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061 - Shared Decision-Making with Indigenous Patients

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Background: While Shared Decision-Making (SDM) emphasizes equalizing power between patients and health care providers (HCPs) to create more equitable healthcare, historical inequities between Indigenous and non-Indigenous peoples sometimes render these healthcare relationships difficult to navigate. We investigated whether SDM could align with Indigenous patient values. Using realist methodology, we developed a program theory that identifies inhibitory and promoting factors for SDM when working with Indigenous peoples. With a specific interest in trust and world view, we conducted a realist review of the healthcare decision-making of Indigenous patients in Canada, Australia, New Zealand and the US.

Aim: Our research question was: "In a situation involving Indigenous patients, for whom, why, how and in what respects do trust and world view influence patient engagement to achieve SDM?"

Target Audience: practitioners who work with Indigenous patients.

Agenda: We will briefly outline our method followed by details of our findings. After each collection of findings we will engage the audience for discussion. Our main findings were: the importance of consultation with Indigenous leadership and engagement with Indigenous scholars; the adoption of the Truth and Reconciliation Commission health Calls to Action; using culturally appropriate materials to train HCPs and to interact with patients; implementing supports such as incorporating community-level resources offering support to families. Policy makers can identify areas where system-level improvements can be made. The incorporation of Indigenous HCPs or peer navigators into Western health systems may guide and support decision-making processes. Our theory postulates that when HCPs accept and include Indigenous worldviews into the decision-making process trust is fostered. This reduces patient anxiety and improves patient engagement in SDM. Fostering Indigenous world views mitigates the negative impact of cultural discrimination and systemic and historical abuse. By understanding the mechanisms of trust and worldview this realist derived program theory may offer suggestions in how to use SDM to benefit Indigenous patients.

166 - International Patient Decision Aid Standards (IPDAS) Collaboration: Special interest group meeting on Update 2.0 working groups

Dawn Stacey[1,2], Robert J. Volk[3], and the IPDAS Working Group Leads[4]

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Established in 2003, the International Patient Decision Aid Standards (IPDAS) Collaboration aims to enhance the quality and effectiveness of patient decision aids (PtDAs) by establishing a shared evidence-informed framework for improving their content, development, implementation, and evaluation.

The IPDAS collaboration resources include:

1) the PtDA checklist with 74 criteria for developing and evaluating PtDAs, produced using a modified Delphi consensus process with a range of stakeholders who were informed with theoretical and empirical evidence (Elwyn, 2006). The IPDAS instrument (IPDASi) has only 47 items rated on a four-point scale (strongly agree to strongly disagree). It was validated and showed adequate inter-rater reliability (Elwyn, 2009). A minimal set of essential criteria for defining (6 criteria) and certifying PtDAs (10 criteria), and evaluating the quality of PtDAs (28 criteria) have also been developed using a modified Delphi consensus process (Joseph-Williams, 2013).

2) the SUNDAE Checklist provides researchers with reporting standards and guidance for PtDA evaluations (Sepucha, 2017).

3) definitions, theoretical justifications, and evidence synthesis underpinning the IPDAS criteria were updated and published as chapters on ipdas.ohri.ca (2005), then published as a series of peer reviewed papers in BMC Medical Informatics and Decision Making (2013), and a systematic review of studies evaluating implementation of PtDAs into clinical practice (Elwyn, 2014).

In 2018, the IPDAS Collaboration launched the Update 2.0 of the evidence underlying the IPDAS criteria. Working groups were established for Systematic Development Process; Providing balanced information, Presenting probabilities, Clarifying Values, Personal Stories, Guidance/coaching, Disclosing Conflicts, Health Literacy, Evidence-informed, Effectiveness, and Implementation.

The overall aim of this special interest group meeting is for individual working groups to discuss the update on their activities and next steps.

 Special Interest Group Meeting Agenda:

 Working Group Leads: RVolk (development), KSteffensen & RMartin (providing balanced information), LTrevena & BZikmund-Fisher (presenting probabilities), HWitteman (clarifying values), HBekker & VShaffer (personal stories), DStacey & SKopke & JJull (guidance/coaching), RThompson (disclosing conflicts), KMcCaffery & MADurand & DMuscat (health literacy), THoffman & JPablo Brito (evidence-informed), RThomson & KSepucha (effectiveness), TvanderWeijden (implementation)

249 - IPDAS Update 2.0 "Guidance and Decision Coaching": A special interest group

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Background

Guidance and decision coaching are structured approaches that can be used within or alongside patient decision aids (PtDAs) to facilitate the process of decision making. Guidance is provided using various interactive strategies including a list of decision making steps, a worksheet, a list of questions, automated decision coaching, and/or an automated summary of the patients' priorities and decisional needs that can be shared with the practitioner, decision coaches or significant others who are preparing to be involved in the decision. Decision coaching by a trained healthcare is non-directive guidance and support to prepare patients to actively participate in making decisions with their healthcare provider and to achieve informed values-based decision. In 2005, the International Patient Decision Aid Standards (IPDAS) Collaboration developed a set of evaluative criteria and identified concepts of guidance and/or decision coaching in deliberation and communication as one of the 12 broad dimensions of PtDAs. Our group is developing the IPDAS 2.0 update for guidance and decision coaching.

Aim

The overarching aim of the special interest group (SIG) is to invite those interested in or currently using guidance and/or decision coaching to learn about and discuss the progress of the IPDAS 2.0 Update.

Target Audience

Interdisciplinary audience (healthcare providers, consumers/patients, administrators, policy and decision makers) with interest in IPDAS, guidance and/or decision coaching.

Agenda Outline

The SIG agenda consists of a presentation and the integration of facilitated discussion:

a) Presentation about IPDAS 1.0 guidance and decision coaching concepts, definitions, and how they relate to one another in the literature about shared decision making.

c) Results of a meta-synthesis of evidence about guidance and/or decision coaching used within or alongside patient decision aids, and that will include reviews of theoretical frameworks and systematic reviews of PtDAs.

d) As well as being invited to respond to each part of the presentation, SIG participants will be encouraged to share their experiences using decision coaching or guidance, identify what they view as emerging issues, and research opportunities in the area of guidance and/or decision coaching.

251 - Special Interest Group for ISDM 2019: Shared Decision Making with Indigenous Peoples

Janet Jull[1], Alex Hizaka[2], Gabriel Jodouin[3], Inuit Medical Interpreter Team Membe[4]

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Background: Indigenous Peoples have strong and resilient cultures; however, in comparison to those who are of European descent, Indigenous Peoples experience relatively poor health status. Health inequities are defined as systematic and socially-produced differences in health between populations that are preventable. Mainstream (Western) healthcare models reflect values, knowledge systems, and care practices that do not necessarily align with Indigenous Peoples and create health inequities. For example, Western-trained healthcare providers operate within health and social systems that typically lack understandings of diverse Indigenous cultures, and may negatively impact the health of Indigenous Peoples. Evidence suggests that SDM can narrow health inequities. Evidence also suggests that some groups of Indigenous Peoples may identify SDM concepts as supporting them in their healthcare.

Aim: To explore how to build evidence about SDM that is most likely to be ethical, equitable, and used by and with Indigenous Peoples.

Audience: Community members, academic researchers, healthcare providers, decision makers who are, or who plan to participate in research partnerships with Indigenous Peoples that lead to development and/or adaptation of SDM tools and approaches.

Proposed Agenda:

We are a group of community healthcare providers and researchers, all of who work with Inuit communities and some who also work with First Nations communities. First, we will provide a brief review of the academic literature about SDM and Indigenous Peoples. Then, we will share experiences with the development and/or adaptation of SDM tools and approaches with Inuit and First Nations communities. For example, we have found that Inuit Qaujimajatuqangit, the societal principles of Inuit culture, promote the SDM process.

We plan to highlight the use of SDM concepts by Indigenous societies, the potential to promote a strengths-based approach, and discuss the opportunities for SDM tools and approaches to meet best meet the needs of Indigenous Peoples in mainstream healthcare systems. A key feature of this SIG will be engagement of participants by the SIG facilitators. We hope to create a meeting event at ISDM 2019 in which community partners and researchers can share their experience, build collaborations, and support one another.

274 - 'Implementation of Patient Decision Aids' and 'Delivering PtDA on the Internet'; update of IPDAS background chapters.

Natalie Joseph-Williams (UK)[1], Purva Abhyankar (UK)[2], Laura Boland[3], Paulina Bravo[4], Suzanne Brodney[5], Alison Brenner[6], Angela Coulter[7], Anik Giguere[8], Aubri Hoffman[9], Aisha Langford[10], Mirjam Körner[11], France Légaré[8], Richard Martin[12], Daniel Matlock[13], Nora Moumjid[14], Sarah Munro[15], Christine Stirling[16], Karina Steffensen[17], Trudy van der Weijden[18]

[1]Cardiff University, [2]University of Stirling, [3]University of Ottawa, [4]Pontificia Universidad Católica de Chile – School of Nursing, [5]Harvard, [6]University of North Carolina at Chapel Hill, [7]NICE, [8]University de laval, [9]University of Texas, [10]New York University School of Medicine, [11]University freiburg, [12]Michigan State University, [13]University Denver, [14]University Lyon, [15]University of British Columbia, [16]University east Anglia, [17]University Southern Denmark, [18]University Maastricht

Background

The International Patient Decision Aids (IPDAS) collaboration aims to enhance the quality and effectiveness of patient decision aids (PtDAs). IPDAS has defined 12 core criteria for assessing the quality of PtDAs. IPDAS background chapters describe the theoretical rationale, current empirical evidence, and emerging issues underlying each of these core evaluative dimensions. In 2019, we will combine and update the theory and evidence underpinning the chapters: 'implementation of PtDAs into routine clinical practice' and 'delivering PtDAs on the internet'.

Aim

The chapter has to be designed along pre-set sections: definition (conceptual/operational) of the quality dimension; theoretical rationale for inclusion of the quality dimension; evidence base underlying the quality dimension; and references. The aim of this special interest group is to discuss and elicit stakeholders' views, experiences and suggestions on the process, content and direction of the updated chapter.

Target audience

Patients, clinicians, PtDA developers, policy makers and researchers with a special interest in implementation of shared decision making are invited to contribute to the discussion on the final direction of this IPDAS chapter.

Brief outline of the agenda

The concept-proposal will be presented. As the literature listing barriers and facilitators of PtDA implementation seems saturated it seems time to address the intention-behaviour gap for the uptake of PtDAs by professionals and patients. We consider systematic review of process evaluations of uptake of PtDAs in real-world studies, and systematic analysis of modes of development and delivery of PtDAs in various countries / regions that are considered as best practices. We will combine plenary and small group work to generate input on how to improve the protocol (methodology, feasibility, planning), and initiate discussions on controversial issues in the area of PtDA implementation, such as e.g.:

315 - The interface between health literacy and shared decision making: a reflection on interventions and measurements

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Background

Health literacy (HL) designates people's capacity to understand and manage the complex demands of health and healthcare. Limited HL is associated with poorer health outcomes, higher burden of disease, poorer health status, greater health resources use and higher mortality. Shared decision making (SDM) is "an approach where physicians and patients make decisions together, using the best available evidence about the likely benefits and harms of each option, and where patients are supported to arrive at informed preferences". Evidence suggests associations between health literacy and SDM. Several studies suggest that patients of limited health literacy are less likely to engage in SDM. Other research emphasizes that patients who are disadvantaged (including those of lower health literacy) are more likely to benefit from shared decision making interventions, provided the content and format are tailored to their needs. Intervening to improve SDM and health literacy are closely connected and could be achieved in tandem. The question of health literacy measurement seems equally relevant. In particular, some subjective multidimensional measures of HL might directly include components of SDM. For example the Health Literacy Questionnaire has a dimension about "patients' ability to actively engage with healthcare providers". It might create tautological association in survey studying the relationships between HL and SDM, but reinforces the idea that interventions could be connected.

Aim

The aim of this SIG is to discuss: 1) the synergy between HL and SDM , 2) how interventions may target both constructs 3) HL measurements (in the context of SDM research), and 4) how to support and empower patients of lower HL to articulate their preferences and values.

347 - Translation, Adaption and Validation of the Integrative Model of Patient-Centeredness into different Cultural Health Care Contexts: what are the main challenges when facing this process?

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Background

Patient-centeredness (PC) stands for high-quality health care and is demanded from international health care organizations as well as patient and health policy groups across the world.

The integrative model of PC proposes 15 dimensions: *essential characteristics of the clinician, clinician-patient relationship, clinician-patient communication, patient as unique person, biopsychosocial perspective, patient information, patient involvement in care, involvement of family and friends, patient empowerment, physical support, emotional support, integration of medical and non-medical care, teamwork and teambuilding, access to care, coordination and continuity of care.* The model has been validated and its dimensions prioritized through 105 experts ratings from 12 different countries (but 71% German, 11% American). This model has provided an important framework for both clinical and research initiatives around the world. However, when using this model, many teams face difficulties related to cultural adaptation. This has been the case of countries such as Chile, where PC is recognized as a desirable process and outcome of health services, but policy-makers have declared no operationalization of it. In this context, providing a depth discussion of the adaptation process is a need for different teams around the world.

Aim

The aims of this group are to (1) introduce the PC model and the pros and cons of procedures for its transcultural adaptation, (2) discuss the overall necessity of transcultural adaptations of models/measures, (3) share experiences of work in this field and build transcultural working groups on PC.

Target Group

Researchers, clinicians and patient representatives interested in transcultural work within the context of PC.

Outline of the Agenda

1) Brief presentation of the original PC model; 2) How to conduct a transcultural adaptation process of PC: lessons learned from the Chilean experience; 3) Adapting the model for target populations: the German experience of translation into plain language for patients. 4) Discussing these examples with the audience by highlighting difficulties (e.g. misunderstandings) as well as differences (e.g. in prioritization in terms of relevance of the dimensions) between the versions. 5) Creating a transcultural team for PC: a working group for research cooperation using the PC framework as a base.

353 - Creating an international collaborative research group for shared decision-making in palliative and end-of-life care.

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Background

Despite an increasing interest in shared decision-making (SDM) in palliative and end-of-life care,[1] there is a recognised paucity of research in the field.[1,2] Palliative care research faces both methodological and ethical challenges. Communication is aimed at maintaining hope whilst also recognising values and preferences.[1] Engaging in SDM can be daunting, least of all dealing with the unpredictable trajectories in incurable illnesses.[1] Establishing a collaborative research group in palliative care, through the ISDM, would provide the opportunity for interested colleagues (both expert and early career) to network, share ideas, information and expertise, and potentially form international collaborations in the future.

Aim

To set-up an international collaborative research group for SDM in palliative and end-of-life care.

Target Audience

All interested in SDM in palliative and end-of-life care research. We would welcome anyone whether they have experience and expertise, or have an emerging interest in this field. Members may be both non-clinical and clinical, at all stages of their careers (including early career researchers and postgraduate students) and, including patient and public representatives.

409 - Evidence Based Methods Standards for Patient Decision Aids

Glyn Elwyn[2], Catherine Saunders[2], Martin Mayer[1], Tammy Hoffmann[3], Lilisbeth Perestelo-Perez[4], Marie-Anne Durand[2], Michelle Dannenberg[2], Anik Giguère[5], Peter Scalia[2], Brian Alper[1], Stephen Campbell[6]

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Background: A subset of the International Shared Decision Making (ISDM) community is actively engaged in a project to identify, harmonize and develop standards for evidence summarization for patient decision aids

Aims: To review progress to date on developing standards, revise developing standards through open dialogue, and plan next steps in standards development and maintenance

Target audience: Any ISDM community members with a special interest in evidence based methods standards for patient decision aids

Brief outline:

10 minutes: Introductions of all participants

15 minutes: Review of progress to date in development of evidence based methods standards for patient decision aids

20 minutes: Open dialogue for key questions for standards refinement

15 minute: Discussion of planning next steps for this special interest group

Target audience

All researchers and stakeholders (patients, caregivers, health professionals) interested in:

1)   Promoting shared decision making across HL levels

2)   Improving communication in healthcare to address health inequalities

3)   Intervening to mitigate limited HL

4)   Measuring HL.

Agenda outline

Brief introductions

Synergy between health literacy and SDM: Brief overview of the literature

Can interventions address both health literacy and SDM? Some examples

Empowering patients of lower health literacy

Measuring health literacy in the context of SDM research

Future directions for HL and SDM

471 - Patient Engagement: From Partners in Care to Research Partners

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Background:

The current Quebec context is marked by several paradoxes like the emphasis on acute care while disease chronicization continues to increase, and the high non-compliance with treatment for chronic diseases despite the existence of proven and efficient methods of care. In addition to that, patients are motivated to be more involved in their own healthcare and decisions and are increasingly becoming more health literate. How should we react to these new reality? Build on the patient's desire to become partner in its care and services to establish a relationship partnership within research teams. Patient partners in research bring a 'lived experience' perspective.

The Research Partnership with Patients and the Public (PPP) strategy of the Quebec SPOR (Strategy for patient oriented research) Support Unit aims to transform front-line clinical and organizational practices and promote the integration of care and services through patient-centred research. Our objective is to support research teams and patient partners to collaborate together in research projects by providing them with tools and resources to support engagement.

Aim :

The aim of this special interest group is to invite those interested in or currently participating in research projects to learn from 'engaged' patients who've been involved with in research and learn if Canadian strategy and other international strategies match on-the-ground.

Target audience :

Patients, care givers, researchers, healthcare providers with interest in patient engagement in research.

Agenda outline :

The agenda includes a presentation followed by a facilitated discussion

a) Share examples of patient partnerships across Canada, from patients who've been partners

b) Discuss about the ethical considerations of health research.

c) With focus on patients, identify their expressed needs and expectancies in ISDM 2019.