and potential impact of artificial intelligence on SDM.

### **The aim of the workshop:**

The overall aim of this workshop is to raise the awareness on artificial intelligence and its potential for improving patient-centered care and SDM among SDM society, exchange ideas, and shed light on the future work in this topic.

### **Target audience:**

All participants with an interest in the topic including researchers, patients and caregivers, health professionals, engineers, policy makers, and trainees.

### **Methods for organizing the workshop:**

An interactive workshop, including analogy introduction, brief presentations, two individual/group activities, and a facilitated discussion. We will produce a report to circulate among participants after the conference. (Participants are required to bring their laptops or tablets or smartphones to be able to participate in the workshop activities).

### **References:**

(1) Hosny, Ahmed et al. Nature reviews. Cancer vol. 18,8 (2018): 500-510.