IMPLEMENTATION OF SHARED DECISION MAKING IN PEDIATRIC CLINICAL PRACTICE

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For my sons, Aden and Darren McIsaac.

"Mom, are you done your PhD yet?"
"Today will you be done your PhD?"
"When will you ever be done your PhD?"
"I want to do a PhD!"

- Aden McIsaac, age 8

"Instead of checking that your thesis is perfect, why not just do it perfect?"

- Darren McIsaac, age 6

Preface

The following research was approved by the University of Ottawa Research Ethics Board (H08-17-10) and Children's Hospital of Eastern Ontario (CHEO) Research Ethics Board (15/42X). LB, the named doctoral candidate of this dissertation, participated in all aspects of the study conceptualization and design and is responsible for the integrity of the data and its interpretation. LB was the lead for all aspects of the dissertation studies, including data collection and analysis, and drafting each manuscript.

Abstract

Shared decision making (SDM) is rarely used in pediatric clinical practice. The purpose of this dissertation was to explore factors influencing SDM implementation in pediatric clinical practice. We conducted three studies that were guided by the Ottawa Model of Research Use (OMRU):

Study 1 was a systematic review using Cochrane methods and the Mixed Methods Appraisal Tool to determine pediatric SDM barriers and facilitators from multiple perspectives. Eighty studies, of low to high quality, were included. At each OMRU level, frequently cited barriers were: option features (decision), poor quality information (innovation), emotional state (adopter), power relations (relational), and insufficient time (environment). Frequently cited facilitators were: lower stake decisions (decision), agreement with SDM (adopter), high quality information (innovation), trust and respect (relational), and SDM tools/resources (environment). Across participant types, frequently cited barriers were: insufficient time (healthcare providers (HCP)), option features (parents), power imbalances (children), and HCPs' SDM skills (observers). Frequently cited facilitators were: good quality information (HCPs) and agreement with SDM (parents/children).

Study 2 was a post-test design that evaluated SDM knowledge and acceptability of learners who completed the Ottawa Decision Support Tutorial (ODST). Most learners were HCPs (62%). Overall, ODST learners had a median knowledge test score of 8/10 (IQR = 7-9; n=6604) and 90% reported good or excellent impressions (n=4276) after completing the tutorial. Few learners suggested improvements.

Study 3 used mixed methods to evaluate pediatric HCPs' perceived SDM barriers and facilitators after training (ODST plus workshop). Participants completed a SDM barrier survey (n=60; 88% response rate) and semi-structured interview (n=11). Their intention to use SDM was high (mean score = 5.6/7, SD=0.8). However, 90% of respondents reported minimal SDM use after training. Main barriers were lack of buy-in (adopter level) and time constraints (environmental level). Healthcare providers wanted a team-based approach to SDM training (training level).

Adopters face numerous and diverse barriers to SDM use, before and after SDM training. Pediatric HCPs who completed the ODST were knowledgeable about SDM. Despite positive intentions, training alone was insufficient to achieve routine SDM use. These findings can inform intervention development to promote SDM implementation in pediatric clinical practice.

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The doctoral journey has fundamentally changed me. It stretched my mind, expanded and deepened my worldview, and transformed my approach to complex problems and potential solutions. These gifts are invaluable and life changing. I will be forever grateful to all those who contributed to, and supported, my journey.

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I am grateful for my life circumstances, which have allowed the rare privilege of pursuing a doctoral education. My parents, Bernie and Sharon, always encouraged curiosity, learning, and taking calculated risks to achieve my goals. Thank you for your unbounded support, confidence and love. Also, thank you Mom, Dad, Janet (mother-in-law), and Grace (sister-in-law) for helping take care of my boys during busy times. I can’t overemphasize how much this support system enabled me to work through the doctoral program. Dan, my brilliant husband, who shares my love of research. Thank you for encouraging me to be my best, changing with me, and stepping up when it was time to finish this dissertation. Another affirmation that I have chosen the right life partner. My boys, Aden and Darren, the humans I love most; you fill my heart with joy, my days with laughter, and keep me balanced. As you grew, so did your intrigue and encouragement toward my studies. I hope that my pursuit of higher education will inspire you to love learning, over the lifecourse, as I do. Thank you to my wonderful friends. You all supported and encouraged me in your own way. Each gesture was more meaningful than you probably know, and I am so grateful to have you in my life.

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List of Abbreviations

SDM	Shared decision making
HCP	Healthcare provider
OMRU	Ottawa Model of Research Use
RCT	Randomized Controlled Trial
PtDA	Patient decision aids
AD	Absolute difference
UK	United Kingdom
USA	United States
Qual	Qualitative
Quant	Quantitative
MM	Mixed methods
Resp	Respondent
CHEO	Children’s Hospital of Eastern Ontario
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
ODST	Ottawa Decision Support Tutorial
STROBE	Strengthening the reporting of observational studies in epidemiology
CIHR	Canadian Institutes of Health Research
IP	Interprofessional

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CHAPTER 1

INTRODUCTION

1 INTRODUCTION

The purpose of this chapter is to introduce readers to the dissertation by describing the problem statement, dissertation objectives, key concepts, and the state of knowledge related to my studies. First, I provide context for the subsequent problem and purpose statements. Second, I describe the guiding conceptual model. Third, I briefly summarize the state of pediatric SDM knowledge, identify gaps in the literature, and provide justification for this dissertation. At the end of the chapter, I describe how this dissertation is organized.

1.1 Context

There is growing consensus, reflected in legislation and policies, that children should be involved in decisions about their health [1-6]. At the legislation level, the United Nations Convention on the Rights of the Child outlined the right of every child to self-determination and to make informed decisions [1]. The United Nations General Assembly on Children highlighted the importance of children's participation in health decisions and respecting their views [2]. Under most Canadian provincial laws[1], children can provide various levels of assent or consent based on their developmental stage and experience with the health condition [3, 4]. As such, healthcare providers (HCPs) must assess the child's decision making capacity prior to treatment and follow an informed consent process, regardless of the child's age. If a child is found incapable of consenting to treatment, the parents or legal guardians can provide consent on the child's behalf [4].

At the policy level, the American Academy of Pediatrics Committee on Bioethics reported that children should be included to the greatest extent possible in decisions about their health [5].

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[1] Under Quebec Civil law, the legal age of majority is 14 in most circumstances [8].

The Canadian Pediatric Society published a policy indicating that children should make decisions jointly with members of the health team and guardians to ensure the highest quality decision is reached [6]. Most Canadian pediatric academic hospitals' have patient and family centered care policy statements that articulated the benefits of including children and parents in health decisions [7].

1.2 Statement of the Problem

Despite legislation and policies, research evidence consistently shows that children are insufficiently involved in health decision making, despite wanting a more participatory role [8, 9]. When children participate in health decisions, they feel more valued, confident, empowered, and demonstrate improved treatment adherence, knowledge of the illness, and experience less anxiety and fear [8, 10, 11]. Similarly, reviews show that parents want a more active role and would prefer to share the decision about their child's health with a HCP [12-14].

Shared decision-making (SDM) is an evidenced-based process that promotes collaboration between patients and HCPs when making health decisions. By exchanging information about the evidence (options, risks, and benefits) and the patient and family's preferences and values, HCPs, patients, and family members can deliberate to determine the best treatment option [15, 16]. A systematic review (n=41) that examined the impact of SDM among adult patients, showed statistically significant and positive associations between SDM and affective-cognitive outcomes (54% of studies), behavioral outcomes (37% of studies), and health outcomes (25% of studies) [17]. SDM has also been described as "perfected informed consent process" and essential for patient centered care [18, 19]. Yet, implementation of SDM into clinical practice remains a challenge [20, 21] and the benefits of SDM have not been extended to pediatric populations [22].

In the adult literature, numerous barriers to SDM have been identified [23-25], but little is known about the factors that influence the implementation of SDM in pediatric clinical practice.

1.3 Purpose of the Dissertation

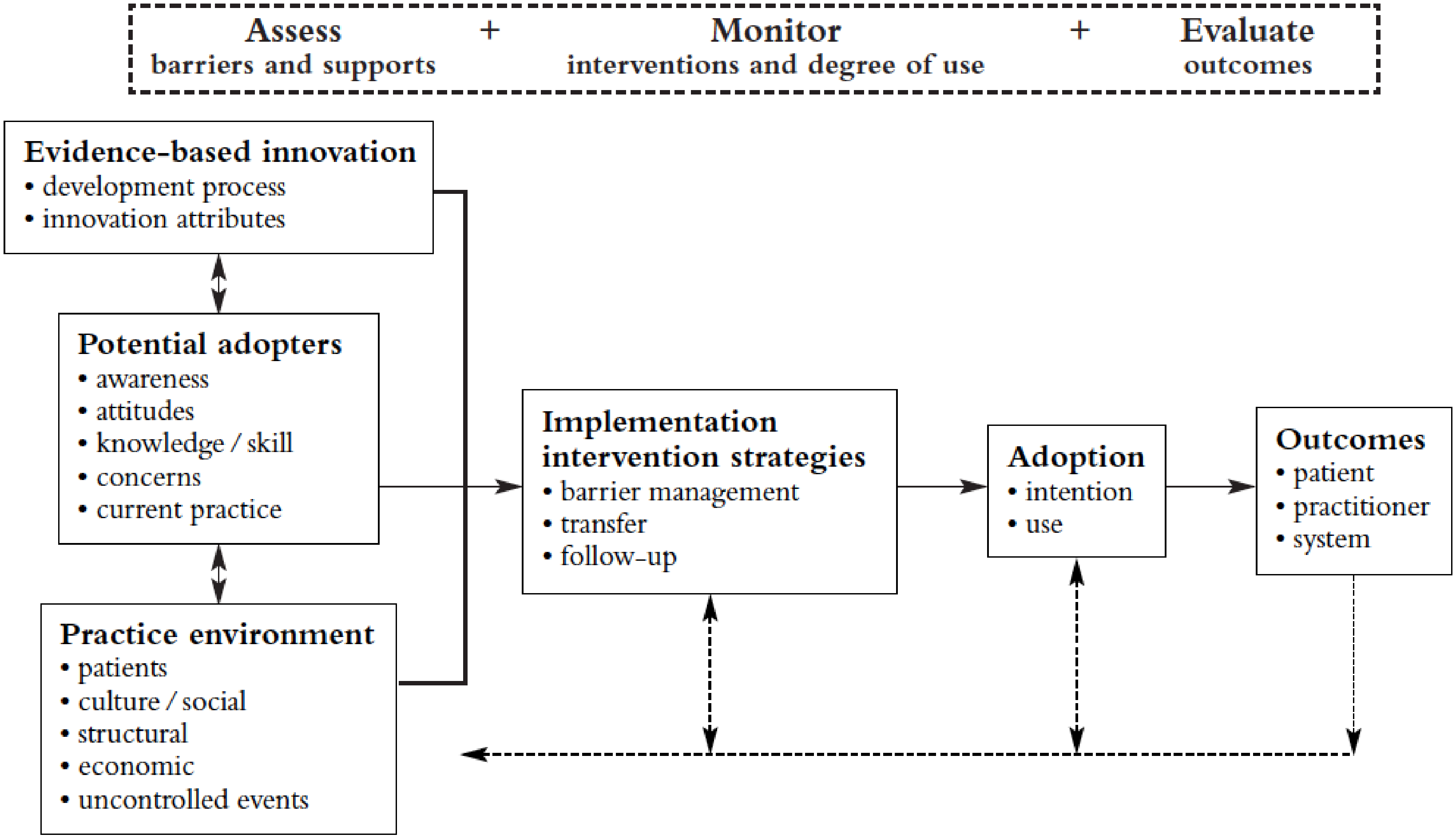
The overarching purpose of this dissertation is to evaluate factors that influence the implementation of SDM in pediatric clinical practice. Specific objectives were to:

1) Synthesize the barriers and facilitators that influence pediatric SDM implementation from the perspectives of HCPs, parents, children and observers.
2) Evaluate the impact the Ottawa Decision Support Tutorial (ODST), a SDM educational program designed to overcome SDM knowledge barriers and promote SDM implementation.
3) Assess pediatric HCPs' self-reported use of SDM in clinical practice and their perceived barriers and facilitators of SDM use, after having been trained in SDM (i.e., using the ODST plus a skill building workshop).

1.4 Guiding Conceptual Model

The Ottawa Model of Research Use (OMRU) guided this dissertation research [26] (Figure 1-1). The OMRU is a conceptual and interdisciplinary model of health research use derived from planned action theories, research utilization, and physician behavior change literature. The model can be used to explain the implementation of evidence into clinical practice using six key components: the innovation, potential adopters, practice environment, implementation interventions, adoption, and outcomes.

Figure 1-1 - The Ottawa Model of Research Use (Graham & Logan, 2010)



Given that these components are context-dependent, the OMRU outlines the following iterative process phases for implementing evidence:

1) assess barriers and facilitators at the level of the innovation, potential adopters, and practice environment;
2) design and implement interventions to minimize barriers and leverage facilitators;
3) monitor the use of evidence in clinical practice, and;
4) evaluate the implementation process and outcomes.

A primary assumption underpinning the OMRU is that barrier and facilitator assessments are essential for informing the implementation of evidence into clinical practice. These assessments should be conducted at the level of the innovation, potential adopters, and practice environment. I chose the OMRU as the guiding framework because it is action oriented, it assesses the broader issues surrounding innovation uptake (e.g., comprehensive multi-level barrier and facilitator assessment), it is dynamic and sensitive to context dependent variations, and it has been successfully used to guide barrier and facilitators assessments and SDM implementation studies [27-29].

1.5 Review of the Literature

The following section presents the main findings of a literature review. Six electronic databases were searched using key terms such as ‘shared decision making’, ‘pediatric’, ‘child’, ‘parent’, ‘HCP’, ‘barriers’, and ‘facilitators’ in various combinations. The search also included systematic reviews about pediatric SDM and key adult patient SDM publications (e.g., Cochrane and systematic reviews). Main findings are grouped under the following OMRU headings: (A) innovation, (B) barriers and facilitators, and (C) implementation interventions.

1.5.1 Innovation

An innovation is an idea, practice or object perceived as novel by an individual or unit of adoption [30]. In other words, a healthcare innovation can represent new knowledge, methods, protocols, or products that change behavior and/or clinical practice. In this dissertation, the innovation is defined as the use of SDM by HCPs with parents and/or children regarding a decision about the child's health.

There are many definitions of SDM in the adult literature [31] (Table 1-1). A systematic review identified 31 SDM concepts for adult patients and proposed the following the key elements: defining and explaining the problem, presenting the options, discussing the benefits and harms, exploring patient values and preferences, discussing the patient's ability and self-efficacy, discussing physician knowledge and recommendations, checking patient understanding, making or explicitly deferring the decision, and arranging for follow-up [15].

Table 1-1 Example SDM definitions in the adult literature, adapted from Bae, 2017 [31]

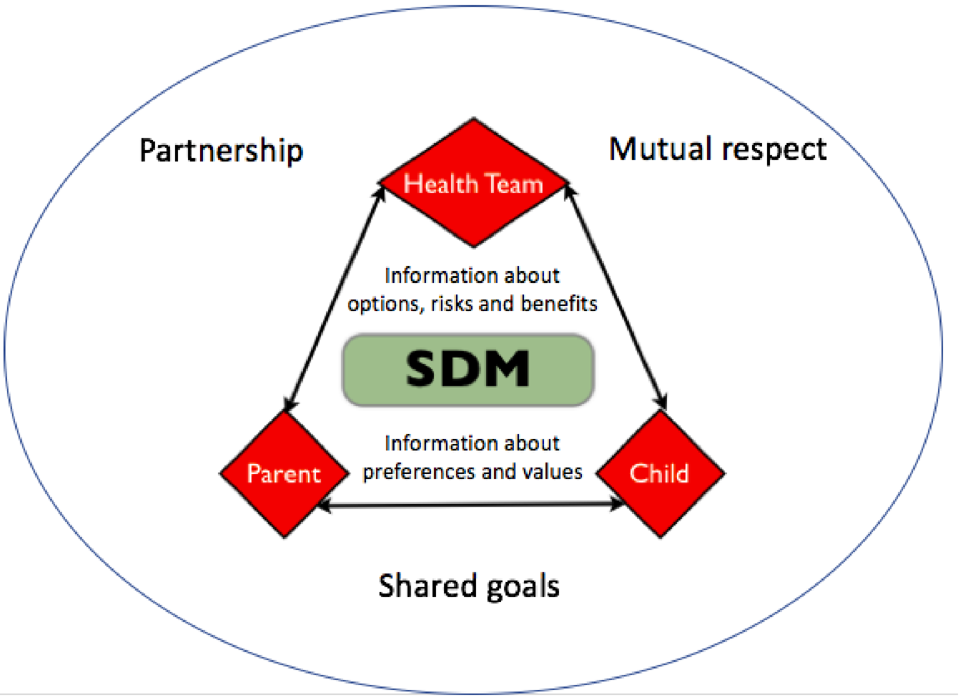
References	Definition
Charles et al (1997) [32]	A two-way exchange of information between the parties concerned with the medical decision either from the professional or from a patient point of view.
Towle et al. 1999 [33]	Decisions that are shared by doctor and patient and informed by the best evidence, not only about risks and benefits but also patient specific characteristics and values.
Frosch et al. (1999) [34]	Is a process by which patients and HCPs consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement.
Sheridan et al (2004) [35]	A process in which patients are involved as active partners with the HCP in clarifying acceptable medical options and in choosing a preferred course of clinical care.
Briss et al. (2004) [36]	When a patient and his or her HCP(s) in the clinical setting, both express preferences and participate in making treatment decisions.
Joosten et al. (2008) [37]	An approach in which the HCP and patient go through all phases of the decision making process together and in which they share the preference for treatment and reach an agreement on treatment choice.
Elwyn et al. (2010) [38]	A method where HCPs and patients make decisions together using the best available evidence, where patients are encouraged to consider available screening, treatment, or management options and the likely benefits and harms of each.
Scholl et al (2011) [39]	An approach where HCP and patients communicate together using the best available evidence when faced with the task of making decisions.
Légaré et al (2011) [40, 41]	Two or more health professionals (who) collaborate with the patient in identifying best options, clarifying patient preferences and enabling patients to take more control over the treatment plan.

Legare & Witteman, 2013 [42]	SDM is an interpersonal, interdependent process in which the HCP and the patient related to and influence each other as they collaborate in making decisions about the patient’s health care.

While most definitions and conceptualizations discuss SDM within the context of the physician-patient dyad, the interprofessional SDM model adds the roles of multiple stakeholders (e.g., patient, family and health professionals) and acknowledges the micro, meso and macro influences on SDM (Appendix A) [40]. This is particularly relevant for pediatrics context, given that decision making often includes the views of multiple adopters (e.g., child, parents, and health team), each with their own preferences and values.

Pediatric SDM is more poorly defined and conceptualized. Until recently, one theoretical paper conceptualized SDM in pediatrics as the exchange of information between the HCPs, parents, and child, in the context of partnerships, common goals, mutual respect, and absence of power differentials to make collaborative health decisions [16] (Figure 1-2). In 2017, a literature review was published that examined 42 studies and conceptualized pediatric SDM as the active participation of HCPs, parents, and children in reaching a compromise via collaborative partnership, with a common goal for the child’s health [43]. In summary, key elements of pediatric SDM include a collaborative decision making approach between HCPs, parents, and children that is based on information about options benefits and risks combined with information on parents’ and child’s preferences and values, using a process that is sensitive to involvement of all adopters.

Figure 1-2 - Visual interpretation Gabe et al. (2004) concept of pediatric SDM



1.5.2 *Barriers and Facilitators of Innovation Use*

Effective implementation of healthcare innovations requires knowledge about the barriers and facilitators influencing its use. A Cochrane review showed that health innovations aligned with prospectively assessed contextual barriers and facilitators are more likely to be implemented and improve professional practice [44]. Similarly, another systematic review found that barriers and facilitators to knowledge use are among the best predictors of intention and actual behavior change [45].

Four reviews have examined barriers and facilitators of SDM in encounters with adult in clinical practice, though none were conducted in pediatric clinical practice [23-25, 46]. One systematic review that was conducted in 2006, and updated in 2008, focused on HCPs' perceived barriers and facilitators of SDM with adult patients [23, 24]. Both reviews showed that HCPs commonly perceived time constraints, lack of applicability due to patient characteristics, and lack of applicability due to the clinical situation, as barriers to SDM. Facilitators included provider motivation and positive effects on patient outcomes and clinical processes. Another systematic review, published in 2014, synthesized studies reporting from the patients' perspective [25]. Adult patients reported SDM barriers and facilitators related to how the healthcare system is organized (e.g., time and workflow) and what occurred during the consultation (e.g., adopter and relational factors). Perceived power asymmetry in the doctor-patient relationship and insufficient knowledge (on options, benefits, harms, patients' preferences) were key barriers that limited patients' capacity to engage in SDM. To overcome these barriers, the authors suggested these influencing factors be considered from the perspective of multiple adopters (i.e., HCPs and patients) and that implementation interventions focus on better provision of information and empowering patients. Finally, a scoping review published in 2017 focused on the organizational and system-level factors influencing SDM [46]. Six main organizational factors influencing SDM were identified: leadership, a culture that is inclusive of patient involvement, HCP teamwork, access to clinical guidelines and resources (e.g., time, space, money), organizational priorities, and workflow (e.g., electronic health records). Four main system level categories were identified: incentives, policies and guidelines, culture of healthcare delivery, and HCP education and licensing. However, none of these systematic reviews specifically addressed barriers and facilitators of SDM in pediatric clinical practice [44].

Although not their primary outcome, five reviews commented on factors that influenced child and parent participation in pediatric health decisions [8, 9, 12-14] (Table 1-2). Reported barriers and facilitators were synthesized and categorized according to the OMRU levels (Table

1-3). To better reflect the data, I added the Relational level, which includes the interpersonal process between the HCP, patient, and family [47].

Table 1-2 Characteristic of the reviews

Reference	Objective	Design	N
Moore et al. (2010) [8]	To review the literature on children's and young people's participation in health care decision-making, to highlight gaps in the research and to identify implications for nursing practice.	Narrative review	25
Coyne et al. (2008) [9]	critique the research literature on children's, parents and healthcare professionals' experiences of children's participation in consultations and decision-making within the healthcare setting.	Narrative review	Not reported
Aarthun et al. (2014) [12]	To describe and synthesize previous research on parents' perceptions of their participation in decision making in child health-care services.	Integrative review	18
Lipstein et al. (2012) [13]	of the current research on parent decision making about pediatric treatments and identify areas in need of further investigation.	Narrative review	55
Jackson et al. (2008) [14]	To identify the decision support needs of parents attempting to make an informed health decision on behalf of a child.	Systematic review	149

In summary, at the innovation level, provision of information is important for enabling parent and child participation in decision making (Table 1-3). At the adopter level, characteristics of various adopters (e.g., child's age, parent's emotional state, and HCP's communication skills) helped or hindered parent and/or child decision making. Parent preference for an active decision making role facilitated inclusion. At the relational level, 4 of 5 reviews reported that power imbalances, usually between the HCP and the parent and/or child, were a barrier to decision making involvement. Parents with a sense of control, trusting and respectful relationship with the HCP, and opportunities to discuss the decision with others, could more readily participate in decision making. At the practice environment level, insufficient time and lack of structure for involving parents and/or children were barriers.

Table 1-3 Reported barriers and facilitators to parent/child decision making participation mapped to the OMRU

OMRU level	Barriers	Facilitators
Innovation	Lack of information [9, 12] Insufficient time spent with parents during the consultation [12]	Good quality information [9, 14]
Adopter	Parental emotional distress [12, 14, 13] Lack of parental self-efficacy [12] Lower socioeconomic status [12] Child's health status [13] Parents beliefs and values [13] Children's age and maturity [9] HCP and Parent attitudes [9] HCP skills [8, 9] Children's ability to skillfully ask questions [8]	Parents preference for SDM [12] HCP skill [12] Parent previous experience with similar decisions [13]
Relational	Power imbalances [8, 9, 12, 14]	Trust and respect in the relationship [12] Parents need the ability to talk with others [12, 13] Parents need a sense of control over the decision making process [14] Parents being present during consultations [8]
Environment	Insufficient time [8, 12, 14] Lack of structure for including parents/children [9, 12] Social norms [9]	

According the OMRU, barrier and facilitator assessments should inform the selection and tailoring evidence-based implementation interventions [26]. Hence, a comprehensive synthesis of SDM barriers and facilitators in pediatric clinical practice is necessary to guide context-specific barrier and facilitator assessments and inform implementation interventions promoting SDM use in clinical practice.

1.5.3 Implementation Interventions

Implementation interventions are designed to increase innovation (e.g., SDM) use in clinical practice. Once introduced, implementation interventions should be monitored to gauge whether the intervention is addressing identified barriers, desired behavior change, and emerging barriers to innovation use [28]. Interventions should also be evaluated to determine their impact on innovation uptake. Follow-up interventions could also be required to support sustained knowledge use over time.

In the adult literature, high quality evidence underpins several implementation interventions that facilitates the SDM process in clinical consultations [21, 48, 49]. A Cochrane review of 105 randomized controlled trials (RCT) showed that patient decision aids (PtDA) improved participation in decision making, knowledge, accuracy of risk perceptions, decision quality, and decisional conflict [48]. A systematic review of 10 trials showed that decision coaching combined with a PtDA, resulted in improved decision-making participation and knowledge [49]. A Cochrane review of 39 studies suggested that SDM education and training can help improve the adoption of SDM [21].

Compared to the adult literature, few pediatric SDM implementation interventions have been developed, monitored or evaluated. In pediatrics, four systematic reviews related SDM interventions have been conducted. One Cochrane review published in 2012 examined interventions to promote patient and family centered care in pediatric hospitals for children 0-12 and identified only one quasi-experimental study that addressed three interventions (information sharing, joint decision making, and participating in care activities) [50]. Findings showed that mothers' satisfaction and self-efficacy for participatory involvement improved compared to controls. The other Cochrane review, published in 2013, sought to evaluate SDM interventions for children with cancer, but failed to identify any RCTs [51]. The third systematic review, published in 2015, evaluated the efficacy of SDM interventions in pediatrics [52]. Of the 54 unique SDM interventions identified, 63% targeted the parents alone, 26% focused on multiple adopters, 7% targeted the child, and 6% targeted the HCP. This review failed to describe the characteristics of the SDM interventions, but indicated that they consisted of various formats (e.g., online, paper based, live sessions), and were designed for use before the clinical consultation (52%), during the consultation (26%), or before and/or during the consultation (13%). Only about half of these interventions were evaluated. Meta-analysis suggested that SDM interventions might reduce parents' decisional conflict and improve their knowledge, but the impact on other adopters (e.g., children) was inconclusive. The fourth systematic review, published in 2014, evaluated interventions targeting children's participation in health decisions [53]. Of the five included studies, two showed that decision coaching improved child satisfaction and parent-child values congruence. One study showed that an educational workshop increased children's decision making quality. Two studies that evaluated coaching and patient education material showed no differences in decision making quality or congruence between the child's preferred and chosen option.

1.6 Implementation Project at the Children's Hospital of Eastern Ontario (CHEO)

In 2009, a research group at CHEO initiated a program to implement SDM within its hospital. A key goal at this hospital was make parents and children partners in decision making and healthcare team members through respect, communication, collaboration, and support. A pre-implementation barrier and facilitator assessment, conducted at CHEO, found that lack of knowledge was the main barrier to SDM use [54]. A Cochrane review of 39 studies indicated the need for SDM education and training among HCPs [21]. As such, the CHEO research group rolled out an education and training program, between 2011 to 2016, to promote SDM within the hospital. The ODST (https://decisionaid.ohri.ca/odst/), which is often combined with a skill building workshop, was among the few of the 148 SDM training programs supported by research evidence [55]. The CHEO SDM program consisted of the ODST plus a 3-hour SDM skill building workshop [56]. The impact of this program, however, had not previously been evaluated.

1.7 Knowledge Gaps and General Methodology

This literature review identified several areas for further inquiry. First, knowledge about factors that influence the implementation of pediatric SDM is lacking. Specifically, the barriers and facilitators of pediatric SDM are poorly understood and described. Second, as SDM knowledge is a key barrier to pediatric SDM use [54], more information is needed about the impact and acceptability of educational programs, such as the ODST, to address SDM knowledge. Third, the effect of SDM training implementation interventions (i.e., the ODST paired with a skill building workshop) has not been monitored or evaluated in the pediatric context. The overarching aim of this dissertation was to evaluate factors that influence the implementation of SDM in pediatric clinical practice. This dissertation includes three multi-method studies (Table 1-4), guided by the OMRU, to address the following research questions:

1a What do HCPs, parents, children, and observers perceive as the barriers to, and facilitators of, SDM in pediatric clinical practice?

2a Does the ODST inform learners about SDM?

2b Is the ODST an acceptable SDM educational program among learners?

3a Do HCPs who completed the ODST paired with a skill building workshop self-report using SDM in pediatric clinical practice?

3b What do pediatric HCPs perceive as the barriers and facilitators influencing their ability to use SDM in pediatric clinical practice, after having been SDM-trained?

Table 1-4 Dissertation studies mapped to OMRU

Study	Objective	Research Question(s)	Design	OMRU process phase
I	To synthesize the barriers and facilitators of pediatric SDM from the perspectives of HCPs, parents, children, and observers.	1a	Systematic review	Assess barriers and facilitators to knowledge use.
II	To evaluate the impact of the ODST on learners' knowledge and acceptability.	2a, 2b	Post-test evaluation	Monitor whether interventions can overcome identified barriers. Evaluate interventions that can be used to implement the innovation (i.e., SDM).
III	To explore HCPs' intention to use SDM, HCPs' self-reported SDM use, and perceptions of SDM barriers and facilitators, after having been SDM-trained.	3a, 3b	Mixed-methods	Monitor implementation and degree of innovation use. Post-implementation assessment of barriers and facilitators of innovation use.

1.8 Dissertation Organization

This dissertation consists of 7 chapters and is organized in an article-based format. Chapter 1 provides a brief introduction to give the reader context, an overview of the problem, state of knowledge, and justification for the dissertation topic. Chapter 2, the first manuscript of this dissertation, presents a systematic review of the factors influencing SDM across studies in pediatrics from the perspectives of HCPs, parents, children, and observers. This manuscript showed that adopters' commonly lack SDM knowledge, a barrier also identified in other systematic reviews [23, 24] and among pediatric HCPs at CHEO [54]. Therefore, CHEO HCPs completed a training intervention consisting of the ODST and a skill building workshop to overcome SDM knowledge gaps [56]. Chapter 3, the second manuscript, evaluated ODST learners' SDM knowledge and acceptability. Chapter 4, the third manuscript, evaluated the impact of the ODST paired with a skill building workshop on HCPs' intention to use SDM, self-reported SDM use, and perceived barriers and facilitators to using SDM in pediatric clinical practice. Chapter 5 presents a discussion that integrates the findings from all three studies, links them to the broader literature, and discusses implications for population health, research and policy. Chapter 6 outlines the contributions of collaborator for the dissertation studies. Chapter 7 presents the relevant appendices.

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CHAPTER 2

BARRIERS AND FACILITATORS OF PEDIATRIC SHARED DECISION MAKING: A SYSTEMATIC REVIEW

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Abstract

Purpose: To systematically review shared decision making (SDM) barriers and facilitators in pediatric clinical practice.

Methods: We conducted a systematic review guided by the Cochrane Handbook for Systematic Reviews. We searched MEDLINE, EMBASE, Cochrane Library, CINAHL, PubMed, and PsycINFO (inception to March 2017). Eligible studies reported SDM barriers and facilitators in pediatric clinical practice from the perspectives of HCPs, parents, children and observers. We included all study designs that presented original data. Guided by a SDM barrier and facilitator taxonomy and the Ottawa Model of Research Use (OMRU), two reviewers independently extracted data. We employed content analysis to synthesize barriers and facilitators according to the OMRU levels: decision, innovation (i.e., SDM), adopters (i.e., healthcare providers, parents, children), relational (i.e., social interactions), and environment (i.e., pediatric clinical practice). We used the Mixed Methods Appraisal Tool to appraise study quality.

Results: Of 20,008 identified citations, 80 were included. At each OMRU level, the most frequent barriers were: features of the options (decision), poor quality information (innovation), parent/child emotional state (adopter), power relations (relational), and insufficient time for SDM (environment). The most frequent facilitators were: lower stake decisions (decision), high quality information (innovation), agreement with SDM (adopter), trust and respect in the relationship (relational), and SDM tools/resources (environment). Across participant types, the most frequently cited barriers were: insufficient time (healthcare providers), features of the options (parents), power imbalances (children), and HCP skill for SDM (observers). The most frequently cited facilitators were: high quality information (healthcare providers) and agreement with and desire for SDM (parents and children). There was no consistent facilitator category for observers. In general, study quality was moderate with quantitative studies having the highest scores and mixed-method studies having the lowest scores.

Conclusions: Many diverse factors influence SDM use in pediatric clinical practice across the OMRU levels and participant types. Organizations and stakeholders can use these findings to guide the identification of barriers and facilitators to pediatric SDM in their unique context and/or inform interventions for implementing SDM in pediatric clinical practice.

2 BARRIERS AND FACILITATORS OF PEDIATRIC SHARED DECISION MAKING: A SYSTEMATIC REVIEW

2.1 Introduction

Shared decision-making (SDM) is an evidenced-based approach that promotes collaboration between patients, family members, and the healthcare provider (HCP) team when making health decisions. By exchanging information about the evidence (options, risks, and benefits) and the patient and family's preferences and values, HCPs, patients, and family members can deliberate to determine the best treatment plan [1]. This approach to decision making is considered essential for patient-centered care [2], has garnered increasing international support among policy makers [3], and is recommended by pediatric regulatory organizations [4]. Nonetheless, implementation of SDM in pediatric healthcare remains limited [5, 6].

Determining the barriers and facilitators that influence clinical use of evidence-based practices is critical for promoting their uptake [7]. Two systematic reviews have examined the barriers and facilitators of implementing SDM in adult medicine from the perspectives of HCPs and patients [8, 9]. Findings showed that HCPs most commonly perceived time constraints, lack of applicability due to patient characteristics, and lack of applicability due to the clinical situation, as the main barriers [8]. Adult patients perceived power imbalances in the doctor-patient relationship and inadequate knowledge as primary barriers to SDM [9].

Several factors make health decision making in pediatrics different from adult clinical practice. Children's evolving developmental context (e.g., biological, cognitive, and psychosocial variables) impacts their participation in health decisions. As such, determining the extent that children should be involved is difficult [10]. Pediatric decision making is also complicated by the inclusion of multiple stakeholders (i.e., child, family members, and HCPs), each with their own preferences and values [11]. Further, the legislation and policy about pediatric health decisions can be complex, with different guiding principles depending on state/provincial laws, treatments being considered, and organizational policy [4]. Given the unique decision making context in pediatrics, the barriers and facilitators that influence SDM in pediatrics likely differ from those identified in the adult literature. However, little is known about the factors influencing SDM in pediatric clinical practice. Therefore, we sought to identify the barriers and facilitators of SDM in pediatric clinical practice from the perspectives of HCPs, parents, children, and observers.

2.2 Methods

2.2.1 Design

We conducted a systematic review, guided by the Cochrane Handbook for Systematic Reviews [12], to systematically review and synthesize barriers and facilitators of pediatric SDM from the perspectives of HCP, parents, children, and observers. We used the PRISMA reporting guidelines to format the report (Appendix B) [13]. Our protocol is registered in PROSPERO (Appendix C) (ID: CRD42015020527) [14].

We used the Ottawa Model of Research Use (OMRU) as our guiding theoretical framework [15]. The OMRU is a planned action model that seeks to explain the implementation of evidence into a healthcare system. The model asserts that the uptake of innovations in clinical practice can be optimized if interventions assess and address barriers and facilitators. The OMRU describes barriers and facilitators at the level of the innovation, adopters, and practice environment. We added two additional levels from the SDM literature to reflect our data: the decision level and the relational level [9,16]. For the purposes of our study, we defined each OMRU level as follows: (A) the decision level includes influencing factors related to the decision itself (e.g., features of the options or higher/lower stake decisions); (B) the innovation was defined as SDM or a collaborative decision making approach between HCPs, parents, and/or children; (C) adopters are the individuals who use the innovation, in this case, HCPs, parents, and children; (D) relational represents the interpersonal process between the HCP, patient, and family [16]; and, (E) the environment is pediatric clinical practice. Although we extracted data from observers, they were not classified as adopters since they do not use the innovation. We collectively refer to HCPs, parents, children, and observers as ‘participants’.

2.2.2 Inclusion Criteria

We used the PICOS framework to guide our eligibility criteria (Table 2-1). Eligible participants included: HCPs (e.g., frontline staff of any discipline, clinical managers, and administrators), parents or guardians (collectively referred to as parents), children aged 18 years or less, and observers (individuals who were not involved in pediatric SDM but evaluated it in some way). Outcomes were barriers or facilitators of SDM, or a collaborative decision making approach regarding a decision about a child’s health [1, 10], in pediatric clinical practice reported in the results section of the included study. We included all study designs with original data, with or without comparisons. There were no language restrictions. These parameters are consistent with another systematic reviews that examined SDM barriers and facilitators in adult clinical practice [8, 9].

2.2.3 Information Sources and Search Strategy

An information specialist (AD) designed the search strategy and conducted electronic searches specific to each database with input from our research team. The search was designed to target SDM barriers and facilitators in pediatric clinical practice. We searched the following electronic databases (from inception to March 2017): MEDLINE, EMBASE, Cochrane Library, CINAHL, PubMed, and PsycINFO (Appendix D). We also searched the reference lists of all included articles for other potentially relevant studies.

Table 2-1 Study eligibility criteria

	Included	**Excluded**
Participants	Healthcare providers Parents, guardians, and/or caregivers Children 18 years of age or younger Observer reported studies	Individuals involved in making a decision about the health of an adult patient (19 years and older)
Intervention	Not specified	
Comparison	All comparisons, including none	
Outcomes	Barriers and/or facilitators of SDM in pediatric clinical and/or health care practice Note: outcomes had to be reported in the results section of the paper	All other SDM outcomes (e.g., impact of a SDM intervention) Barriers and facilitators related to the following decisions: non-SDM interventions, hypothetical decisions, health decisions in a non-clinical setting (e.g., schools), decisions about pregnancy/perinatal care (before birth), and decisions about participation in research

2.2.4 Study Selection

We uploaded citations onto a title and abstract screening web application, designed by an information technologist at our research institute (AS). This application allowed reviewers to independently evaluate study eligibility in a three-stage screening process. First, titles were randomly assigned to two independent reviewers and screened to determine their relevance to decision making in pediatrics. Reviewers did not know if they were screening first or second and indicated whether an article is ‘included’, ‘excluded’ or ‘unsure’ based on the eligibility criteria. Both reviewers were required to determine that an article was excluded for it to be screened out, while titles deemed included or unsure by at least one reviewer moved to the second screening stage. We followed the same process for abstracts. Finally, two reviewers independently read full texts to determine eligibility. At this stage, reviewers reached consensus for study inclusion and exclusion.

2.2.5 Data Collection

Two reviewers independently extracted data using a standardized and pre-piloted data extraction form (Appendix E). We extracted citation information (e.g., country of origin, language), study information (e.g., objectives, design and methodological approaches), participant types (i.e., HCP, parent, child, and observer) and findings (i.e., barriers and facilitators). Inconsistencies in extracted data were resolved through consensus.

2.2.6 Data Analysis

Pooling of quantitative data was inappropriate due to the heterogeneity across included studies regarding design, decision type and timing, adopters involved, methods, and measures used. We counted the barrier and facilitator frequency per study. Specifically, if one paper reported the same barrier or facilitator multiple times, we only counted it once. However, if the same factor was reported as both a barrier and facilitator, we counted it once as a barrier and once as a facilitator. If a study reported the perspectives of multiple participant types, we counted the factor once (as defined above) for each participant type.

We synthesized the barriers and facilitators using deductive and inductive content analysis [17]. First, we transferred the extracted text representing the barriers and facilitators into NVivo qualitative analysis software (NVivo; QSR International Pty Ltd. V10, 2012). Second, two coders deductively analyzed the content using the OMRU barrier and facilitator levels (decision, innovation, adopter, relational, and environment) and a SDM barrier and facilitator taxonomy (Appendix F) [8, 18]. Then, we inductively coded remaining content to identify new categories. This involved identifying units of relevant data, open-coding, category development, compiling data, and continuous data comparison between coders [19]. All inductive categories were slotted under the appropriate OMRU categories. Then, under each OMRU level, we rank ordered the influential factor according the frequency of studies that reported it.

2.2.7 Quality Assessment

Two independent raters appraised study quality using the Mixed Method Appraisal Tool (MMAT) (Appendix G) [20, 21]. This tool was selected because it was specifically developed for mixed-methods studies, is efficient, is recommended by the National Institute of Excellence in Health Services in Quebec, and has been used in up to 50 systematic reviews of mixed studies [20]. The MMAT's reliability ranges from fair to perfect [22]. Raters resolved discrepancies through discussion and consensus.

2.3 Results

2.3.1 Identified Studies and Characteristics

Our search yielded 20,008 citations (Figure 2-1). After removing duplicates and screening citations, we examined 461 full texts. Of those, 80 publications, representing 79 distinct studies, were eligible for inclusion. Included studies were published between 1996-2017, with a trend of increasing publications over time (Figure 2-2).

Studies used qualitative (n=47; 59%), quantitative (n=18; 23%), and mixed methods (n=15; 19%). All studies were published in English except one, which was French [23]. Studies originated from 15 countries: United States (n=36), United Kingdom (n=13), Canada (n=9), Ireland (n=5), Sweden (n=3), Australia (n=3), the Netherlands (n=2), one study from each of France, Italy, Israel, Kenya, South Africa, Switzerland, Amsterdam, Turkey, and both Canada and the United States together (Table 2-2).

Figure 2-1 - Literature flow chart

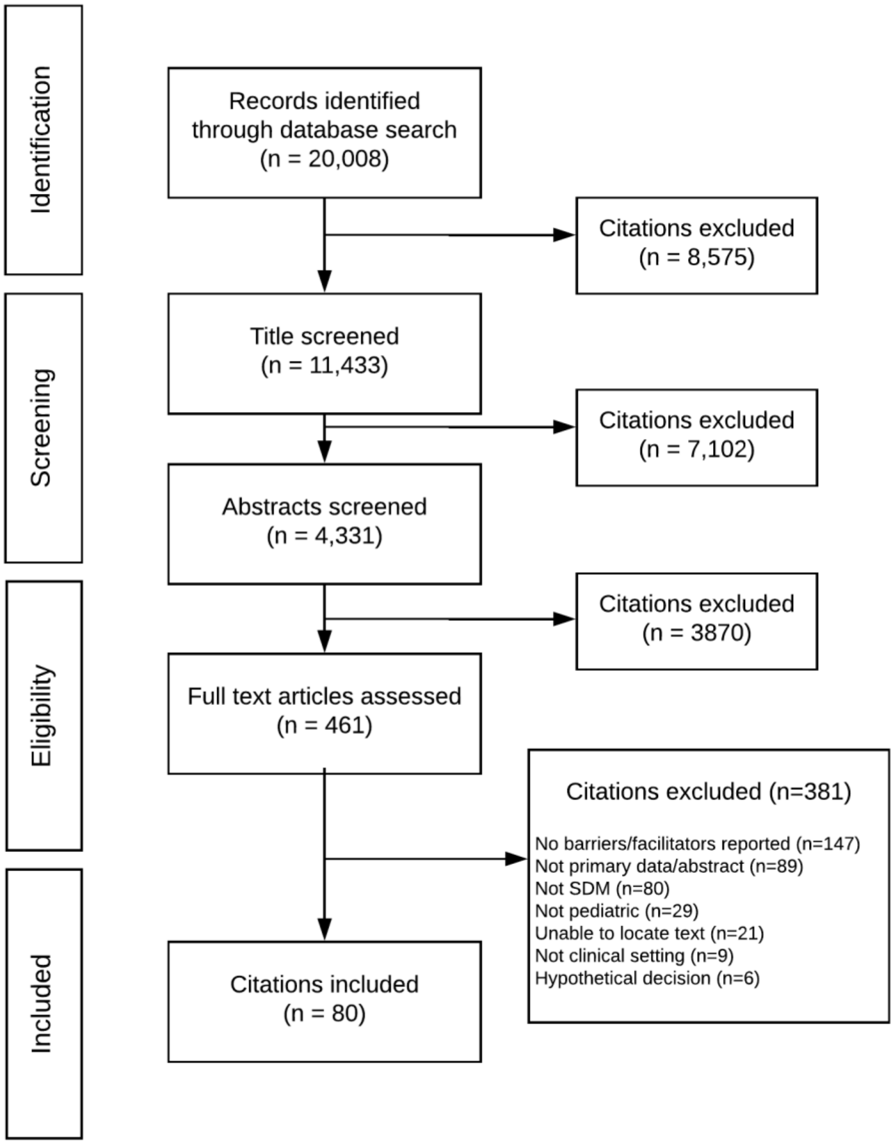
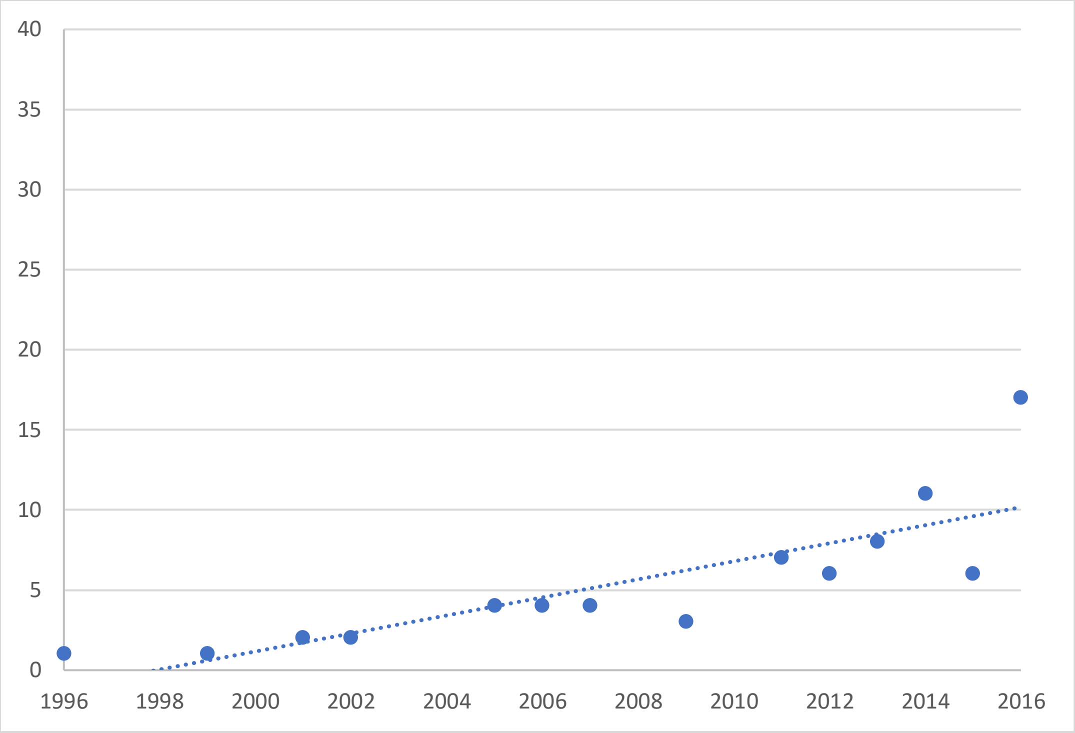


Figure 2-2 Frequency of publications per year (1996-2016)



Barriers and facilitators were reported from the perspective of: HCPs (n=20), parents (n=18), children (n=8), multiple participant types (n=26), and observers (n=7). Data from 44,482 participants were synthesized, including: 42,183 parents (95%), 1,815 HCPs (4%), and 484 children (1%). We also included data from more than 138 observed consultations (n=6) plus 135 observed consultation hours (n=1). Observer studies focused mainly on HCP behavior.

Table 2-2 Characteristics of the included studies

Author, year, country of origin	Study objective related to this systematic review	Methodological approach and data collection*	Response rate*	Participants*
Citations reporting healthcare professional perceptions only				
Abrines-Jaume, 2016, UK [24]	To explore the implementation of SDM in pediatric mental health services and identify clinician-determined facilitators to SDM.	Qualitative; log- book of post-encounter stories	NR	23 HCPs
Andre, 2005, France [23]	To describe how pediatric residents involve children during medical decision making.	Quantitative; survey	75%	43 HCPs
Bejarano, 2015, USA [25]	To evaluate the feasibility of implementing SDM practices in pediatrics and to assess physicians' satisfaction with SDM.	Mixed methods; survey	NR	5 HCPs
Boss, 2009, USA [26]	To determine fellows' training in communication and decision and their perceived preparedness to lead family discussions.	Mixed methods; survey	72%	101 HCPs
Delany, 2017, Australia [27]	To get clinicians' views about resources designed to aid parents facing end-of-life decisions for their child.	Qualitative; interviews	NR	18 HCP
Dellon, 2012, USA [28]	To describe the physician perspective on communication with patients about use of mechanical ventilation for respiratory failure.	Mixed methods; web survey	88%	30 HCPs
Dodds, 2016, USA [29]	To understand pediatric physicians' use SDM and their perceptions of barriers and facilitators to SDM for decisions about tumor necrosis factor-α inhibitor treatment.	Quantitative; survey	66%	196 HCPs
Fay, 2016, USA [30]	To assess the impact, acceptability and feasibility of a tool designed to enhance SDM.	Mixed methods; interview	80%	4 HCPs
Frize, 2013, Canada [31]	To translate information, using a decision support tool, for parents making decisions in the neonatal intensive care unit.	Mixed methods; HCP data collection not specified	NR	5 HCPs
Honeycutt, 2005, USA [32]	To examine physicians reported use of participatory decision making with children/parents.	Quantitative; survey	47%	219 HCPs
Lee, 2006, USA [33]	To explore clinician views and practice regarding assent and compare practice with existing guidelines.	Mixed methods; interviews and questionnaire.	NR	35 HCPs

Lipstein, 2013, USA [34]	To understand the barriers and facilitators to SDM for juvenile idiopathic arthritis.	Qualitative; interviews	NR	10 HCPs
Miller, 2001, UK [35]	To investigate the ways children's nurses see themselves facilitating youth in decision making.	Qualitative; interviews and focus groups	NR	8 HCPs
Partridge, 2005, South Africa [36]	To characterize South African pediatricians' practices and attitudes related to parent counseling and life-support decisions for premature infants.	Quantitative; survey	24%	394 HCPs
Runeson, 2001, Sweden [37]	To identify factors influencing children's participation in healthcare decision making.	Qualitative; critical incident technique.	40%	140 HCPs
Schalkers, 2016, Amsterdam [38]	To investigate HCPs' perspectives on child participation, and improving child participant, in paediatric hospital care.	Qualitative, interviews	NR	10 HCPs
Simmons, 2013, Australia [39]	To explore clinicians' experiences and beliefs about treatment decision making for youth diagnosed with depressive disorders.	Qualitative; interviews	NR	22 HCPs
Shirley, 2015, USA [40]	To describe the production, implementation, and evaluation of a decision aid for pediatric orthopaedics.	Quantitative; satisfaction scale	NR	4 HCPs
Tam-Seto, 2015, Canada [41]	To better understand SDM in adolescent mental health using the Canadian Model of Client-Centered Enablement.	Qualitative; interviews	NR	6 HCPs
Vaknin, 2011, Isreal [42]	To examine HCPs' attitudes, perceptions and reported practices regarding the inclusion of paediatric patients in simple decisions.	Quantitative; survey	66%	143 HCP
Citations reporting child perceptions only				
Coyne, 2012, Ireland [43]	To elicit children's perspectives on participation in information sharing and decision making.	Qualitative; interviews	NR	55 children
Coyne, 2011, Ireland [44]	To explore hospitalised children's experiences and preferences for participation in decision making.	Qualitative; interviews and focus groups	82%	55 children
Kelly, 2016, USA [45]	To better understand how children viewed their treatment decision making involvement.	Qualitative; interviews	NR	29 children
Kelsey, 2007, UK [46]	To explore children's perceptions of their involvement in healthcare decisions.	Qualitative; audio diary and interview	NR	10 children
Koller, 2017, Canada [47]	To examine how children with chronic medical conditions	Qualitative; interviews	NR	26 children

	view healthcare education and decision making.			
Lambert, 2013, Ireland [48]	To describe information exchange between HCPs and children in hospital.	Qualitative; interviews and observation	NR	49 children
Lipstein, 2013b, USA [49]	To understand adolescents' roles and preferences in chronic disease treatment decisions.	Qualitative; interviews	75%	15 children
Weaver, 2015, USA [50]	To investigate decision making preferences of child oncology patients and parent/clinician behaviors that support their preferred decision-making role.	Qualitative; interviews	78%	40 children
Citations reporting parent perceptions only				
Butler, 2014, USA [51]	To investigate perceptions of SDM among low-income minority parents of children referred to mental health services.	Quantitative; questionnaire	69%	36 parents
Butler, 2015a, USA [52]	To examine associations between parental reported SDM and parental perceptions of children's mental health care.	Quantitative; survey	NR	21,721 parents
Butler, 2015b, USA [53]	To examine whether SDM varies by child health and whether receiving medical home care attenuates differences in SDM among child health conditions.	Quantitative; survey	NR	21,721 parents
Fiks, 2010, USA [54]	To identify SDM patterns among children with attention deficit/hyperactivity disorder or asthma and determine if demographics, health status, or access to care are associated with SDM.	Quantitative; survey	58-65% for general survey; uncertain for subpopulation	60 parents
Gkiousias, 2016, UK [55]	To explore parents' decision-making process for pediatric management otitis media with effusion.	Qualitative; interviews	NR	12 parents
Hummelinck, 2007, UK [56]	Explore parents' perspectives on the relationship with HCPs and their involvement in decisions about their child's care.	Qualitative; interviews	51%	23 parents
Kline, 2012, USA [57]	To evaluate family satisfaction and decision-making with a pediatric hematology–oncology palliative care program.	Mixed methods; interviews and survey	56%	20 parents
Lerret, 2016, USA [58]	To report parents' medical decision making experiences for children who had a solid organ transplant.	Qualitative; interviews	86%	48 parents

Li, 2016, Canada [59]	To explore parents' perceptions of decisional needs for genome-wide sequencing for their child.	Qualitative; interviews	71%	15 parents
Mack, 2011, USA [60]	To evaluate parents' involvement and preferences for decision making regarding their child's cancer care.	Quantitative; survey	70%	194 parents
Mak, 2014, Canada [61]	To understand parents' perspectives on decision making for child anxiety treatment and to identify ways to promote parental involvement in treatment decisions.	Qualitative; interviews	68%	19 parents
Pyke-Grimm, 2006, USA [62]	To determine factors that parents identified as influencing their role in treatment decision making for their child with cancer.	Mixed methods; interviews and questionnaires	NR	36 parents
Rosati, 2017, Italy [63]	To explore general parental views on SDM and patient-physician SDM relationships in paediatric outpatients' clinic.	Quantitative survey	85%	458 parents
Smalley, 2014, USA [64]	To determine families' perceptions of SDM in their child's health care and correlates of perceived SDM.	Quantitative; database analysis	NR	11,102 parents (weighted)
Valenzuela, 2014, USA [65]	To describe caregiver-report of SDM with their child's health care provider with youth with type 1 diabetes.	Quantitative; database analysis	NR	439 parents
Walker-Vischer, 2015, USA [66]	To describe the experience of Latino parents of hospitalized children during family-centered rounds.	Qualitative; survey	85%	17 parents
Walter, 2016, USA [67]	To learn about parent's experiences of having goals of care discussions with their child's HCP.	Mixed methods; interviews and survey and interviews	75% (survey)	55 parents
Xu, 2004, USA [68]	To explore whether there are ethnic differences in parents' perceptions of the participatory styles of their children's physicians.	Quantitative; survey	52%	5941 parents
Yin, 2012, USA [69]	To assess whether parental health literacy is associated with differences in perceived barriers to care and attitudes regarding participatory decision-making with the HCP.	Quantitative; questionnaire	71%	823 parents
Citations reporting observation only				
Brinkman, 2011, USA [70]	To describe physician behavior during treatment-planning encounters for children newly diagnosed as having ADHD.	Quantitative; video-recorded clinical consultations	65% for parents	26 observed consultations

Cahill, 2007, UK [71]	To identify interaction features between doctors, children, and their caregivers in the consultation that are associated with the child's participation.	Qualitative; video-recorded clinical consultations	8% of HCPs	31 observed consultations
Elwyn, 1999, UK [72]	To examine the feasibility of SDM in consultations that conflict occurs between parents and clinicians about antibiotics for an upper respiratory tract infection.	Qualitative; discourse analysis techniques	NR	2 observed consultations
Hallstrom, 2002, Sweden [73]	To investigate the extent to which parents participate in decisions concerning their hospitalized child's care and identify factors influencing a parent's participation.	Quantitative; field notes of observations	96%	35 parents of 24 children were observed
Lipstein, 2014, USA [74]	To understand how decisions about higher-risk treatments are made in pediatric chronic conditions.	Qualitative; video-recorded clinical consultations	91% of HCPs	21 observed consultations
Runeson, 2002, Sweden [75]	To identify that illustrate children's participation in decision making and various levels of participation.	Mixed methods: ratings and field notes of observations	96%	135 observed hours of 24 hospitalized children
Wiering, 2016, the Netherlands [76]	To explore how oncologists involve families in SDM and which factors are associated with this process.	Quantitative; rating scale	NR	43 observed consultations
Citations reporting perceptions for multiple participants				
Angst, 1996, USA [77]	To describe how children with chronic illness and their parents are involved in health care decisions.	Qualitative; secondary analysis of interviews	NR	16 parents; 28 children
Astbury, 2017, UK [78]	To explore the processes that support SDM when HCPs and parents are creating plans to improve the well-being of children.	Qualitative; interviews	NR	11 HCPs; 11 parents
Beck, 2014, Canada [79]	To examine the treatment decision making process for children hospitalized with newly diagnosed immune thrombocytopenia.	Qualitative; focus groups	NR	10 HCP; 16 parents; 7 children
Boland, 2016, Canada [80]	To explore barriers and facilitators to implementing SDM and decision support in a children's hospital.	Qualitative; interviews and focus groups	Convenience sample	35 HCP; 15 parents; 7 children
Coyne, 2006, Ireland [81]	To explore children's, parents' and nurses' views on participation in care in the healthcare setting.	Qualitative; Interviews, observations, and drawings	NR	12 HCPs; 10 parents; 11 children
Coyne, 2014, Ireland [82]	To explore children with cancer participation in SDM and identify confounding and	Qualitative; interviews	NR	40 HCP; 22 parents; 20 children

	facilitating factors that influence children's participation in SDM.			
Daboval, 2016, Canada [83]	To document interactions between parents and neonatologist that parents linked to their satisfaction with SDM for their infant at risk of being born at the limit of viability.	Qualitative; interviews	NR	6 HCPs; 10 parents
Fiks, 2011, USA [84]	To compare how parents and clinicians understand SDM in attention-deficit/hyperactivity disorder.	Qualitative; interviews	100% HCPs; NR parents	30 HCPs; 60 parents
Garnett, 2016, UK [85]	To explore child-parent SDM for childhood asthma management.	Qualitative; interviews	NR	9 parents; 8 children
Heath, 2016, UK [86]	To explore how parents and HCPs make decisions regarding putting children forward for pediatric epilepsy surgery.	Qualitative; interviews	NR	10 HCPs; 9 parents
Iachini, 2015, US [87]	To explore youth and parent perspectives of practitioner behaviors important for fostering treatment engagement.	Qualitative; focus group	NR	11 parents; 19 children
Kahveci, 2014, Turkey [88]	To examine SDM in management of critically ill children and the experiences of parents, physicians and nurses.	Qualitative; interviews	72% physicians; 69% nurses; 28% parent	17 HCPs; 6 parents
Karnieli-Miller, 2009, Israel [89]	To analyze SDM regarding medical treatment in real-time encounters.	Qualitative; interviews and observations	NR	17 HCPs; 17 observed consultations
Kavanaugh, 2005, USA [90]	To describe life support decision making and the decision support needs of parents, physicians, and nurses for extremely premature infants.	Qualitative; interviews	NR	8 HCPs; 6 parents
Lecouturier, 2015, UK [91]	To explore management and treatment of intermittent distance exotropia decisions and what can be done to support decision-making for clinicians, parents and children.	Qualitative; interviews	NR	21 HCPs; 37 parents
Levy, 2016, USA [92]	To describe influences on SDM between primary care pediatricians and parents of children with autism.	Qualitative; interviews	22% for HCPs; NR parents	20 HCPs; 20 parents
Markworo, 2014, Kenya [93]	To determine parental involvement in decision making about their hospitalised children.	Mixed methods; interviews and questionnaires	83% HCPs; 88% parents	144 HCPs; 161 parents

Miller, 2009, USA [94]	To explore parent–child collaborative decision making for chronic illness management.	Qualitative; interviews and focus groups	NR	16 parents; 18 children
Pentz, 2012, Canada and USA [95]	To create a theory of family decision making regarding pediatric allogeneic transplantation for the treatment of childhood cancer.	Mixed methods; interviews	NR	192 parents 5 children;
Ruhe, 2016, Switzerland [96]	To explore how patient participation was put into practice in a pediatric oncology setting.	Qualitative; interviews	NR for HCPs; 81% for children; 90% for parents;	16 HCPs; 19 parents; 17 children
Sajeev, 2016, Australia [97]	To develop and pilot test a decision aid to assist parents making cancer or hematological decisions with their HCPs.	Mixed methods; questionnaires/open-ended questions.	65% for HCPs; 72% for parents;	15 HCPs; 31 parents
Sleath, 2011, USA [98]	To examine the extent HCPs engaged in SDM with caregivers and children; and factors associated with question asking and SDM.	Quantitative; interviews and observations	95% HCP 88% parents (some children in sample, not separated)	41 HCP; 320 parents (some children in sample, not separated)
Smith, 2013, UK [99]	To investigate parent–HCP SDM during the diagnosis of suspected shunt malfunction and their perceptions/experiences of SDM within this clinical context.	Mixed methods; interviews, questionnaires, and video-taped interactions	NR	14 HCP; 28 parents
Stille, 2013, USA [100]	To describe factors that influence parent–clinician partnerships in SDM when children are referred to subspecialists.	Qualitative; focus groups	NR	23 HCPs; 19 parents
Young, 2006, UK [101]	To explore SDM in the context of community-based physiotherapy services for children with cerebral palsy.	Qualitative; interviews and focus group	NR	10 HCP; 10 parents; 11 children;
Zwaanswijk, 2007, the Netherlands [102]	To explore interpersonal, informational, and decisional preferences of participants involved in paediatric oncology.	Qualitative; online focus groups	29% parents; 36% children; 34% adults with childhood experience	18 parents; 27 children + 32 adults with childhood illness experience

2.3.2 Study Appraisal

The MMAT appraisal results are shown in Table 2-3. For qualitative studies, 100% of studies received credit for having sources of data relevant to address the research question. Sources of bias included not reporting how: findings related to researchers' influence (n=39/47, 83% missed), findings related to context (n=12/47, 26% missed/unsure), and the process for analysis was relevant to address the research question (n=4/47, 9% missed/unsure).

For quantitative studies, all studies received credit for having a sampling strategy relevant to the research question. Sources of bias included not reporting: if the sample was representative (n=5/18, 28% missed/unsure); if the measures used were appropriate (i.e., of known origin, valid, or standardized approach) (n=4/18; 22% missed/unsure), and whether the response rate was 60% or above (n=4/18, 22% missed/unsure).

The mixed method studies had the lowest ratings. All studies received credit for having relevant sources of data appropriate for the research question and a research design that was relevant to address a qualitative and quantitative research question. Other sources of bias were: how findings related to researchers' influence (n=15/15, 100% missed), limitations associated with integration of qualitative and quantitative approaches (n=13/15, 87% missed), how findings related to the context (n=10/15, 67% missed), if the sample was representative of the population under study (n= 6/15, 40% missed), if measurements used were appropriate (n=5/15, 33% missed), if an acceptable response rate was reported (n=5/15, 33% missed), integration of qualitative and quantitative data relevant to address the research question(s) (n=3/15, 20% missed), if the data analysis was relevant to the research question (n=1/15, 7% unsure), and if the sampling strategy was relevant to address the research question (n=1/15, 7% unsure).

Table 2-3 Results of the MMAT appraisal

MMAT ITEMS	Qualitative studies	Are the sources of data relevant to address the research question?	Is the process for analyzing data relevant to address the research question?	Is appropriate consideration given to how findings relate to the context?	Is appropriate consideration given to how findings relate to researchers' influence?	Quantitative descriptive studies	Is the sampling strategy relevant to address the research question?	Is the sample representative of the population under study?	Are measurements appropriate?	Is there an acceptable response rate (60% or above)?	Mixed methods	Is the research design relevant to address the qualitative and quantitative research questions?	Is the integration of qualitative and quantitative data relevant to address the research questions?	Is appropriate consideration given to the limitations associated with this integration?
Qualitative studies														
Abrines-Jaume, 2016 [24]		○	○	○	○									
Angst, 1996 [77]		○	○	●	●									
Astbury, 2017 [78]		○	○	○	●									
Beck, 2014 [79]		○	○	○	●									
Boland, 2016 [80]		○	○	○	●									
Cahill, 2007 [71]		○	○	○	○									
Coyne, 2006 [81]		○	○	●	●									
Coyne, 2011 [44]		○	○	○	●									
Coyne, 2012, [43]		○	○	○	●									
Coyne, 2014 [82]		○	○	○	●									
Daboval, 2016 [83]		○	○	●	●									

Delany, 2017 [27]		○	○	○	●									
Elwyn, 1999 [72]		○	○	●	●									
Fiks, 2011 [84]		○	○	○	●									
Garnett, 2016 [85]		○	○	○	●									
Gkiousias, 2016 [55]		○	○	○	●									
Hallstrom, 2002 [73]		○	○	○	●									
Heath, 2016 [86]		○	○	○	●									
Hummelinck, 2007 [56]		○	○	●	●									
Iachini, 2015 [87]		○	○	○	●									
Karnieli-Miller, 2009 [89]		○	○	◉	●									
Kavanaugh, 2005 [90]		○	◉	●	●									
Kahveci, 2014 [88]		○	●	○	●									
Kelly, 2016 [45]		○	○	○	○									
Kelsey, 2007 [46]		○	○	○	●									
Koller, 2017 [47]		○	○	○	○									
Lambert, 2013 [48]		○	○	●	●									
Lecouturier, 2015 [91]		○	○	●	●									
Lerret, 2016 [58]		○	○	○	●									
Levy, 2016 [92]		○	○	○	●									
Li, 2016 [59]		○	○	○	●									
Lipstein, 2013 [34]		○	○	○	●									

Lipstein, 2013b [49]		○	○	○	●									
Lipstein, 2014 [74]		○	○	○	○									
Mak, 2014 [61]		○	○	○	●									
Miller, 2001 [35]		○	⦿	●	●									
Miller, 2009 [94]		○	○	●	●									
Ruhe, 2016 [96]		○	○	○	●									
Runeson, 2001 [37]		○	○	●	●									
Schalkers, 2016 [38]		○	○	○	●									
Simmons, 2013 [39]		○	○	○	○									
Stille, 2013 [100]		○	○	○	○									
Tam-Seto, 2015 [41]		○	○	○	●									
Walker-Vischer, 2015 [66]		○	○	○	●									
Weaver, 2015 [50]		○	○	○	○									
Young, 2006 [101]		○	○	○	●									
Zwaanswijk, 2007 [102]		○	⦿	○	●									
Quantitative Studies														
Andre, 2005 [23]							○	○	●	○				
Brinkman, 2011 [70]							○	●	○	○				
Butler, 2014 [51]							○	○	○	○				
Butler, 2015; 2015b [52,53]							○	○	○	⦿				
Dodds, 2016 [29]							○	⦿	○	○				
Fiks, 2010 [54]							○	○	○	○				

Honeycutt, 2005 [32]							○	○	○	●				
Mack, 2011 [60]							○	○	○	○				
Partridge, 2005 [36]							○	○	●	●				
Rosati, 2017 [63]							○	○	●	○				
Smalley, 2014 [64]							○	○	○	○				
Shirley, 2015 [40]							○	●	○	○				
Vaknin, 2011 [42]							○	○	○	○				
Valenzuela, 2014 [65]							○	○	○	○				
Wiering, 2016 [76]							○	○	○	○				
Xu, 2004 [68]							○	⊙	⊙	●				
Yin, 2012 [69]							○	⊙	○	○				
Mixed methods studies														
Bejarano, 2015 [25]		○	○	●	●		○	●	○	○		○	○	○
Boss, 2009 [26]		○	○	●	●		○	○	○	○		○	⊙	●
Dellon, 2012 [28]		○	○	●	●		○	○	○	○		○	○	○
Fay, 2016 [30]		○	○	●	●		○	○	○	○		○	○	●
Frize, 2013 [31]		○	⊙	●	●		○	●	⊙	⊙		○	⊙	⊙
Kline, 2012 [57]		○	○	●	●		○	⊙	○	●		○	○	●
Lee, 2006 [33]		○	○	○	●		○	●	○	⊙		○	⊙	●
Markworo, 2014 [93]		○	○	●	●		○	○	●	○		○	○	●
Pentz, 2012 [95]		○	○	○	●		○	○	⊙	○		○	○	●
Pyke-Grimm, 2006 [62]		○	○	○	●		○	●	○	○		○	○	●

Runeson, 2002 [75]		○	○	●	●		○	○	●	⦿		○	○	●
Sajeev, 2016 [97]		○	○	○	●		○	○	○	○		○	○	●
Sleath, 2011 [98]		○	○	○	●		○	○	○	○		○	○	●
Smith, 2013 [99]		○	○	●	●		⦿	⦿	○	⦿		○	○	●
Walter, 2016 [67]		○	○	●	●		○	○	●	○		○	○	●

* ○ = yes; ● = no; ⦿ = unsure

2.3.3 Pediatric SDM Barriers and Facilitators

Our findings are reported in three formats: (A) a condensed taxonomy of pediatric SDM barriers and facilitators organized by OMRU levels and participant types (Table 2-4); (B) a detailed taxonomy of pediatric SDM barriers and facilitators, including frequency counts across OMRU levels and participant types (Table 2-5); and, (C) a synthesis of influential factors (i.e., value-neutral barriers and facilitators) mapped to the OMRU (Figure 2-3). Below we narratively report frequently cited barriers and facilitators under each OMRU level.

2.3.3.1 Decision Level (n=21 studies)

Barriers. Features of the options were the most frequently cited barrier at this level (n=15 citations) (Table 2-5), reported by all adopters, and the main barrier reported by parents (n=7). Features included a perceived lack of options, unacceptable alternatives, and affordability. Adopters (n=6 citations), particularly parents (n=4 citations), also reported that uncertainty or lack of research evidence for the various options was barriers to engaging in the SDM process.

Facilitators. The magnitude of the decision being discussed influenced the extent to which SDM was encouraged and preferred (n=9 citations). In general, lower stake decisions were reported by all adopters to facilitate SDM in pediatrics. HCPs and parents reported being more willing to involve children in the decision making process for ‘smaller’ decisions. Similarly, children reportedly preferred to be involved in lower stake decisions.

Table 2-4 Summary of pediatric SDM barriers and facilitators from multiple perspectives

Influencing factor (# unique studies)	**Citations**	**HCP**		**Parent**		**Children**		**Observer**	
Decision level (21)		B	F	B	F	B	F	B	F
Option features (13)	[34, 42, 45, 59, 74, 84, 91, 92, 94, 95, 99, 100, 103]	-		-		-	+		+
Big versus small decision (9)	[38, 41, 44, 45, 47, 79, 82, 94, 96]	-	+	-	+	-	+		
Availability of medical and research information (8)	[42, 45, 59, 74, 82, 92, 94, 95, 99, 100]	-		-		-	+		
Atypical decision or uncomfortable topics (2)	[39, 94]	-					+		
Innovation level (i.e., SDM) (35)		B	F	B	F	B	F	B	F
Level of quality/tailored information that is given to the family (31)	[29, 34, 35, 39, 43–45, 47–50, 55, 58, 59, 61, 66, 67, 71, 72, 77, 79, 81, 83, 84, 86, 87, 90, 91, 96, 99, 100]		+	-	+	-	+	-	+
Impact of SDM on time (7)	[24, 31, 39, 40, 79, 80, 91]	-	+				+		
Adopter level (i.e., HCP, parent, and child) (71)		B	F	B	F	B	F	B	F
Attitudes (45)									
Agree with/desire for SDM/DM involvement (31)	[33, 35, 39, 42–45, 47–50, 55, 56, 58, 60–63, 69, 77, 81, 82, 84, 87, 88, 91, 94, 96, 99, 100, 102]	-	+	-	+	-	+		
Beliefs about capabilities (7)	[23, 24, 26, 28, 80, 88, 90]	-	+	-	+	-			
Beliefs about consequences (7)	[31, 39, 45, 66, 80, 90, 94]		+		+	-	+		
Parents/children can't understand information (7)	[34, 36, 39, 56, 78, 88, 99]	-		-					
Motivation (5)	[24, 25, 31, 80, 100]	-	+	-	+	-			
Knowledge of SDM, policy (4)	[23, 33, 80, 93]	-		-		-			
Satisfied with current DM approach (3)	[80, 82, 99]	-		-		-			
Characteristics of the adopters (60)									
Child/parent health status (18)	[28, 33, 38, 39, 41, 45, 46, 51-54, 59, 64, 65, 70, 82, 85, 94, 96]	-	+	-	+	-	+		+
Parent/child's emotional state (17)	[23, 28, 29, 33, 36, 41, 50, 59, 61, 62, 72, 79, 82, 88, 90, 91, 94]	-	+	-	+	-		-	
Child's age and competence (15)	[23, 32, 33, 37–39, 43, 47–49, 65, 81, 82, 91, 94]	-	+		+	-	+		
HCP's SDM skills (14)	[23, 39, 41, 43, 44, 50, 70, 72, 74–76, 83, 91, 99]	-	+		+	-	+	-	
Parent/child race, ethnicity, culture and language (7)	[33, 42, 64, 68, 70, 78, 100]	-	+	-				-	+
Parent socioeconomic status (7)	[63–65, 68, 70, 79, 93]		+	-	+				+
HCP age/seniority/specialty (7)	[28, 32, 33, 36, 48, 65, 98]	-	+			-		-	
Child's behavior/maturity (6)	[33, 42, 43, 54, 82, 94]		+	-	+	-			

Parent’s health insurance (6)	[29, 34, 64, 68, 70, 84]	-	+	-				-	
HCPs role as advocate (6)	[35, 48, 66, 86, 88, 90]	-	+		+		+		
Child experience with condition (4)	[42, 44, 47, 79]		+				+		
HCP assuming parent/child preference for involvement (3)	[36, 60, 87]	-		-		-			
Parental absence during SDM discussion (2)	[48, 85]						+		
Parent health literacy (2)	[69, 100]	-		-					
Parent gender (2)	[83, 98]				+				+
Relational level (i.e., social influences) (50)		B	F	B	F	B	F	B	F
Trust and respect in relationship (29)	[24, 29, 36, 41, 44, 45, 47, 50, 56, 58–63, 66, 67, 75, 77, 79, 82–84, 87, 91, 94, 99, 100]	-	+	-	+	-	+		+
Extent adopters invite/support parent/child participation in DM (24)	[23, 28, 35, 41, 44–46, 50, 58, 67, 69, 71, 73, 77, 82–84, 86, 87, 90–92, 98, 99]	-	+	-	+	-	+	-	+
Power relations (17)	[41, 43–45, 48, 56, 62, 71, 81, 82, 85, 86, 89, 91, 94, 96]	-		-	+	-	+	-	
Biasing other adopters (11)	[33, 34, 39, 49, 72, 74, 79, 84, 89, 94, 95]	-		-		-		-	
Recognition of HCP/parent expertise (6)	[47, 56, 61, 62, 87, 99]		+	-	+	-			
Conflict (4)	[28, 39, 91, 94]	-		-		-			
Environmental level (38)		B	F	B	F	B	F	B	F
Time (12)	[23, 28, 37–39, 44, 80, 82, 84, 94, 99, 100]	-	+	-		-			
Access to tools/resources/training to promote SDM (12)	[26–28, 30, 31, 40, 42, 57, 78, 79, 97, 100]	-	+		+		+		
Workflow and continuity of care (11)	[28, 38, 44, 59, 79, 80, 84, 90–92, 100]	-	+	-		-			
Norms (e.g., organizational policy consistent with SDM, expectations that HCP make the decision) (11)	[23, 39, 43, 49, 69, 79, 80, 82, 88, 101]	-	+	-	+	-	+		
Clinical setting (e.g., emergency room) or situation (e.g., urgency) (8)	[23, 33, 62, 79, 80, 82, 89, 102]	-	+	-	+	-			
Physical arrangement (e.g., seating) (3)	[71, 79, 99]	-				-			+
Stability of home environment (2)	[34, 94]	-		-			+		

* B = barrier; F = facilitator; HCP = healthcare provider; SDM = shared decision making; (-) = barrier identified in one or more studies; (+) = facilitator identified in one or more studies

2.3.3.2 Innovation Level (i.e., SDM; n=35 studies).

Barriers. Poor quality information about the condition and/or options that were inappropriately tailored to the child and family’s health literacy needs hindered SDM (n=13 citations) and were reported by all participant types (Table 2-5). In addition, HCPs reported that the SDM process took too much time, and therefore, was difficult to apply in the pediatric clinical setting (n=5 citations).

Facilitators. Receipt of high quality and appropriately tailored information facilitated SDM (n=31 citations). This factor was the most frequently cited overall and reported by all participant groups. A few studies showed that HCPs (n=2 citations) and children (n=1 citation) reported that SDM might improve the way time was used in the clinical encounter.

2.3.3.3 Adopter Level (i.e., HCPs, parents, children; n=71 studies).

Barriers. All participant types most commonly reported barriers at this level (Table 2-5). The parent’s and child’s emotional state was most commonly reported (n=15 citations), with the parent/child feelings of being overwhelmed, anxious, in denial, or defensive, as hindering the SDM process. Similarly, health status of the parent and child affected their decision making participation (n=12 citations), with perceptions of poorer health resulting poorer participation or efforts to include that adopter. Studies showed that some children did not agree with SDM principles or did not prefer a SDM approach (n=7 citations). Participants commonly reported that HCPs lacked SDM skills, such as knowing how to elicit or incorporate family values and preferences (n=10 citations). Lack of HCP skill for SDM was the top barrier reported by observers (n=5 citations).

Facilitators. All participant types most commonly reported facilitators at this level. Agreement with, and desire for, a SDM approach was the most commonly reported facilitator at the adopter level (n=31 citations), reported by all adopters (Table 2-5), and was particularly important to parents (n=15 citations). Adopters thought SDM was the 'right thing to do', that parent and child involvement was important and generally wanted to use a SDM approach. Adopters also believed that SDM would improve patient outcomes (n=10 citations), such as satisfaction with the decision making process. When parents and children were perceived to be in better health, they were more likely to be included by other adopters and preferred to participate themselves in the decision making process (n=10 citations). Children's age, competence, and perceptions of whether they should be involved facilitated efforts to engage children in SDM (n=9 citations), particularly among HCPs (n=6 citations). Generally, the older the child, the more likely he or she was to be included, or wanted to be included, in decision making.

2.3.3.4 Relational Level (n=50 studies)

Barriers. Power imbalance was the most cited relational barrier (n=16 citations), and the main barrier reported by children (n=9 citations). Power imbalances were described as the systematic exclusion of children from the decision making conversation or the child feeling too disempowered or intimidated to participate. All participant types reported that deliberately biasing the opinion of another undermined the SDM process (n=10 citations). This was often characterized as the HCP providing only one option, providing information on his or her preferred options only, using SDM to achieve compliance for his or her preferred option, or giving a specific recommendation.

Facilitators. Trust and respect in relationships between adopters, primarily between the HCP and family, was a highly cited facilitator (n=29 citations), and particularly important for parents (n=13 citations). This category was characterized by positive relationships due to respectful communication between the adopters, appreciation for an adopter's expertise, trusting that children will participate in a meaningful way and that adopters will be open and forthcoming. All participant groups (Table 2-5) reported that inviting and supporting the child and/or family to participate in the SDM process was a facilitator (n=24 citations).

2.3.3.5 Environment Level (i.e., pediatric clinical practice; n=38 studies).

Barriers. Insufficient time due to being too busy or heavy workloads was the main environmental barrier (n=13 citations), and the top barrier reported by HCPs (n=9 citations). Similarly, workflow and lack of continuity of care (e.g., integrating SDM into the care pathway and across multiple HCPs or high staff turnover) was reported to hinder SDM (n=12 citations). Practice norms, such as the cultural expectation that a HCP's duty was to provide specific recommendations or make the decision, was a barrier (n=12 citations), mostly reported by HCPs (n=5 citations) and children (n=4 citations).

Facilitators. The most commonly cited environmental facilitator, primarily by HCPs (n=7 citations), was access to SDM tools (e.g., patient decision aids; PtDA), resources (e.g., decision coaches or experts in SDM), and/or training (n=10 citations).

Table 2-5 Taxonomy and frequency counts of pediatric SDM barriers and facilitators from multiple perspectives

Influencing factor (# unique studies)	**Design and citations**			**Barrier (B) and Facilitator (F) frequency counts**									
				HCP		**Parent**		**Children**		**Observer**		**Total barrier and facilitator citations**	
Decision level (21)	Qual n (%)	Quant n (%)	MM n (%)	B	F	B	F	B	F	B	F	B	F
Option features (13)	9 (69%) [34, 45, 59, 74, 84, 91, 92, 94, 103]	1 (8%) [42]	3 (23%) [95, 99, 100]	5		7		3	2		1	15	3
Higher/lower stake decision (9)	9 (100%) [38, 41, 44, 45, 47, 79, 82, 94, 96]			2	3	1	2	1	4			4	9
Availability of medical and research information (8)	5 (42%) [45, 59, 74, 82, 92, 94, 100]	1 (12%) [42]	2 (25%) [95, 99]	1		4		1	2			6	2
Atypical decision or uncomfortable topics (2)	2 (100%) [39, 94]			1					1			1	1
Totals				9	3	12	2	5	9		1	26	15
Innovation level (i.e., SDM) (35)	Qual n (%)	Quant n (%)	MM n (%)	B	F	B	F	B	F	B	F	B	F
Level of quality/tailored information that is given to the family (31)	28 (90%) [34, 35, 39, 43–45, 47–50, 55, 58, 59, 61, 66, 71, 72, 77, 79, 81, 83, 84, 86, 87, 90, 91, 96, 100]	1 (3%) [29]	2 (7%) [67, 99]		10	4	11	8	9	1	1	13	31
Impact of SDM on time (7)	5 (71%) [24, 39, 79, 80, 91]	1 (14%) [40]	1 (14%) [31]	5	2				1			5	3
Totals				5	12	4	11	8	10	1	1	18	34
Adopter level (i.e., HCP, parent, and child) (71)	Qual n (%)	Quant n (%)	MM n (%)	B	F	B	F	B	F	B	F	B	F
Attitudes (45)													
Agree with/desire for SDM/DM involvement (31)	24 (77%)	4 (13%)	3 (10%)	1	5	2	15	7	11			10	31

	[35, 39, 43–45, 47–50, 55, 56, 58, 61, 77, 81, 82, 84, 87, 88, 91, 94, 96, 100, 102]	[42, 60, 63, 69]	[33, 62, 99]										
Beliefs about capabilities (7)	4 (57%) [24, 80, 88, 90]	1 (14%) [23]	2 (29%) [26, 28]	3	3	2	1	1				6	4
Beliefs about consequences (7)	6 (86%) [39, 45, 66, 80, 90, 94]		1 (14%) [31]		4		3	1	3			1	10
Parents/children can't understand information (7)	5 (71%) [34, 39, 56, 78, 88]	1 (14%) [36]	1 (14%) [99]	6		1						7	
Motivation (5)	3 (60%) [24, 80, 100]		2 (40%) [25, 31]	3	2	1	1	1				5	3
Knowledge of SDM, policy (4)	1 (25%) [80]	1 (25%) [23]	2 (50%) [33, 93]	4		2		1				7	
Satisfied with current DM approach (3)	2 (67%) [80, 82]		1 (33%) [99]	1		1		2				4	
Characteristics of the adopters (60)													
Child/parent health status (18)	9 (50%) [38, 39, 41, 45, 46, 59, 82, 85, 94, 96]	7 (39%) [51-54, 64, 65, 70]	2 (11%) [28, 33]	4	3	5	3	3	3		1	12	10
Parent/child's emotional state (17)	11 (65%) [41, 50, 59, 61, 72, 79, 82, 88, 90, 91, 94]	3 (18%) [23, 29, 36]	3 (18%) [28, 33, 62]	6	5	5	1	3		1		15	6
Child's age and competence (15)	11 (73%) [37–39, 43, 47–49, 81, 82, 91, 94]	3 (20%) [23, 32, 65]	1 (7%) [33]	4	6		1	4	2			8	9
HCP's SDM skills (14)	9 (64%) [39, 41, 43, 44, 50, 72, 74, 83, 91]	3 (21%) [23, 70, 76]	2 (14%) [75, 99]	3	3		1	2	1	5		10	5
Parent/child race, ethnicity, culture and language (7)	2 (29%) [78, 100]	4 (57%) [42, 64, 68, 70]	1 (14%) [33]	3	2	2				1	1	6	2

Parent socioeconomic status (7)	1 (14%) [79]	5 (72%) [63–65, 68, 70]	1 (14%) [93]		2	1	3				1	1	6
HCP age/seniority/specialty (7)	1 (14%) [48]	4 (57%) [32, 36, 65, 98]	2 (28%) [28, 33]	2	3			1		1		4	3
Child's behavior/maturity (6)	3 (50%) [43, 82, 94]	2 (33%) [42, 54]	1 (17%) [33]		3	2	1	1				3	4
Parent's health insurance (6)	2 (33%) [34, 84]	4 (67%) [29, 64, 68, 70]		2	1	2				1		5	1
HCPs role as advocate (6)	6 (100%) [35, 48, 66, 86, 88, 90]			1	3		2		1			1	6
Child experience with condition (4)	3 (75%) [44, 47, 79]	1 (25%) [42]			2				2				4
HCP assuming parent/child preference for involvement (3)	1 (33%) [87]	2 (67%) [36, 60]		1		1		1				3	
Parental absence during SDM discussion (2)	2 (100%) [48, 85]								2				2
Parent health literacy (2)	1 (50%) [100]	1 (50%) [69]		1		2						3	
Parent gender (2)	1 (50%) [83]		1 (50%) [98]				1				1		2
Totals				45	45	29	33	28	25	9	4	111	108
Relational level (i.e., social influences) (5)	Qual n (%)	Quant n (%)	MM n (%)	B	F	B	F	B	F	B	F	B	F
Trust and respect in relationship (29)	21 (72%) [24, 41, 44, 45, 47, 50, 56, 58, 59, 61, 66, 77, 79, 82–84, 87, 91, 94, 100]	4 (14%) [29, 36, 60, 63]	4 (14%) [62, 67, 75, 99]	2	7	2	13	1	7		1	5	28
Extent adopters invite/support parent/child participation in DM (24)	18 (75%) [35, 41, 44–46, 50, 58, 71, 73, 77, 82–84, 86, 87, 90–92]	2 (8%) [23, 69]	4 (17%) [28, 67, 98, 99]	2	4	3	8	1	4	2	1	8	17
Power relations (17)	16 (94%)		1 (6%) [62]	3		3	1	9	1	1		16	2

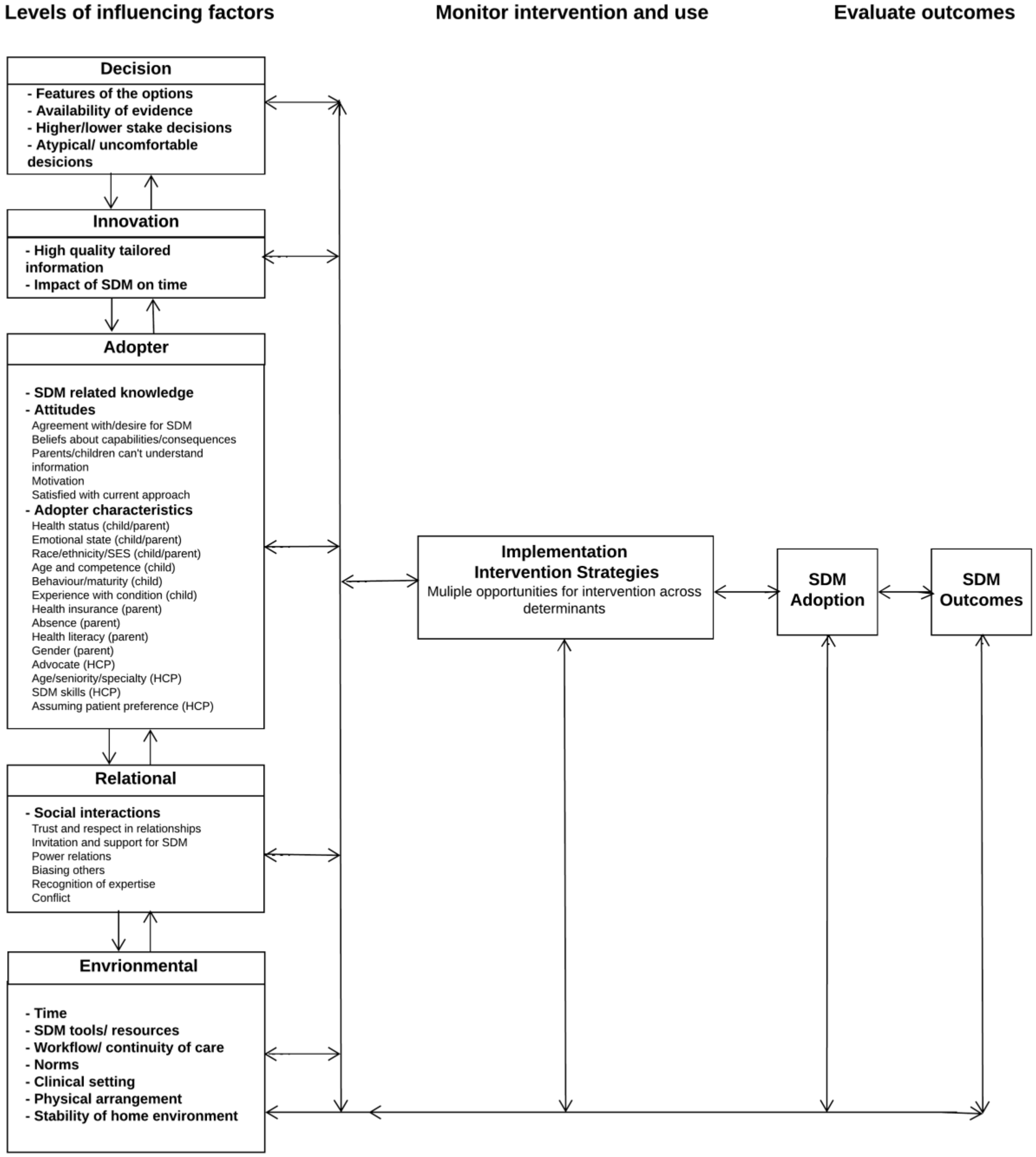
	[41, 43–45, 48, 56, 71, 81, 82, 85, 86, 89, 91, 94, 96]												
Biasing other adopters (11)	9 (82%) [34, 39, 49, 72, 74, 79, 84, 89, 94]		2 (18%) [33, 95]	6		1		2		3		12	
Recognition of HCP/parent expertise (6)	4 (67%) [47, 56, 61, 87]		2 (33%) [62, 99]		1	1	4	1				2	5
Conflict (4)	3 (75%) [39, 91, 94]		1 (25%) [28]	2		2		1				5	
Totals				15	12	12	26	15	12	6	2	47	52
Environmental level (38)	Qual n (%)	Quant n (%)	MM n (%)	B	F	B	F	B	F	B	F	B	F
Time (12)	9 (75%) [37–39, 44, 80, 82, 84, 94, 100]	1 (8%) [23]	2 (17%) [28, 99]	9	1	2		2				13	1
Access to tools/resources/training to promote SDM (12)	3 (25%) [78, 79, 100]	2 (17%) [40][42]	7 (58%) [26–28, 30, 31, 57, 97]	4	7		2		1			4	10
Workflow and continuity of care (11)	10 (91%) [38, 44, 59, 79, 80, 84, 90–92, 100]		1 (9%) [28]	9	2	2		1				12	2
Norms (e.g., organizational policy consistent with SDM, expectations that HCP make the decision) (11)	9 (82%) [39, 43, 49, 79, 80, 82, 88, 101]	2 (18%) [23, 69]		5	2	3	1	4	1			12	4
Clinical setting (e.g., emergency room) or situation (e.g., urgency) (8)	5 (63%) [79, 80, 82, 89, 102]	1 (13%) [23]	2 (25%) [33, 62]	4	2	3	1	1				8	3
Physical arrangement (e.g., seating) (3)	2 (67%) [71, 79]		1 (33%) [99]	1				1			1	2	1
Stability of home environment (2)	2 (100%) [34, 94]			1		1			1			2	1
Totals				33	14	8	4	9	3		1	53	22

* Qual = qualitative; Quant = quantitative; MM = mixed methods; B = barrier; F = facilitator; HCP = healthcare provider; SDM = shared decision making

2.3.4 Synthesis of Results

We synthesized results to develop a taxonomy of HCP, parent, child, and observer reported barriers and facilitators of SDM in pediatric clinical practice (Table 2-5). We also mapped influential factors of pediatric SDM to the OMRU (Figure 2-3). Influencing factors are value-neutral barriers and facilitators and were categorized at the decision, innovation, adopter, relational, and environment levels. An underlying assumption of the OMRU model is that all elements (i.e., levels, influencing factors, and process steps) are dynamic, interrelated, and function in an open system. Therefore, specific influential factors can be present or absent (in different combinations), are influenced by other elements (depicted by the double arrows and feedback loops), and exist within a system that interacts with, and is affected by, the external and societal contexts [15]. The model highlights multiple opportunities for interventions targeting identified barriers and/or leveraging facilitators, which can then be monitored and evaluated to promote implementation.

Figure 2-3 Factors influencing SDM in pediatric clinical practice mapped to the OMRU



2.4 Discussion

We conducted a systematic review of factors influencing pediatric SDM across OMRU levels and from the perspective of HCPs, parents, children, and observers. At each OMRU level, the most frequent barriers were: features of the options (decision), poor quality and/or insufficiently tailored information (innovation), parent/child emotional state (adopter), power relations (relational), and insufficient time for SDM (environment). The most frequent facilitators were: lower stake decisions (decision), agreement with SDM (adopter), trust and respect in the relationship (relational), and SDM tools/resources (environment). Across participant types, the most frequently cited barriers were: insufficient time (HCPs), features of the options (parents), power imbalances (children), and HCP skill for SDM (observers). The most frequently cited facilitators were: good quality information that is tailored to the families' literacy and developmental needs (HCPs), and agreement with and desire for SDM (parents and children). There was no consistent category for observers. As shown in our model (Figure 2-3), we propose that influencing factors work within a dynamic system. In the following discussion, we consider the interrelated nature of barriers and facilitators across OMRU levels and participant types and ways barriers and facilitators can inform the implementation of pediatric SDM.

SDM, like many health innovations, is context dependent and influenced by many factors. Characteristics of the decision can immediately impact adopters' perceptions about SDM. For example, when adopters perceived only one reasonable option, SDM seemed unnecessary. Similarly, the perceived magnitude (higher or lower stakes) of the decision could determine whether adopters tried to include the child or whether the child wished to be included. These influences are antecedent to SDM, and should be considered for each decision context. To promote SDM, adopters could broaden their conceptualization of SDM. Traditionally, the SDM approach prescribed that HCPs provide the medical evidence, patients provide information about preferences and values, and both parties deliberate about the best treatment option [24]. When options are limited, HCPs can expand their SDM role to empowering the patient and family by enabling discussion, participation, and providing support [25].

The innovation level examined perceptions around the SDM process itself. In our review, few barriers were identified at this level, implying that adopters were satisfied with SDM as an innovation when they received high quality information. In contrast, the complex dynamic of influential factors at the adopter and relational levels provide insight about why SDM is difficult to implement. In our study, most adopters expressed a positive attitude about SDM, recognizing that SDM leads to positive outcomes. However, several children expressed uncertainty about SDM's utility and preferred to avoid the burden of decision making. HCPs and parents agreed, assuming younger children were incompetent decision makers. SDM, however, does not imply children should independently make decisions or be solely responsible for them. In pediatrics, implementation interventions need to emphasize that SDM is a partnership and the decision making responsibility is shared. Children can be included and empowered by eliciting and incorporating their preferences and views in the decision making process.

Interestingly, some HCPs reported doubts about parents' and children's ability to understand medical information, regardless of age, creating an informed consent paradox. Under most circumstances, informed consent for treatment is a legal requirement, yet unachievable if parents do not understand the information. Observers, however, reported that HCPs lacked the skills needed to translate information and engage parents and children in SDM. Furthermore, some HCPs presented biased views of the information and focused the discussion around their own preferred option. Thus, limiting parent and children’s opportunities to get high quality information. As agents of medical knowledge, power imbalances can stem from the fact that HCPs can largely determine the level of patient and family engagement based on information shared [26]. This, in part, contributes to the power imbalances commonly reported by children and parents at the relational level.

Power imbalances are widely recognized in the patient-HCP relationship, yet empirical research characterizing their nature in pediatrics is sparse. In the pediatric healthcare context, adopters in our review recognized that children and parents are vulnerable (i.e., less empowered), had difficulty negotiating decision making involvement, and required HCPs’ encouragement and support to participate. A systematic review that evaluated the impact SDM among disadvantaged groups (e.g., low literacy, minority, lower socioeconomic status) found that SDM interventions significantly improved outcomes for vulnerable populations [27]. In fact, disadvantaged groups could derive more benefit than individuals in higher literacy and socioeconomic situations. This suggests that vulnerable groups, such as children, are good candidates for SDM.

Parents and children wanted to be empowered with knowledge and an invitation to participate in SDM. This finding is consistent with another systematic review examining adult patients’ views about SDM [9]. As parents and children become more knowledgeable with the condition and healthcare system, they report increased capacity for SDM [28, 29]. Also, trusting and respectful relationship between HCPs and families (i.e., important facilitator reported by all adopters), decreases power imbalances by making the parent and child more comfortable asking questions [30]. The invitation to participate in decision making must be supported with information that is consistent with the child’s developmental stage or the parent’s literacy level. This can be achieved by assessing health literacy levels and tailoring the information accordingly, using child-friendly and developmentally-appropriate information (i.e., important SDM facilitator), and eliciting and incorporating the parent/child's preferences and values [31,32]. Parents' and children's understanding of the information can be assessed using teach back methods [33,34]. Importantly, HCPs require training and support to ensure they have the skills to engage families in SDM [35].

At the practice environment level, HCPs commonly reported insufficient time for SDM (e.g., too busy to use SDM) as barriers to SDM. Of note, time was also a problem for HCPs at the innovation level (i.e., SDM takes up too much time). Another systematic review also found that HCPs most commonly identified insufficient time as the main barrier to SDM in adult medicine [8]. Despite perceptions, a Cochrane review examining PtDAs to support SDM found limited evidence that this SDM intervention took more time [36]. A pilot study evaluating decision coaching using a PtDA to prepare children and parents for SDM with their physician took a median of 35 minutes [37], though the time subsequently spent with the physician was not measured. A recent scoping review that evaluated environmental characteristics influencing the implementation of SDM also identified time a limiting factor [38]. Given widespread perceptions about insufficient time, implementation interventions could emphasize that time spent on SDM is time spent differently, with potential to increase downstream efficiencies, treatment adherence, and build decision making capacity in children [39]. Similarly, at the environmental level, workloads could be better distributed, pressure for short interactions with patients decreased, and flexibility for patient pathways and scheduling enhanced [38].

Our review has several limitations to consider. Meta-analysis was not possible due to heterogeneity across methodological approaches and measures in the quantitative studies. Therefore, we conducted a narrative review. Due to the large number of included studies with qualitative and quantitative data, we synthesized barriers and facilitators using counting techniques; therefore, not accounting for the effect size. Researcher influence inherently impacts the analysis of qualitative data. At the level of a systematic review, participant reported data is subject to third reviewer interpretation (those of the original authors and ours), therefore, posing a fidelity risk between the participants' original statement and our interpretations [40].

Our literature synthesis was used to create a SDM barrier and facilitator taxonomy that is unique for three reasons. First, it was derived from pediatric literature. Second, it provides the perspectives of multiple participant types. Third, it was used to tailor a conceptual model for implementing SDM in pediatrics (Figure 2-3). The synthesized perspectives of multiple participant types allow readers to quickly identify the differences and similarity in barriers and facilitators when targeting specific adopter groups or levels of influence (Table 2-4). Organizations and/or clinics seeking to implement SDM in pediatrics can use our taxonomy as an overarching guide for identification of potential influencing factors or items to include in context-specific barrier and facilitator assessments. Our conceptual model can help stakeholders consider the interrelated nature of influencing factors and identify knowledge translation interventions to minimize barriers and promote facilitators to increase use of SDM in pediatrics. Future research should examine the nature of the relationships between influential factors to better understand the circumstances under which they interact in a system to impact SDM.

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CHAPTER 3

EVALUATION OF A SHARED DECISION MAKING EDUCATIONAL PROGRAM: THE OTTAWA DECISION SUPPORT TUTORIAL

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Highlights

- ODST learners have good shared decision making and decision support knowledge.
- Most learners passed the ODST knowledge test (>75%) on their first attempt.
- Learners rate the ODST as an acceptable shared decision making educational intervention.

Funding Sources

Financial support for the original development of the Tutorial in 2007 was provided by Annette O'Connor's Tier 1 Canada Research Chair. Updates were paid for in kind by the University of Ottawa Research Chair in Knowledge Translation to Patients. The funding agreement ensured the authors' independence in designing the educational intervention, interpreting the data, writing, and publishing the report. LB holds a Canadian Institutes of Health Research Integrated Knowledge Translation Research Network Doctoral Fellowship. FL holds the Tier 1 Canada Research Chair in Implementation of Shared Decision Making in Primary Care. IDG holds a Canadian Institutes of Health Research Foundation Grant (#143237).

Abstract

Objective: To evaluate the Ottawa Decision Support Tutorial (ODST), an open-access shared decision making educational program.

Methods: We conducted a post-test study. Eligible participants completed a knowledge test and/or acceptability survey after completing ODST version 1 (2007-2013), version 2 (2013-2015), or version 3 (2015-2017). We conducted descriptive analysis and compared outcomes across versions using log transformed linear regression (knowledge) and log binomial regression (acceptability). Thematic analysis explored verbatim suggestions to improve the ODST.

Results: Overall, 6604 learners completed the knowledge test and 4276 completed the acceptability survey. The median knowledge test score was 8/10 (IQR=7-9) with 68% of learners achieving a passing grade of 7.5/10. Learners who completed version 2 had the highest median knowledge scores (version 1=7.9, version 2=8.5, version 3=8.0, $p<0.001$) and pass rate (version 1=63%, version 2=73%, version 3=69%). Acceptability was high, with 90% reporting a good or excellent overall impression. Few learners suggested improvements (readability, presentation, multimedia).

Conclusions: Most learners passed the ODST knowledge test and rated the tutorial as acceptable. We will use feedback to improve the ODST.

Practice Implications: The ODST is an inexpensive and widely accessible intervention that can be used to educate healthcare providers about SDM and decision support.

3 EVALUATION OF A SHARED DECISION MAKING EDUCATIONAL PROGRAM: THE OTTAWA DECISION SUPPORT TUTORIAL

3.1 Introduction

Healthcare providers (HCP) often fail to meet patient expectations for sharing in decisions [1, 2]. In fact, many HCPs exhibit low levels of patient-involving behaviors and lack the requisite skills for engaging patients in shared decision making (SDM) [3, 4]. SDM is a process whereby HCP, patients, and family members collaborate to make health decisions [5]. Key elements of SDM include discussing: the problem and the decision to be made; options and evidence of their effects; patient's values, preferences, and ability to implement the choice; HCP's knowledge of the situation; patient's understanding; decision or its deferral; and, plan for follow-up [6]. Decision support helps patients engage in SDM by providing structured assistance in deliberating about the options and communicating with others. Engaging patients as partners in health decisions is a cornerstone of patient-centered care and necessary for informed consent [7].

Despite support among policy makers for its implementation, SDM and decision support have not been widely adopted in clinical practice [8]. A Cochrane review suggested that SDM training and education might increase the likelihood that HCPs share decisions with patients [9]. A recent environmental scan identified 148 SDM training programs targeting HCPs; however, evidence supporting most of these interventions was lacking [10]. The Ottawa Decision Support Tutorial (ODST) (https://decisionaid.ohri.ca/odst/) was one of the SDM training programs supported by research evidence [11-14].

The ODST is a unique theory-based online open access training program designed to improve learners' knowledge about SDM and decision support [15]. A randomized controlled trial (RCT) found that nurses exposed to the ODST had improved SDM-related knowledge compared to controls [11]. Subsequent studies have also suggested that the ODST improved knowledge among HCPs and nursing students [12-14]. The ODST has been completed by thousands of learners since its launch in 2007. The objective of this study was to evaluate learners' knowledge of SDM after completing the ODST, and their perceptions of its acceptability and suggestions for improvement.

3.2 Methods

3.2.1 Design

We conducted a cross sectional post-test study and obtained research ethics board approval from the University of Ottawa (H08-17-10) (Appendix H). To enhance accurate and complete reporting of this study, we followed STROBE reporting guidelines (Appendix I) [16].

3.2.2 Participants

Among all ODST learners, eligible participants were those who completed the knowledge test[2] and/or ODST acceptability survey (Appendix J) between 2007 and 2017, in English or French.

3.2.3 Intervention

The ODST was originally developed in 1997 on an internal university online platform for graduate students (i.e., version 0). The tutorial content was based on evidence and informed by a theory-based clinical practice framework known as Ottawa Decision Support Framework [17, 14]. This framework asserts that patients' unresolved decisional needs can adversely affect

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[2] The knowledge test is not made available as it is still used to evaluate learners' performance.

decision outcomes such as decision quality (i.e. informed, values-based choices), decision implementation, and downstream effects on health outcomes, decisional regret, blame, and use of health services. Decision support can improve decision outcomes by addressing decisional needs using clinical counseling, patient decision aids (PtDAs), and decision coaching.

Upon completion of the ODST, participants are expected to: (A) describe SDM and decision support concepts, (B) identify difficult decisions requiring decision support, (C) explain how to assess patient's decisional needs, (D) tailor decision support to the patients' needs, (E) explain how to use PtDAs, and (F) discuss how to evaluate decision support interventions. The tutorial includes 10 modules (Table 3-1). Formative evaluation comprises of quizzes at the end of each module with response feedback. Summative evaluation includes a learner evaluation survey eliciting acceptability of the ODST, and a final knowledge test. A certificate of completion is provided for those who score 75% or more on the knowledge test.

In 2007 (version 1), the ODST was moved to a website and made publicly available, free of charge. We have updated the tutorial twice. In 2013 (version 2), we included more SDM content and reduced material on basic communication skills. Also, we translated the ODST to include a French version. In 2015 (version 3), we reduced theoretical and research content and focused more on the application of SDM and decision support in clinical contexts (https://decisionaid.ohri.ca/ODST).

Table 3-1 ODST modules and contents

	Module	Content covered
1	Decision support and SDM	• Introduction to decision making, difficult decisions, decision support and SDM.
2	Conceptual foundation	• Ottawa Decision Support Framework.
3	Clarifying the decision	• Assessing the patient's understanding of the decision; classes of difficult decisions.
4	Decisional conflict and other needs	• Assessing and addressing decisional needs such as decisional conflict, decision type, urgent/delayed timing, decision making stage, polarized leaning, and special personal/clinical needs.
5	Knowledge and expectations	• Assessing and addressing inadequate knowledge and unrealistic expectations.
6	Personal values	• Assessing and addressing unclear personal values.
7	Support and resources	• Assessing and addressing inadequate support from others and resources.
8	Monitoring and facilitating	• Monitoring progress in decision making and providing additional decision support to facilitate progress.
9	Delivering decision support	• Elements of clinical counseling, decision aids and guides, and decision coaching.
10	Case study	• Clinical example of providing decision support to patients.

*SDM = shared decision making

3.2.4 Data Sources

The ODST is a web application that uses a Microsoft SQL Server database to store summative evaluation information in two separate datasets: (A) knowledges test scores, and (B) responses to the ODST acceptability survey. The web server has restricted access and is located on a secure research institute data center. The ODST requires that learners pick their own username and password to gain access. Knowledge test data are associated with this unique username (to provide a certificate of completion), which was blinded for this analysis after deduplication. To protect learner anonymity, the datasets were designed so that knowledge test scores cannot be linked to the ODST acceptability survey.

Progress through the ODST and end of module quizzes are not recorded. However, the database stores final knowledge test score and the date completed. The knowledge test was developed by experts in SDM to reflect the tutorial content. It consisted of 10 multiple choice questions, each with 4 possible answers, except one, which required choosing all the correct responses. Learners must score at least 7.5 out of 10 on the knowledge test to receive a certificate of completion, which can only be attempted once per username. This knowledge test can distinguish learners who have, and have not, completed the ODST [11].

The ODST acceptability survey included multiple choice and open-ended questions (Table 3-2) (Appendix J). Additional items asked learners their reason for completing the tutorial, profession, which module(s) they found most helpful, whether they would like to receive accreditation for completing the ODST, and suggestions for improvement (open-ended question). This survey was available to all learners regardless of their progress through the ODST, and was voluntary and anonymous.

3.2.5 Outcomes

We evaluated two primary outcomes: (A) learners' knowledge after completing the ODST, measured by the final test score (continuous variable from 1 to 10); and (B) learners' acceptability of the ODST, measured by learners' rating of overall impression of the tutorial (pre-planned binary variable categorized as excellent/good versus fair/poor). Secondary outcomes were pass rates (the pre-determined passing score was >7.5/10 versus a failing score of <7.4/10, which was consistent with the score required to receive a certificate of completion), and suggestions for improvement (i.e., qualitative acceptability responses) on the survey.

3.2.6 Data Analysis

The two raw datasets were exported from the server database into Microsoft Excel (Microsoft Corporation, Redmond, WA, USA) and transferred to Statistical Analysis Software for Windows (version 9.4: SAS, Cary, NC, USA). We explored ODST usage by calculating the frequency of unique logins from learners who completed the knowledge test, two ODST acceptability survey items (i.e., ‘what is your profession and why did you complete ODST?’), and the time-date stamp. To determine temporal trends in usage, we plotted the number of unique logins by year of complete data (i.e., 2008 to 2016 because data from all months were available).

For the knowledge test scores, we removed obvious duplicate cases (i.e., same learner who completed the final test multiple times, using slightly different usernames, such as JohnSmith1, JohnSmith2, etc.) and analyzed the scores from the first knowledge test attempt. We analyzed learners’ knowledge about SDM and decision support (primary outcome) using the knowledge test scores. The explanatory variable was version number (1, 2, or 3). We performed a log transformed linear regression to account for the left skewed distribution of scores (skewness -0.93). Knowledge test pass rates (secondary outcome) were also analyzed using log binomial regression with version number as the explanatory variable. We also conducted a sensitivity analysis by repeating the knowledge test score analysis without removing duplicate attempts to determine if learners’ initial score were significantly different than the average of all attempts.

We analyzed ODST acceptability (co-primary outcome) using log binomial regression with the version number as the explanatory variable and overall impression as the dependent variable. Acceptability was further explored descriptively using the other acceptability survey items (secondary outcome). On an exploratory basis, we plotted a run chart of learners’ overall impression between 2007 and 2017 to evaluate whether acceptability ratings were naturally occurring or due to changes between versions. Additionally, we examined whether acceptability differed between learners who had to complete the ODST (i.e., for participation in a research study or course credit) and those who chose to complete it (i.e., all other learners) by creating a dichotomous variable and running a Chi squared test to determine if there was a difference between groups. All *p* values were two-sided with statistical significance set at 0.05. We analyzed open-ended comments (suggestions for improvement; secondary outcome) using thematic content analysis for the most recent ODST version (i.e., version 3; 2015-2017) only. We did this because qualitative data from previous versions have already been used to update subsequent versions.

3.2.7 Missing Data

For our primary outcomes, we had no missing data for the final knowledge test scores and 47 (1%) missing cases for overall impression. Given the low risk of bias from missing items, we did not impute data and used case-complete analysis [18].

3.3 Results

We analyzed data recorded in the ODST database between May 2007 and October 2017 (Figure 3-1). For the first dataset (knowledge test scores), we removed 1410 duplicates and analyzed 6604 knowledge tests. For the second dataset, we analyzed 4276 ODST acceptability questionnaires.

3.3.1 Learner Characteristics and ODST Usage

Learners represented various professional disciplines and had different reasons for completing the ODST (Table 3-2). Overall, nurses were the main professional group, accounting for 39% of completers. The most common reason for completing the ODST was for a research study or course work requirement (80%). Overall, trends show that ODST use has increased over time (Figure 3-2). When asked what accreditation options would best meet their needs, 2911 (69%) agreed that the current certificate of completion was sufficient, while 1296 (31%) wanted professional education credits.

Figure 3-1 Flow chart of ODST learners

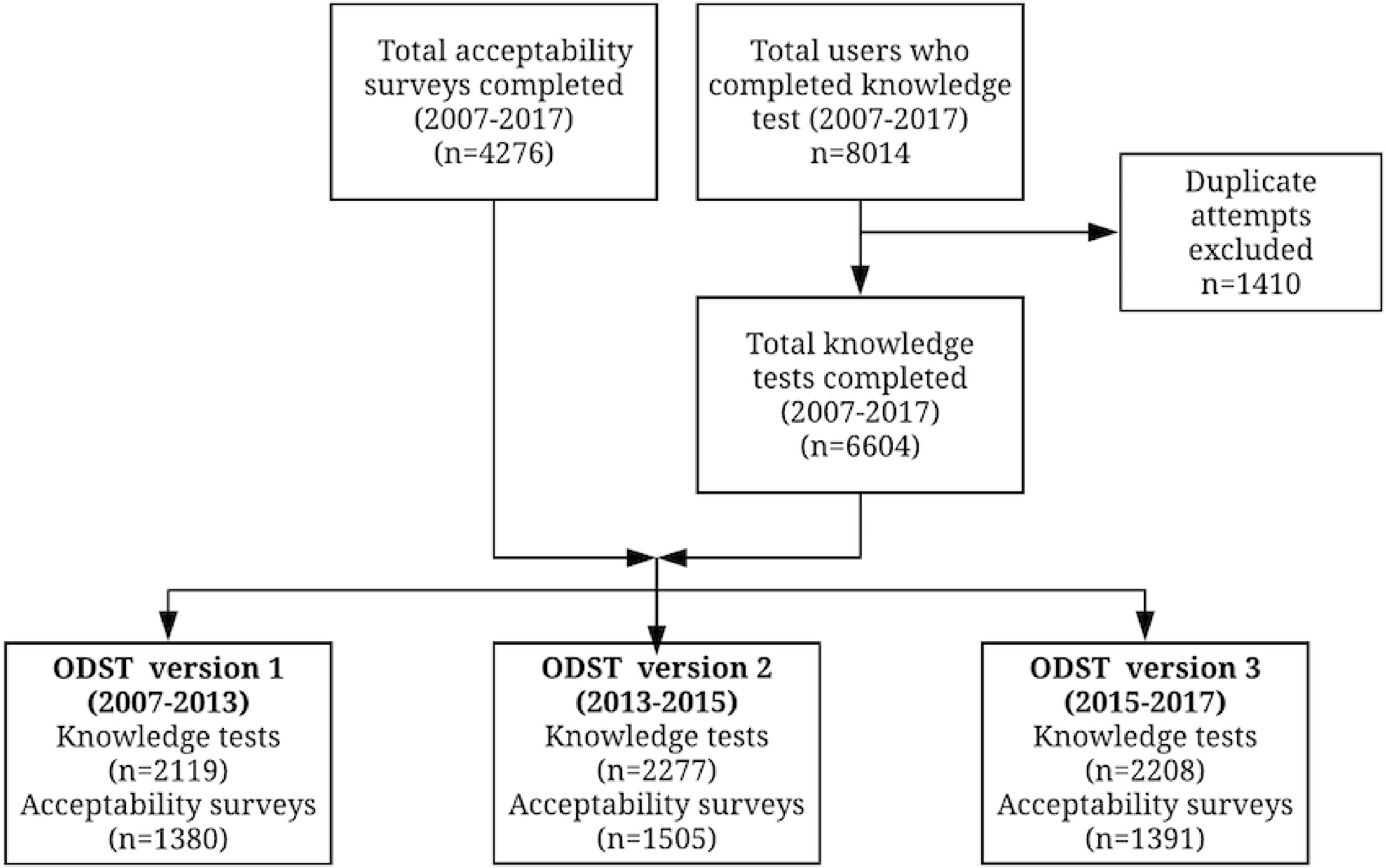
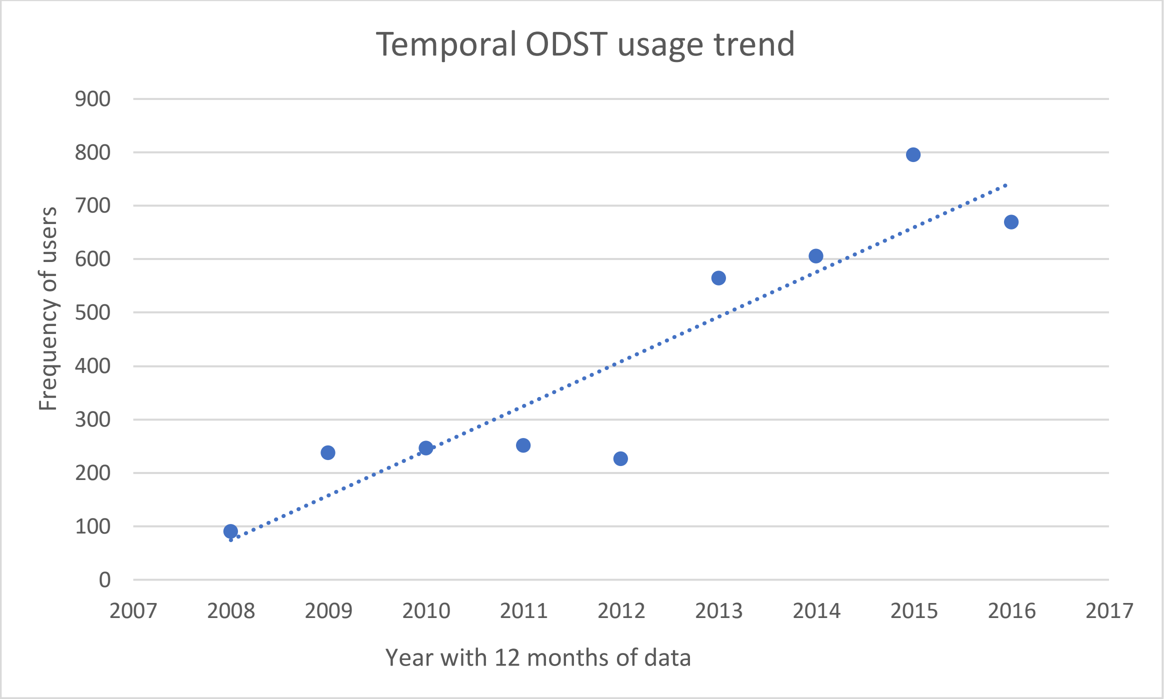


Figure 3-2 Temporal ODST usage trend



3.3.2 Learners' SDM Knowledge

Overall, the median knowledge test score was 8 out of 10 (IQR = 7-9). Sixty-eight percent of learners achieved a passing score of 7.5 out of 10 or greater and received a certificate of successful completion (Table 3-3). Comparisons across versions show that learners who completed version 2 were most likely to have the highest median scores (version 2 = 8.5 versus version 1 = 8.0 and version 3 = 7.9) and pass rates (version 2 = 73% versus version 1 = 63% and version 3 = 69%). Sensitivity analysis showed no substantive difference in knowledge scores when all attempts were analyzed compared to when learners' first attempt only was analyzed.

3.3.3 ODST Acceptability

Ninety percent of learners had a good or excellent overall impression of the ODST (Table 3-2). Learners who completed version 1 gave the highest ratings for overall impression (93% positive versus 87% (AD = 6) and 89% (AD = 4) for versions 2 and 3). The run chart suggests that changes in overall impression ratings decreased with the ODST version 2 (Figure 3-3). Comparisons across versions showed that learners who completed version 2 were 6% less likely to give a positive overall impression rating compared to those who completed version 1 (RR 0.94, 95% CI 0.92 – 0.96, p<0.001). Those who completed version 3 were 5% less likely to give the ODST a positive overall impression compared to version 1 (RR 0.95, 95% CI 0.93 – 0.98, p=0.001). However, learners' overall satisfaction on ODST version 2 and version 3 did not differ (AD = 2, RR 0.99, 95% CI, 0.96 – 1.01, p=0.3). Learners who chose to complete the ODST were 5% more likely to give a positive rating on overall impression compared to learners who had to complete the tutorial for school or research study reasons (AD = 5, RR 0.95, 95% CI, 0.92 – 0.97, p<0.001).

Table 3-2 Learner characteristics and ODST acceptability ratings

Learner Characteristics	**Version 1 n (%)**	**Version 2 n (%)**	**Version 3 n (%)**	**Total n (%)**
Profession	N = 1380	N = 1505	N = 1391	N 4276
Nurse	589 (43%)	587 (39%)	479 (34%)	1655 (39%)
Student	356 (26%)	300 (20%)	349 (20%)	1005 (24%)
Allied health professional	154 (11%)	352 (23%)	369 (27%)	875 (21%)
Physician	46 (3%)	32 (2%)	26 (2%)	104 (2%)
Researcher	23 (2%)	16 (1%)	22 (2%)	61 (1%)
Administrator	25 (2%)	18 (1%)	6 (0.4%)	49 (1%)
Educators	15 (1%)	12 (1%)	5 (0.4%)	32 (1%)
Other*	172 (13%)	188 (13%)	135 (10%)	492 (12%)
Reasons for completing the ODST	N = 1362	N = 1493	N = 1380	N = 4235
Course or research study	1036 (76%)	1271 (85%)	1063 (77%)	3370 (80%)
Recommended by a colleague	181 (13%)	86 (6%)	104 (8%)	371 (9%)
Continuing education credits	59 (4%)	68 (5%)	144 (11%)	271 (6%)
Just curious	86 (6%)	68 (5%)	69 (5%)	223 (5%)
Acceptability items	Version 1 n (%)	Version 2 n (%)	Version 3 n (%)	Total n (%)
Overall impression (excellent/good)	1267 (93%)	1300 (87%)	1217 (89%)	3784 (90%)
Easy to understand information (very/somewhat)	1294 (95%)	1344 (90%)	1288 (90%)	3926 (93%)
Information is comprehensive (very/somewhat)	1345 (99%)	1448 (98%)	1345 (98%)	4138 (98%)
Ease of navigating the ODST webpages (very/somewhat)	1338 (99%)	1429 (96%)	1338 (98%)	4105 (98%)
New information was provided	1290 (95%)	1401 (94%)	1303 (95%)	3994 (95%)
Will help to support others making difficult decisions	1179 (87%)	1245 (84%)	1150 (84%)	3574 (85%)
Would tell others about the ODST	1032 (76%)	1051 (71%)	907 (66%)	2990 (71%)

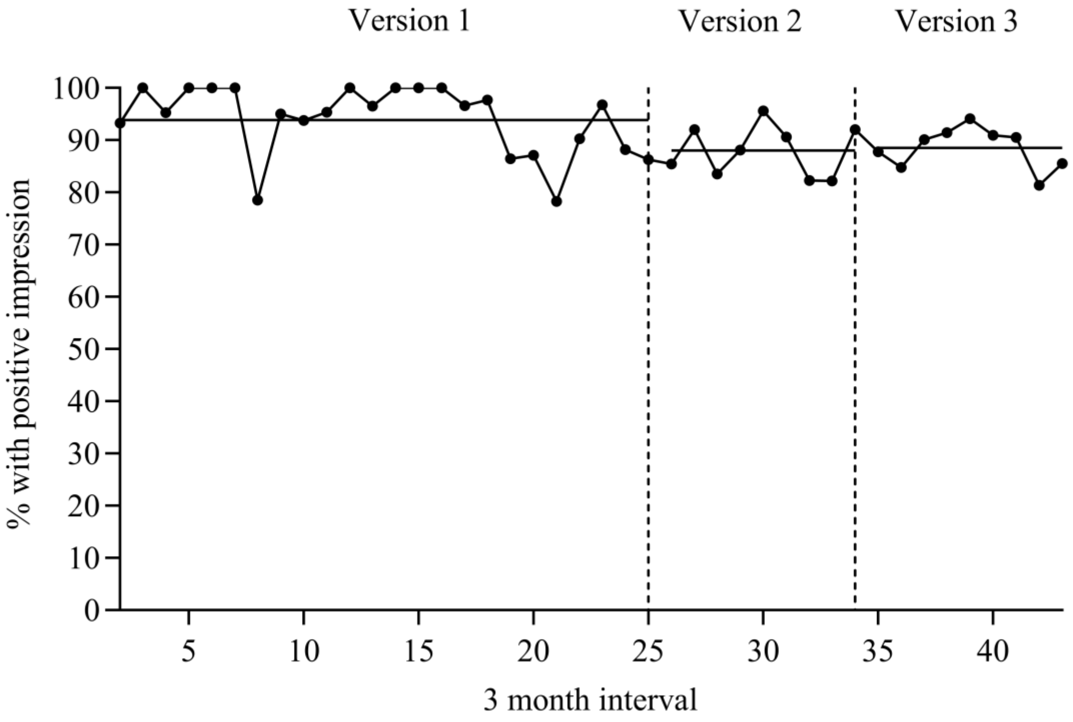
*Others included chaplains, chiropractors, journalists, kinesiologists, librarians, and policy makers

Table 3-3 ODST knowledge scores and pass rates

ODST versions	**Knowledge score (median)**	**IQR**		**Percent who achieved a passing score**		
Total	8.0	7.0-9.0		68%		
Version 1	7.9	6.7-8.3		63%		
Version 2	8.5	7.0-9.5		73%		
Version 3	8.0	7.0–9.0		69%		
Newer vs. older ODST versions	**Knowledge score (RR)**	**95% CI**	**P value**	**Pass rates (RR)**	**95% CI**	**P value**
Version 2 vs. Version 1	1.08	1.06-1.09	p<0.001	1.14	1.10-1.18	p<0.001
SA*	1.07	1.06-1.09	p<0.001			
Version 3 vs. Version 1	1.04	1.03-1.06	p<0.001	1.10	1.06-1.14	p<0.001
SA*	1.05	1.04-1.07	p<0.001			
Version 3 vs. Version 2	0.97	0.96-0.98	p<0.001	0.97	0.94-0.99	p=0.001

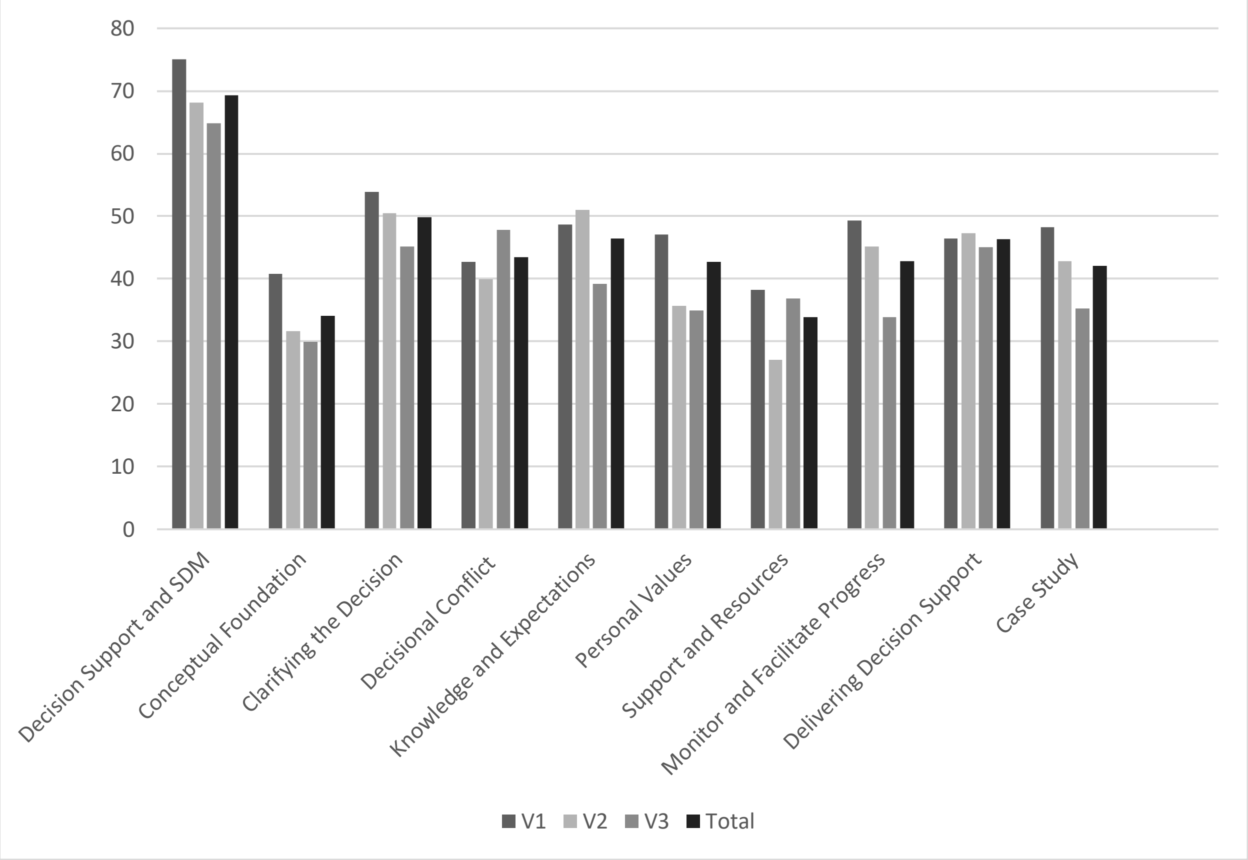
ODST=Ottawa Decision Support Tutorial; IQR=Interquartile range; RR=Risk ratio; CI=Confidence interval; SA=Sensitivity analysis; vs = versus

Figure 3-3 Run chart of learners' overall impression of the ODST (2007-2017)



Among the other acceptability survey items, comprehensive information and ease of navigating the ODST web pages were the most highly rated (Table 3-2). Learners rated the SDM and decision support module as most helpful (Figure 3-4). The lowest rated item was learners' willingness to recommend the ODST to others. Between 42% to 50% of learners rated clarifying the decision, decisional conflict, knowledge and expectations, personal values, monitoring progress, delivering decision support, and the case study, as most helpful. The percent of learners evaluating version 3 had lower ratings for all modules, except the decisional conflict module, which had increased ratings.

Figure 3-4 Learner ratings of the most helpful ODST modules



*V1 = ODST version 1; V2 = ODST version 2; V3 = ODST version 3

Analysis of open-ended questions revealed ten themes and nine recommendations for improving version 3 of the ODST (Table 3-4). Of the 1391 learners that completed an acceptability survey, 429 (31%) provided open-ended comments. Most comments (n=177; 13%) indicated that the learner liked the ODST and/or had no suggestions for change. The most common suggestions were to make the tutorial more concise and improve readability, add multi-media elements (e.g., video and audio) and case studies, and improve the overall format and visual appeal.

Table 3-4 Learners' suggestions for improving ODST version 3 (n=1391)

Themes (2015-2017)	**Example Quote**	**Frequency* n (%)**
Liked the tutorial/ No suggested changes	"I thought the tutorial was very effective." "Nothing, it was very helpful."	177 (13%)
Make tutorial more concise, simplify language, improve readability	"Most pages included comprehensive information but it was too wordy. I prefer information to be more concise while including all content." "Vulgariser l'information d'avantage. Tel que présenté ici, elle peut être difficile à la compréhension." Translation: Update/simplify the language to improve. As presented here, it can be difficult to understand.	102 (7.3%)
Add multi-media and case studies	"Make portions of this into a video. People learn in different ways and this only appeals to people visually. If you had some video, you would appeal to those who learn auditorally [sic]." "Include more case studies, as I find application to a scenario is the most helpful for me."	66 (4.7%)
Improve format and visual appeal	"It is somewhat dense on the page and the print is very small. If there is a way to improve the layout it would help."	56 (4.0%)
Improve French version; ensure all material is available in French	"Faire une meilleure traduction de l'anglais au français. Certaines phrases traduites et questions sont ambigüe." Translation: Improve the translation from English to French. Some translated sentences and phrases are ambiguous.	17 (1.1%)
Tailor to special populations	"Donner davantage d'exemples de décisions à prendre concernant les conditions de retour à domicile sécuritaire vs la convalescence ou l'hébergement, décisions qui constituent une réalité de plus en plus fréquente…" Translation: Give more examples of decisions to be taken regarding the conditions of safe homecoming vs. convalescence or accommodation, which are becoming more and more frequent.	7 (1.2%)
Provide more realistic timelines for completion	"Give a more realistic time for completion at the beginning of tutorial. This definitely took me longer than 2 hrs to complete."	7 (0.5%)
Fix links	"Some of the links could not be accessed."	6 (0.4%)
Allow saving of content more often	"Meilleur système pour enregistrer volet de formation lorsque déjà débutée. J'ai du recommencer en intégralité à quelques reprises." Translation: Need a better system to save your information after having started. I had to start all over again a few times.	5 (0.4%)
Include a summary sheet	"Fiche synthèse avec points repères." Translation: A summary sheet with key points	3 (0.2%)

*Frequency percentages were tabulated by dividing the number of learners that provided a quote within each theme by the number of learners who completed an acceptability survey for version 3 of the ODST and multiplying by 100. Note, if provided several suggestions, all were included.

3.4 Discussion and Conclusion

3.4.1 Discussion

Since 2007, over 6600 unique ODST knowledge tests and 4275 acceptability surveys were completed, with increased use over time. Learners represented a variety of professionals, with the highest proportion being nurses and students. Most learners completed the ODST as part of a course requirement or a research study. Knowledge test scores were high (median 80%). Overall, learners rated the ODST as acceptable (90%), with version 1 having the highest overall impression ratings (93%). These findings lead us to make the following observations.

Our knowledge test findings (i.e., mean knowledge test scores for version 1 (79%), version 2 (85%) and version 3 (80%)) are consistent with other studies that analyzed subsets of ODST knowledge test scores on version 1 or earlier (i.e., version 0; before publically available online). A randomized controlled trial showed that nurses exposed to the ODST version 0 had significantly higher mean knowledge test scores post-ODST compared to controls (74% versus 60%, p=0.007) [11]. Another study evaluated ODST versions 0 and 1 with three cohorts of nursing students and showed median knowledge test scores of: 83% (n=73), 90% (n=110), and 92% (n=92) [14]. Students reported being highly satisfied with the ODST but recommended adding more case studies. A pre/posttest of version 0 showed that HCPs had improved knowledge (61% at baseline to 84% post-ODST, t=7.4; p<0.001) [13]. As such, the ODST can be used to overcome lack of SDM knowledge, a commonly reported SDM barrier among HCPs [19, 20].

Despite multiple revisions to improve the ODST, our data suggests that learners were most satisfied with version 1 and less likely to provide equally high satisfaction ratings for subsequent versions. We suggest three potential explanations for this trend. First, our data showed that individuals who completed the ODST voluntarily were more likely to provide higher satisfaction ratings compared to those who had to complete it for course credit or a research project; the proportion completing it for course credit or a research project increased for versions 2 and 3. This suggests that learners' underlying motivation for completing the ODST could have influenced satisfaction. Previous research suggests that HCPs' motivation is influenced by a multitude of factors (e.g., personal and environmental characteristics) and can impact educational and behavioral outcomes [21].

Second, over a 20-year time period, we expect that learners' expectations of tutorials and learning modalities evolved, and that the ODST did not keep pace with these expectations. Learners might have been less satisfied with our inability to include video or audio learning modalities due to resource constraints. Although 90% of learners rated the ODST to be acceptable, qualitative analysis suggests that several learners were dissatisfied with the ODST plain text format and want more multi-media options. A systematic review that examined the effectiveness of electronic continuing education for HCPs found that a multicomponent online intervention was more effective than flat text [22]. Indeed, capitalizing on technological capabilities could help improve acceptability and advance SDM training. Researchers in the United States have begun developing and evaluating interactive educational tools to help HCPs foster patient-centered communication skills, which may also be relevant for enhancing SDM knowledge [23, 24].

Third, the ODST content might not be an ideal match to all learner audiences. In earlier versions, more learners were physicians, nurses, and students (many in nursing), for whom the ODST material is a clear match. For subsequent versions, however, more learners from other professions/occupations completed the tutorial and the material (e.g., communication and case studies) might have been less relevant for some of these groups, thus decreasing satisfaction. Additionally, versions 2 and 3 were translated into French and qualitative comments suggested issues with the translation quality, potentially limiting the satisfaction of individuals who completed the French version.

This study should be interpreted within the context of its limitations. First, our data were initially collected for quality improvement, and not research purposes. Therefore, we were unable to distinguish feedback from those who scored high versus low on the knowledge test or those who chose to do the ODST compared to those who had to complete the ODST for research or school purposes. Our databases did not capture the number of learners who started, but did not complete, the tutorial. Additionally, our evaluation was limited to learners who completed the knowledge test or the acceptability survey. Therefore, our data might be biased if the perceptions of learners who opted not to complete these components differed from those who did complete them. Third, learners could have completed the knowledge test multiple times under a different username. Similarly, as the acceptability surveys were not linked to unique usernames, we were unable to identify learners who might have completed the acceptability questionnaire multiple times. Of note, minuscule effects can become statistically significant with very large samples, such as ours [25]. Therefore, statistically significant differences in our outcomes do not necessarily translate to meaningful significant changes.

3.4.2 Conclusions

Our study evaluated a SDM educational program that is online, open-access, and widely used. Post-tutorial, most ODST learners demonstrated good SDM and decision support knowledge and rated the tutorial as acceptable. To improve learner satisfaction, subsequent

ODST versions should consider learner motivation, updating interactive elements within the tutorial, and matching content (e.g., case studies) to learner disciplinary background. Future research should examine ODST outcomes among specific learner types (e.g., HCPs versus students) and interventions to promote its uptake. Findings from this study will be used to improve the current version of the ODST.

3.4.3 Practice Implications

Educational SDM interventions are an important first step for improving SDM knowledge and use among HCPs [9]. It is well established that learners who complete the ODST have good knowledge of SDM and decision support strategies. English and French versions of the ODST are openly available to anyone with internet access. As such, the ODST is an inexpensive intervention that can be used to overcome lack of knowledge, which is a common barrier interfering with SDM implementation. However, completing the ODST is unlikely to be sufficient to change HCP behavior and achieve routine SDM use in clinical practice [26]. Additional SDM implementation interventions, tailored to the context, should be used to promote SDM uptake among HCPs [9].

Declaration of Conflicting Interests: All authors (LB, FL, MC, IG, AO, ML, DS) indicate that they have no conflicting interests.

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CHAPTER 4

POST-TRAINING SHARED DECISION-MAKING BARRIERS AND FACILITATORS FOR PEDIATRIC HEALTHCARE PROVIDERS: A MIXED METHODS STUDY

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Abstract

Objective: To assess barriers and facilitators of shared decision-making (SDM) for pediatric healthcare providers (HCP) after they have been trained in SDM.

Methods: A mixed methods study using triangulation of data sources. Pediatric HCPs with SDM training who worked at a Canadian tertiary care pediatric hospital were eligible. Participants completed a validated SDM barriers survey (n=60) and a semi-structured interview (n=11). We calculated descriptive statistics. Univariate and multivariable ordinary least squares linear regression models determined predictors of HCPs' intention to use SDM. Interviews were audiotaped and transcribed verbatim. We analyzed qualitative data using deductive and inductive content analyses and organized categories according to the Ottawa Model of Research Use.

Results: Intention to use SDM was high (mean score = 5.6/7, SD=0.78) and positively correlated with SDM use (RR=1.46, 95% CI 1.18-1.81). However, 52% of survey respondents reported not using SDM after training. HCPs identified factors influencing SDM at the levels of innovation, adopter, environment, and training. Insufficient time (barrier) and buy-in and agreement with SDM (facilitators) were most commonly cited. To improve SDM use, HCPs want a more team-based approach to SDM training, continuing education, and implementation.

Conclusion: Despite training and positive intentions, many HCPs report not subsequently using SDM and identified numerous post-training barriers to its use. To overcome SDM barriers and improve uptake, HCPs recommend creating a socially supportive environment through a team-based approach to SDM training and implementation. These findings can inform SDM training and implementation interventions at pediatric health care centers.

What's new: Despite training and good intentions, SDM is rarely used in pediatric clinical practice. This study identifies the factors associated with shared decision-making use among pediatric HCPs after they have been trained.

4 POST-TRAINING SHARED DECISION-MAKING BARRIERS AND FACILITATORS FOR PEDIATRIC HEALTHCARE PROVIDERS: A MIXED METHODS STUDY

4.1 Introduction

Although children and parents want an active role in health decision-making, they are insufficiently involved [1, 2]. Shared decision-making (SDM) is a collaborative decision-making process between healthcare providers (HCP), the patient, and family members [3, 4]. This approach is particularly useful when there is more than one reasonable treatment option or the best decision depends on what matters to most the patient and family (i.e., preference–sensitive decision) [5]. By exchanging information about the evidence (options, risks, and benefits) and the family's preferences and values, HCPs, patients, and family members can deliberate to determine the best treatment plan.

SDM training experts identified relational skills and risk communication on options, benefits, and harms, as minimal SDM competencies for HCPs [6]. The most commonly used instrument for measuring HCPs' SDM competencies is the Observer OPTION (available here: http://www.glynelwyn.com/observer-option-instrument.html) [7]. Multiple studies using OPTION reported that many HCPs exhibit low levels of patient-involvement behaviors and lack skills needed for engaging patients in SDM [8]. A Cochrane review suggested that SDM training combined with patient-targeted interventions are likely to increase HCPs' SDM use [9]. A recent environmental scan identified 148 SDM training programs targeting HCPs [10]. Although evidence supporting most training programs was lacking, the Ottawa Decision Support Tutorial (ODST) (available here: https://decisionaid.ohri.ca/odst/) paired with a 3-hour skill building workshop improved HCPs' knowledge and skill for SDM [11]. This SDM training program teaches HCPs evidence-based decision support strategies (e.g., patient decision aids (PtDAs) and decision coaching).

Despite recommendations for using SDM among pediatric regulatory organizations [12], routine use of SDM is limited. To promote SDM in our pediatric hospital, we trained HCPs in SDM using the ODST and 3-hour skill building workshop. The purpose of this study was to evaluate pediatric HCPs' SDM use and factors influencing use, after SDM training. Outcomes were HCPs' intention to use SDM, self-reported SDM use, and SDM barriers and facilitators. Barrier and facilitator assessments promote the implementation of healthcare innovations and can improve professional practice [13].

4.2 Methods

4.2.1 Design

We conducted a mixed methods study using triangulation of survey and interview data. This design uses multiple methods to gather and cross-verify data for the purposes of providing a rich and robust account of SDM barriers and facilitators in pediatric clinical practice, increasing validity of the findings, and enhancing understanding of the phenomena under study [14].

We used the Ottawa Model of Research Use (OMRU) as our guiding framework [15]. The OMRU seeks to explain implementation of evidence in healthcare and recommends barrier and facilitator assessments at the level of the innovation (i.e., SDM), potential adopters (i.e., SDM-trained HCPs), and practice environment (i.e., pediatric hospital). Our hospital's Research Ethics Board approved this study (Appendix K) and participants provided informed consent (Appendix L). We followed the STROBE guidelines [16] (Appendix M), which include a checklist of 22 items considered essential for accurate and complete reporting of observational studies (available here: https://www.strobe-statement.org/index.php?id=available-checklists).

4.2.2 Setting and Participants

We conducted the study at a Canadian tertiary pediatric academic hospital that offers inpatient and outpatient services to approximately 600,000 children and youth aged 0 to 18 years. SDM training was offered between 2012 and 2016 as part of a research funded program. Invited HCPs were primarily from clinical units that expressed interest in SDM.

Eligible participants were pediatric HCPs who completed the SDM training program (i.e., ODST and 3-hour skill building workshop) offered within our hospital by our research program. HCPs were excluded if they were no longer employees/consultants at our hospital, or were on extended leave. Sixty-eight HCPs met the inclusion criteria and were invited to complete the survey. For interviews, we purposefully sampled HCPs to ensure a range of disciplinary perspectives (e.g., physicians, nurses, and allied HCP).

4.3 Data Collection Procedures

The online survey was built using REDCap software and distributed using Dillman's mixed mode guidelines (i.e., online and paper) [17]. First, we sent HCPs an introductory letter (Appendix N), $5 cash (i.e., compensation), and request to participate. Two days later, we sent a personalized invitation email, consent letter (Appendix O), and link to the online survey. Non-respondents received a reminder email 5 business days after the invitation email. Fifteen days after, non-respondents received a reminder letter (Appendix P), a paper-based survey and pre-paid postage envelope. We sent an electronic final reminder 5-weeks post-invitation. All surveys were coded to ensure no duplicate responses. HCPs could defer study participation by not responding. HCPs were invited via email to participate in an interview, which were audio-recorded, conducted in a private hospital conference room or office, and lasted between 20 and 90 minutes.

4.4 Data Collection Tools

Our survey (Appendix Q) consisted of five sections: (A) introduction, consent, and SDM definition; (B) items asking about SDM use; (C) the Continuing Professional Development (CDP) Reaction Questionnaire [18]; (D) items specific to SDM barriers and facilitators [19]; and (E) demographics questions.

Following a study introduction, invitation to participate, and consent, we provided the following definition to ensure survey respondents understood the target behavior being assessed: "SDM is when HCPs, patients, and/or parents collaborate in decision making by exchanging medical information and the family/patient's values and preferences. Together they determine the best treatment decision for the patient." Then, the survey posed seven questions to probe HCPs' current use of SDM.

Next, the survey posed the 12 questions in the CDP Reaction Questionnaire, for which validity evidence was gathered for a purpose, and within a clinical context, similar to our study [18]. This theory-based instrument evaluates the impact of continuing professional development activities on HCPs' intention to change their clinical behavior. The questions, using a 7-point Likert scale, evaluate five constructs: intention, beliefs about capabilities, beliefs about consequences, moral norm, and social influences. This questionnaire's test-retest reliability with weighted kappa values are between 0.4 and 0.6 and Cronbach alpha coefficients range from 0.79 to 0.89. Exploratory factorial analysis showed the presence of five constructs, with the proportion of variance explained by each factor superior to 5% [18]. The CDP Reaction Questionnaire was also shown to be acceptable to HCPs, responsive, and predictive of subsequent behavior change [20].

Fourth, we assessed HCPs' perceived SDM barriers and facilitators using selected items from an adult SDM survey, originally developed using the OMRU and a literature review, and modifying it to our context (i.e., pediatrics) [21]. These items asked about: child and family decision-making involvement (4 items), SDM training (4 item), SDM use among SDM-trained colleagues (2 items), access to SDM resources (1 item), time for SDM (1 item), support for SDM (3 items), and SDM acceptability (2 items). Items were rated on a 5-point scale from 1 (strongly disagree) to 5 (strongly agree), plus the option of no response. Open-ended questions asked respondents to list up to three main pediatric SDM barriers and facilitators. These survey items have been used in other studies assessing barriers and facilitators related to SDM interventions [22-24]. Finally, demographic questions asked about professional discipline, years of experience, age, gender, education level, and SDM training. Our survey questionnaire was reviewed for content validity by a panel of pediatricians, SDM experts, and knowledge translation experts (n=6) and was piloted with pediatric HCPs (n=2) to assess response processes. Based on the feedback, we changed the order of the questions.

Our semi-structured interview guide was based on systematic reviews of SDM barriers and facilitators in adult medicine, HCP behavior change theories, and previous interview guides for assessing barriers to clinical guideline implementation [19, 22, 25] (Appendix R). Questions elicited information about demographics, SDM use, and SDM barriers and facilitators. We asked interview participants to describe their understanding of SDM and corrected misperceptions to be consistent with the definition provided above. We piloted the interview guide with pediatric HCPs (n = 2) and subsequently made minor changes (e.g., order of questions to improve flow). Consistent with a semi-structured approach, the interviewer used these questions as a guiding framework to explore SDM barriers and facilitators, while allowing participants to discuss new ideas.

4.5 Analysis

Raw survey data were exported from REDCap and transferred to Statistical Analysis Software for Windows (version 9.4: SAS, Cary, NC, USA). We calculated univariate descriptive statistics for all quantitative data. We assigned a construct score for the CDP Reaction Questionnaire by calculating the mean and standard deviation of items within each construct. Associations between theoretical constructs and intention to engage SDM were calculated using univariate (unadjusted) and multivariable (adjusted) ordinary least squares linear regression models. We calculated a coefficient of determination (R2) to determine the proportion of variance between the theoretical constructs and intention to use SDM. On an exploratory basis, we used a linear regression model to examine whether HCP characteristics predicted intention to use SDM and a log-binomial regression model to measure the association between intention to use SDM and self-reported SDM use.

Open-ended survey responses were collated in Microsoft Excel and interviews were transcribed verbatim. We imported qualitative data into NVivo 9 software (QSR International, Australia) for analysis. Two reviewers independently analyzed all data using deductive and inductive approaches for content analysis [26]. Deductive analysis was based on the OMRU and informed by the SDM barrier and facilitator taxonomy [15, 19] (Appendix F). We conducted inductive analysis to identify new categories using six iterative steps: reviewing transcripts, creating a code book, coding, establishing consensus, modifying the code book, and final coding [26]. We organized categories according to the OMRU barrier constructs, added a fourth category called ‘training’ to reflect our analysis, and calculated their frequency of occurrence.

Our rate of missing data was low. Thirty (67%) items had no missing data, 14 (30%) items were missing 1-2 cases, and 1 item (2%) (i.e., children prefer SDM) was missing 4 cases. Given the low risk of bias from missing items, we did not impute data and used case-complete analysis [27].

4.6 Results

4.6.1 Participants

Of the 68 eligible, 60 HCPs responded to the survey with a response rate of 88%. Of those 60 HCPs, 11 also completed an interview. The typical participant was a woman, who worked full time, had 20+ years of clinical experience, was aged between 51 and 60 years, and completed the SDM training in 2014 or 2015 (Table 4-1).

Table 4-1 Characteristics of the survey and interview respondents

	Survey, n (%) n=60	**Interview, n (%) n=11**
Profession		
Medical Doctor	17 (28%)	3 (27%)
Nurse	15 (25%)	4 (36%)
Allied Healthcare Provider	33 (55%)	4 (36%)
Years of experience		
1 to 5	7 (12%)	2 (18%)
6 to 10	6 (10%)	1 (9%)
11 to 19	18 (30%)	2 (18%)
20+	29 (48%)	6 (55%)
Full time equivalent (FTE)		
Full time	50 (86%)	10 (91%)
Part-time	8 (14%)	1 (9%)
Age		
21-30	3 (5%)	2 (18%)
31-40	9 (15%)	1 (9%)
41-50	30 (50%)	4 (36%)

>51	18 (30%)	4 (36%)
Prefer not to disclose	1 (2%)	0
Gender		
Man	9 (15%)	1 (9%)
Woman	49 (83%)	10 (91%)
Transexual or transgender	1 (2%)	0
Highest Education Level		
High school	1 (2%)	0
College	3 (5%)	0
Undergraduate	11 (18%)	5 (45%)
Master's	27 (45%)	3 (27%)
Doctoral	7 (12%)	1 (9%)
Professional degree	13 (22%)	2 (18%)
Completed SDM training in:		
2011	2 (3%)	1 (9%)
2012	2 (3%)	1 (9%)
2013	5 (8%)	0
2014	16 (27%)	5 (45%)
2015	20 (33%)	4 (36%)
Do not remember	17 (28%)	0
Use SDM occasionally or not at all	54 (90%)	6 (55%)

4.6.2 Intention to Use SDM

After training, 43% of survey respondents agreed that they intended to use SDM. The CPD Reaction Questionnaire ratings for intention to use SDM post-training was 5.6 out of 7 (Table 4-2). Unadjusted associations showed that all theoretical constructs were significantly associated with intention to use SDM. However, adjusted analysis revealed that only social influence and beliefs about capabilities were significant predictors of intention to use SDM. Overall, inclusion of all constructs accounted for approximately 47% of variation in intention to use SDM (R2 = 0.47). Compared to physicians, allied HCPs had significantly less intention to use SDM (0.48 points lower, 95% CI -0.93 to -0.04); however, there was no difference between physicians and nurses (-0.30 points lower, 95% CI -0.83 to 0.22). There were no significant differences in respondent demographic characteristics (e.g., gender, experience level) and intention to use SDM. All 11 interviewees reported that they intended to use SDM post-training.

Table 4-2 Association between theoretical constructs with HCPs' intention to use SDM

Construct	Score, mean, (SD)	Univariate Regression Coefficient	95%CI	Multivariate Regression Coefficient	95%CI
Intention	5.6 (0.78)	-	-	-	-
Social Influence	3.6 (1.12)	0.39	0.24 - 0.54	0.28	0.11 - 0.43
Beliefs about capabilities	5.7 (0.71)	0.56	0.31 - 0.81	0.34	0.10 - 0.60
Beliefs about consequences	6.3 (0.66)	0.42	0.12 - 0.72	0.19	- 0.14 - 0.52
Moral norm	6.3 (0.61)	0.54	0.24 - 0.85	0.09	-0.30 - 0.50

4.6.3 SDM Use

Survey respondents reported using SDM: not at all (52%), occasionally (38%), frequently (8%), or were unsure (2%). In the last two weeks, HCPs reported using decision coaching: not at all (38%), 1-2 times (32%), 3-5 times (18%), 5-10 times (5%), more than 10 times (2%), and unsure (5%). Similarly, HCPs reported using PtDAs: not at all (73%), 1-2 times (17%), 3-5 times (3%), more than 10 times (3%), and unsure (3%). Of the interview respondents, 55% reported routine SDM use, 46% reported occasional use, and 9% indicated not using SDM at all.

Of the 43% (n = 26/60) of survey respondents who intended to use SDM, 81% (n=21/26) reported using SDM. Intention to use SDM was positively correlated with SDM use (RR=1.46, 95% CI 1.18-1.81).

4.6.3.1 Barriers and Facilitators

Innovation Level (i.e., SDM). Ninety-two percent of survey respondents reported that SDM was useful. Interview respondents identified that they could try SDM, which facilitated its use (Table 4-3).

Adopter Level (i.e., HCPs). Most respondents (survey and interview) agreed with SDM and thought it was the right thing to do. However, interview respondents thought the appropriateness of using SDM often depended on the clinical setting or situation (e.g., SDM was less applicable to urgent decisions) (Table 4-3). Quantitative survey data showed that most respondents believed that trained HCPs could involve parents in decision making, though they were less confident for involving children. Sixty-four percent of interview respondents expressed a lack of confidence about their abilities to use SDM. Most respondents (survey and interview) agreed that SDM would improve patient and family outcomes (e.g., improved involvement, reduced uncertainty about a decision). Although some interview respondents described negative experiences resulting from using SDM (e.g., conflict within the healthcare team), most expressed positive experiences (e.g., satisfied patients and families).

Table 4-3 Innovation and adopter level SDM barriers and facilitators identified by pediatric HCPs

		Interview resp. Qual (n=11)		**Survey resp. Qual (n=60)**		**Survey resp. Quant (n=60)**	
Categories	**Example quotes**	**B**	**F**	**B**	**F**	**B**	**F**
Innovation level							
SDM is triable	• I think the pilot [SDM program] was a useful way to test the waters.		√				
Adopter level							
Attitudes							
Agreement with SDM	• I think it is [SDM] 100% of what we should do.		√		√		
Applicability of SDM	• A very urgent decision that must be made right away…sometimes the decision has already been made because of time or because of urgency. (B) • I found it [SDM strategies] very useful for families facing decisions about starting growth hormone. (F)	X	√	X			
Beliefs about capabilities							
Self-efficacy	• I think the basics are there but I haven't really taken it [SDM] as far as it could go….so lack of confidence of actually being able to sit down and do it. (B) • It [SDM] gives you the knowledge, and the opportunity to think it through and then you feel more confident in your decision. (F)	X	√	X			
Most trained HCPs can engage parents in SDM						4 (8%)	46 (92%)
Most trained HCPs can engage children in SDM						20 (33%)	39 (65%)
Beliefs about consequences							
Patient/family outcomes	• Some colleagues…don't believe it [SDM] facilitates or helps a family. (B) • We know it [SDM] can produce positive outcomes…it reduces regret, it reduces blame, those positive outcomes make people able to live with the decision they make. (F)	X	√		√		
SDM improves parent involvement						1 (2%)	59 (98%)

SDM improves child involvement						7 (12%)	52 (87%)
Reinforcement	• [SDM is] causing undue upset within the department and that's causing people to be unsettled. (B) • 99% of the time they [the family] say 'yes it's been helpful. (F)	X	√		√		
Memory and attention							
Forgetting and reminders	• It is difficult to remember to incorporate this new element into my existing clinical practice; I would say the barrier is simply that I haven't used the tools learnt in the workshop and have somewhat forgotten. (B) • Prompts in the [electronic medical record] would be excellent. (F)		√	X	√		

*B = Barrier; F = Facilitator; Resp = respondent; Qual = qualitative; Quan = quantitative; X=Barrier; √=Facilitator

Environment Level. The most frequently reported barrier was insufficient time for SDM, due to workload, feeling overwhelmed, other priorities, patient caseloads, and clinic workflow inefficiencies (Table 4-4). However, some respondents thought that allocating additional time to consultations could facilitate SDM, thus improving consultation efficiency by reducing repeat visits.

Survey and interview respondents cited characteristics of other stakeholders that helped or hindered SDM. Frequently reported barriers by stakeholder type were: HCP clinical experience, parent preference for non-involvement in decision making, and the child's age and competence. Parent and child preferred involvement in decision making was also a commonly reported facilitator. HCPs indicated that support from the organization, management, and other leaders or champions, facilitated SDM, while lack of support from these groups hindered it.

Respondents reported several social factors that impacted SDM. The mean social influence score on the CPD questionnaire (3.6 out of 7) was lower than other theoretical constructs (range 5.7 – 6.3 out of 7). Qualitative data showed that social barriers included conflict between stakeholders, power imbalances, lack of buy-in from other stakeholders, and social norms (e.g., doctor makes the decision). Facilitators included buy-in from stakeholders, cultural and practice norms that are consistent with SDM, the HCP's professional role as a patient advocate, and team cohesion and support.

Survey respondents agreed that they had access to the resources needed for SDM (77%), particularly onsite access to SDM experts, decision coaches, and SDM tools. Most respondents thought PtDAs and decision coaching facilitated SDM by providing a structured approach or improving families' acquisition of medical information. However, some reported that PtDAs were difficult to use, insufficiently tailored for children, and that pediatric condition-specific PtDAs were lacking. Interview respondents also cited limited funds supporting the SDM program as a barrier.

Table 4-4 Environmental level SDM barriers and facilitators identified by pediatric HCP

		Interview resp. Qual (n=11)		**Survey resp. Qual (n=60)**		**Survey resp. Quant (n=60)**	
Categories	**Example quotes**	**B**	**F**	**B**	**F**	**B**	**F**
Environmental level							
Time							
	• The hard sell is time...the people...providing care every day who are busy, overwhelmed, and are struggling with all sorts of other priorities. This is just yet again another thing... (B) • More time allocated to meet with families and children…and more staff in order to have the time to spend with families and children [would facilitate SDM]. (F)	X	√	X	√	31 (52%)	29 (48%)
Characteristics of other stakeholders							
HCPs' experience	• I think this [SDM] is difficult for new grads to do. I don't think they would feel confident enough doing it. (B)	X					
HCPs who think they do SDM, but don't	• Often HCPs will say, 'yes, we do SDM' and in fact when you watch them, when you listen to them, and when you talk to them about it…what they describe is not SDM. (B)	X		X			
HCPs' motivation		X		X			

	• It is motivation to want to learn, hear, change, read things…we set up a website with the tools as in the guideline, parent handouts, the decision aid, the choice cards. There's many, many who've never gone to it, never looked. (B)						
HCPs lack knowledge of SDM	• Lack of knowledge and training [is a barrier to SDM] (B)	X		X			
Parent SDM preferences	• Some parents and patients prefer not to be involved in the decision making process. (B) • I find that most of the time the parents do want the kids to have a say. (F)	X	√	X		8 (13%)	52 (87%)
Parent negative emotion	• It's very easy to be paternalistic when you've got frightened parents who just want you to tell them what to do. (B)	X					
Parent culture and language	• They [the family] were from a different culture and in that culture the father has a lot of say. And the girl…was 9 years old and so she was giving honest answers but then the father got mad because he said, 'you're putting words in her voice and we know what is best thing for her'. (B) • No language barriers [facilitates SDM]. (F)	X		X	√		
Parent availability for SDM	• In general, there's one parent there…so then you're not getting all the stakeholders involved. (B) • Both parents in attendance for decision making. (F)	X		X	√		
Child age and competence	• The age... some people will say no [children can't participant in decision making] when they're 12. (B) • I think you [engage a child in SDM] as soon as the child's capable of making an informed decision... if the child has the capacity to participate in decisions they should be part of it. (F)	X	√	X	√		
Child SDM preference						21 (36%)	37 (62%)
Support from leadership							
Managerial support for SDM						23 (38%)	37 (62%)
Organizational support for SDM						20 (33%)	43 (72%)
Involvement of leaders/ champions	• There's been no headway in some teams [for implementing SDM] and constant resistance in leadership from the top of that team. (B) • We wouldn't have been able to do what we've done so far without having the key people in the management team who embraced this [SDM]. (F)	X	√		√		

Social influences							
Conflict	• When there is conflict within the interprofessional team about the decision to be made, the options on the table and the risks and benefits of each option. This presents a problem when trying to communicate with the family. (B)	X		√			
Power and empowerment	• They [HCPs] are not able to let go of control enough to do it [SDM]. (B) • Most parents say that this [SDM process] enabled them to listen to their child or youth and recognized that that was critically important in making the right decision. (F)	X	√				
Buy in	• The lack of buy-in from all team members has affected implementation…for those who haven't [bought into SDM]… it's a barrier, and those people are vocal. (B) • Buy-in from the nurses and the people in the delivery room and elsewhere has been well received. (F)	X	√	X	√		
Team cohesion and support	• Lack of full team using a SDM approach. (B) • Team approach [facilitates SDM]. It cannot be successfully implemented if not shared and supported by everyone. (F)	X	√	X	√	23 (38%)	37 (62%)
Relationships	• I think that if they're new patients, springing the concept of SDM...is difficult when they're not patients that you know. (B) • A trusting relationship between the family and child and HCP [facilitates SDM]. (F)	X	√	X			
Norms	• The other big barrier is the culture of the hospital or of the people working in it. For one, people don't like change. (B) • It [SDM] supports the inclusion of families as partners in their children and infants' care so it fits within the vision and mission of [our hospital]. (F)	X	√	X	√		
Professional role model	• Patients come to them [HCPs] to make decisions and that's what they perceive as their job. (B) • As a nurse being an advocate for the patient and family obviously is a key role. (F)	X	√	X	√	10 (17%)	18 (30%)
Other trained HCPs use SDM with parents						26 (43%)	24 (40%)
Other trained HCPs use SDM with children						42 (70%)	17 (28%)
SDM tools and strategies (infrastructure)							

Patient decision aids	• With some kids…the ranking somehow [on the patient decision aid] needs to be a little more [appropriate] for young people. (B) • The rigorously developed and current decision aids support the SDM discussion. (F)	X	√	X	√		
Resources and funding							
Funding and tools	• We’re now looking at wanting to get the promised hospital funding [for the SDM program]...and that hasn’t materialized yet ...we’ve got to go back to depending on [research] grants for sustainability. (B) • From taking the course and knowing the different tools that I can use...I have resources [for SDM]. (F)	X	√	X	√	14 (23%)	46 (77%)

*B = Barrier; F = Facilitator; Resp = respondent; Qual = qualitative; Quan = quantitative; X=Barrier; √=Facilitator

Training Level. Sixty-two percent of survey respondents agreed that additional training would improve HCPs ability to use SDM (Table 4-5). This was echoed by interview respondents who suggested booster sessions, team-based retreats, and lunch and learns would enhance SDM knowledge and skills. Respondents reported that not completing the SDM training with their clinical team hindered their ability to use SDM in clinical practice. To promote SDM use, interview respondents wanted a team-based approach to training and protected time with their clinical team to practice SDM and develop an implementation plan that suited their clinical context. Survey (3%) and interview respondents (36%) thought patients and families should also receive SDM education through awareness campaigns, provision of PtDAs, and encouragement to ask for and use SDM tools.

Table 4-5 Training level SDM barriers and facilitators identified by pediatric HCP

		Interview resp. Qual (n=11)		**Survey resp. Qual (n=60)**		**Survey resp. Quant (n=60)**	
Categories	**Example quotes from interviews or survey**	**B**	**F**	**B**	**F**	**B**	**F**
Training level							
Skill building and continuing education	• Not enough learning opportunities [was a barrier to SDM]...We still never had any dedicated time to develop tools or we never actually practiced it [SDM]. (B) • I don't know if there's more courses to take or anything else to sort of give us that refresher. (F)		√	X	√	19 (32%)	37 (62%)
Team approach	• Not everyone on the clinical team has had the SDM training so we're not always all speaking the same language. (B) • We need protected time to get together with the team and choose a decision, populate the decision aid and decide as a team how we're gonna [sic] roll this out in our clinic. (F)	X	√	X			
Educate patients and families	• Having families push for this [SDM] and doing workshops with families directly so that they show up with the tools ready to review with the docs [sic]. (Facilitator)		√		√		

*B = Barrier; F = Facilitator; Resp = respondent; Qual = qualitative; Quan = quantitative; X=Barrier; √=Facilitator

4.7 Discussion

This study used mixed methods to evaluate pediatric HCPs' intentions to use SDM, their SDM use, and SDM barriers and facilitators, after SDM training. Although HCPs had positive intentions to use SDM, only half of survey respondents reported using SDM in clinical practice. Despite training, HCPs reported numerous factors influencing their ability to use SDM in pediatric clinical practice. Our results lead us to the following observations.

After training, most pediatric HCPs had positive intentions to use SDM in their clinical practice. Nonetheless, HCPs reported low levels of SDM use. This finding is consistent with known intention-behavior gaps between evidence and clinical practice, as well as literature documenting slow uptake of SDM interventions [9, 28]. However, higher intention scores were correlated with self-reported SDM use. Furthermore, social influences and personal beliefs about capability were significant predictors of intentions to use SDM. This was supported by qualitative data showing that HCPs thought positive social influences (i.e., buy-in from other stakeholders) facilitated SDM. Therefore, interventions designed to promote SDM should emphasize social acceptability of SDM.

Beyond the triability of SDM, HCPs reported few influential factors at the innovation level (i.e., SDM), suggesting that HCPs are satisfied with SDM itself. At the level of the adopter (i.e., HCPs), HCPs reported doubts about their ability to use SDM after training. Yet, they maintained positive attitudes, shown by their agreement with SDM principles and beliefs that SDM would improve patient and family outcomes. Implementation interventions could focus on improving HCPs' self-efficacy for SDM with continuing education while capitalizing on positive attitudes among HCPs to drive cultural change and a socially supportive environment for pediatric SDM.

Insufficient time was the most commonly reported SDM barrier overall and at the level of the environment. Although this perceived barrier is widespread among HCPs [19], a Cochrane review suggests that the evidence supporting the claim is limited, but more research is needed [29]. Future studies should prospectively evaluate the impact of SDM on consultation efficiency and process, including in pediatrics. Similarly, many HCPs cited the child's age as a SDM barrier, with younger children being harder to involve in decision making about their own health. Yet most studies are unable to link age with decision-making competence [30]. Instead, competence depends on multiple dynamic factors, including developmental stage, the child's experience with the disease, clinical circumstances, and decision type [31]. As such, implementation interventions need to debunk commonly held misconceptions about SDM and emphasize how SDM can be tailored to various situations and patients [32]. For example, training interventions could focus on how SDM uses the decision-making time differently by having patients and families come prepared for SDM after reviewing a PtDA with a decision coach [33].

At the training level, HCPs offered ideas to promote SDM based on their perceived barriers. Most notably, HCPs suggested a team-based approach to SDM training, continuing education, and implementation. Such an approach could improve the social influences perceived to facilitate SDM uptake and is consistent with the American Academy of Pediatrics guiding principles for team-based care [12]. This document provides guidance on creating effective support systems and partnerships to address children and families' health needs. Additionally, the Quality Chasm report describes a future healthcare system comprised of cooperation and teamwork, including recommendations to train HCPs to work in teams [34]. A key component of fostering a collaborative environment is training individuals from various disciplines together [35]. A study suggested that team-based SDM training helped HCPs legitimize and use SDM in their practice [36]. Nonetheless, more work is needed in this area. An inventory showed that only 10 of 148 SDM training interventions (7%) focused on the interprofessional team [10]. Given that many health decisions require interprofessional collaboration, our findings suggest that team-based approaches should be reflected in SDM training program content and delivery.

Educational interventions designed to change HCP behavior are promising, but show mixed effects [9, 37, 38]. In our case, SDM training alone was insufficient for achieving routine SDM use among HCPs. Mapping prospectively assessed barriers to implementation strategies has been shown to improve uptake [13], but determining specific interventions to address barriers remains a challenge. Our findings suggest that a multifaceted implementation strategy, with focus on team-based approaches to training, self-efficacy, and social acceptability, could improve SDM uptake. Specifically, HCPs could benefit from completing the SDM training within their interprofessional team. An overview of systematic reviews showed that multi-professional collaboration and teamwork could improve HCP practice change [38]. To improve self-efficacy, HCPs could be granted protected time to practise their SDM skills (e.g., role play) using audit and feedback techniques [9]. Social acceptability could be fostered by leveraging the high rates of buy-in from leaders and other champions to create changes in the social context around SDM (e.g., SDM promotion campaigns) [39]. Finally, helping HCPs reframe commonly (mis)perceived barriers (e.g., insufficient time for SDM) could promote implementation [32]. The effectiveness of such an intervention, however, would need to be evaluated.

Our study should be considered within the context of its strengths and limitations. We used methodological triangulation to provide a rich account of HCPs' perceived SDM barriers and facilitators in pediatrics and to strengthen the use of quantitative and qualitative data. There was no divergence in categories resulting from our data. However, some barriers and facilitators were described differently between phrasing in the survey questions and respondents' qualitative responses. For example, respondents' quantitative data indicated that SDM would improve parent and child outcomes. Qualitative data added insight regarding what outcomes they believed would result from SDM (e.g., less regret or blaming of HCPs for undesired outcomes); highlighting the strength of a mixed method approach. Our survey also included a measure for which relevant validity evidence had been collected. We also gathered evidence for content validity of the complete survey questionnaire, and for clear response processes. Our survey had a high response rate (88%), which reduced the likelihood of nonresponse bias. Although characteristics between survey and interview respondents were similar, differences in SDM use might reflect a selection bias whereby those who accepted the interview were SDM champions or early adopters. This study was conducted in a single pediatric hospital with HCPs who completed a specific SDM training program, potentially limiting the transferability of the findings to other contexts, training programs, or populations.

In conclusion, our study suggests that knowledge and skill-based training alone is insufficient to achieve routine use of SDM in pediatric clinical practice. Despite good intentions, 52% of trained HCPs reported limited SDM use. HCPs identified numerous factors that were perceived to influence SDM use. To improve SDM uptake, implementation strategies should focus on creating a more socially supportive environment for SDM and team-based approaches to SDM training, continuing education, and implementation. HCPs also require additional opportunity to enhance their self-efficacy for SDM. To further advance the field, future studies need to develop, describe, and evaluate interventions to implement SDM in pediatric clinical practice. Our findings can inform such SDM training and implementation efforts at our hospital, in pediatrics, and at other centers.

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CHAPTER 5

INTEGRATED DISCUSSION

5 INTEGRATED DISCUSSION

This purpose of this chapter is to integrate and discuss the findings from the three dissertation studies and place them within the broader literature. First, I will briefly summarize each manuscript. Then, I will discuss three main points: power and capacity building, implementing SDM in pediatric clinical practice, and implications of my findings for population health, research and policy.

5.1 Summary of Studies

My dissertation studies evaluated factors that influence SDM in pediatric clinical practice. The first study, guided by the Ottawa Model of Research Use (OMRU), was a mixed methods systematic review of 80 studies that synthesized the barriers and facilitators of pediatric SDM from the perspectives of healthcare providers (HCP), parents, children, and observers. At each OMRU level, frequent barriers were: features of the options (decision); poor quality and/or insufficiently tailored information (innovation); parent/child emotional state, health status, the child's age, and lack of SDM knowledge (adopter); power relations (relational); and, insufficient time for SDM (practice environment). The most frequent facilitators were: lower stake decisions (decision), high quality information (innovation), agreement with SDM (adopter), trust and respect in the relationship (relational), and SDM tools/resources (environment). Across participant types, frequent barriers were: insufficient time (HCPs), feature of the options (parents), power imbalances (child), and HCP skill for SDM (observer). Frequently cited facilitators were: good quality information (HCPs) and agreement with SDM (parents and children). These influential factors can inform the development of interventions to overcome barriers and leverage facilitators in pediatrics.

Given that SDM knowledge was an important barrier among adopters, the second study was a post-test evaluation the Ottawa Decision Support Tutorial (ODST), a SDM educational program. Learners from different disciplinary backgrounds completed a knowledge test (n=6604) and/or acceptability survey (n=4276). The median knowledge test score was 8 out of 10 (IQR = 7-9). Acceptability was high, with 90% reporting a good or excellent overall impression. Few learners suggested improvements, which included improving ODST readability, presentation, and multimedia material. The ODST is a highly acceptable intervention that can be used to educate HCPs, trainees, and members of the public about SDM.

As part of a hospital-wide initiative to implement SDM in pediatric services at the Children's Hospital of Eastern Ontario (CHEO), participating HCPs completed the ODST and a skill building workshop. The third study used a mixed method approach using a survey (n=60, 88% response rate) and interviews (n=11) to evaluate HCPs' intention to use SDM, self-reported SDM use, and perceived SDM barriers and facilitators in pediatric clinical practice, after having completed the training. Intention to use SDM was high and positively correlated with SDM use among 39% of HCPs. However, more than half of all survey respondents reported not using SDM after training. HCPs identified insufficient time for SDM as a barrier. Facilitators included buy-in and agreement with SDM. To improve SDM use, HCPs want a more team-based approach to SDM training and continuing education.

Collectively, my dissertation findings suggested that many diverse factors influence SDM use in pediatric clinical practice, before and after HCPs have been trained. Although ODST learners demonstrated knowledge of SDM, the ODST combined with a skill building workshop was insufficient to change HCP self-reported SDM behavior in clinical practice. The findings from this dissertation leads to three broader discussion points.

5.2 Power and Capacity

Addressing inequitable distribution of power, or one's ability to exert influence, is a key strategy for improving the health of populations [1, 2]. In clinical consultations, HCPs typically exert power over patients by holding expert knowledge and patients are reliant on HCPs to deliver the required care and services [3, 4]. Findings of reviews show that pediatric patients experience power imbalances through systematic exclusion and marginalization from healthcare decisions [5, 6]. The results of Study 1 are consistent with these reviews, showing that some HCPs failed to provide all available options or used 'participatory decision making' to achieve compliance for the HCP's preferred option. In fact, HCPs report wanting to 'protect' children from decision making; albeit infringing on children's rights and potentially limiting their opportunity to derive the best possible health outcomes [5].

The SDM process has potential to mediate power differentials between HCPs and children, as it is meant to empower children with a voice in decision making and provide a supportive structure for meaningful participation [7]. A systematic review showed that SDM interventions empowered vulnerable adult patient populations by improving their participation in decision making, decision self-efficacy, preference for collaborative decision making, and reducing decisional conflict [8]. Therefore, children are likely to derive similar benefit from SDM interventions. Unfortunately, few interventions have been developed to help redress power imbalances and improve children's participation in decision making [9, 10]. Interventions need to empower children by enhancing their individual capacity for SDM [11].

Building individual capacity is key strategy for improving the health of populations [12]. Capacity building involves the development of conditions in which individuals can enhance and retain their knowledge and skills to fulfill a role [1, 13]. Supporting patients in SDM builds individual capacity for making high quality decisions by: making the decision explicit; gaining knowledge about the options, and the harms and benefit of those options; clarifying values in relation to the harms and benefits of each option; communicating preferences to others; and deliberating with others about the best treatment plan [14]. Pediatric HCPs indicated that children need capacity building interventions to promote SDM use in pediatrics (Study 3).

A systematic review published in 2014 identified only one educational program to improve children's health decision making involvement and capacity [9]. In this controlled before and after study, cancer survivors between the ages of 13 and 21 attended a 5-hour workshop with weekly assignments [15]. The intervention improved youth decision making skills at 1 month, 6 months, and 12 months post-training. However, in the absence of other proven interventions for building SDM capacity in children, it can be possible to tailor effective interventions designed for adults to the pediatric context. One such intervention, included decision coaching using a patient decision aid (PtDA) tailored for children and families deciding about insulin delivery [16]. Importantly, children were invited to express their values and preferences about the treatment options first, which was a key element of mitigating power imbalances. The pilot study demonstrated it was feasible to tailor and administer an evidence-based SDM intervention and collect data from children as young as 9 years old [16]. The subsequent unpublished study showed that in using this intervention, children felt more informed, supported, clear about their values and preferences, and certain about their choice [17].

The AskShareKnow intervention also has potential to build SDM knowledge and skills among children and parents. This evidence-based intervention encourages patients to ask three questions during their clinical consultation: (A) what are my options? (B) what are the benefits and harms? and, (C) how likely are these to happen to me? [18, 19]. HCPs responding to standardized patients who asked the three questions provided higher quality information and demonstrated more behavior supporting patient involvement [19]. However, lower literacy adults (n=26) had difficulty understanding the question stems [20]. With a 45 minute training video, lower literacy adults were more likely to recall and use the three questions in subsequent clinical consultations [21]. With training, children could ask similar appropriately tailored questions, potentially enhancing their capacity to ask HCPs questions, acquire high quality information, and feel empowered to participate in health decisions. The Cardiff Hospital's pediatric tonsillectomy team implemented SDM using the AskShareKnow questions and an option grid (i.e., type of patient decision guide) for families considering tonsillectomy or watchful waiting [22]. The clinic displayed AskShareKnow materials (e.g., posters and cards) inviting families to ask the 3 questions (and essentially participate in SDM). Nurses coached families through the option grids in the pre-consultation phase. Although not empirically evaluated, HCPs reported providing a more patient-centered approach during the consultation, resulting in more collaborative and informed decision making. Given the promise of pediatric SDM, more research is needed to develop and evaluate capacity building interventions targeting children (and parents) [23, 24].

Building HCPs' and trainees' SDM capacity is also essential for promoting SDM in pediatric clinical practice (Study 3). HCPs commonly lack SDM knowledge in pediatrics (Study 1) as well as adult clinical practice [25]. Provision of education and training can help close this knowledge gap [26]. An environmental scan identified 148 SDM training programs targeting HCPs [24]. Half targeted licensed HCPs and a quarter were designed for both licensed HCPs and trainees. One such program is the ODST, an online SDM training program that improves learners' SDM knowledge (Study 2). Previous studies have demonstrated that HCPs and trainees exposed to the ODST and skill building workshops have statistically significantly improved

SDM knowledge and skills compared to controls [27, 28]. Still, SDM knowledge and skills did not translated to behavior change (Study 3). Pediatric HCPs reported needing continuing SDM education with their interprofessional team to use SDM use in their clinical practice (Study 3). The effectiveness of SDM boosters is poorly understood. In one study, a SDM training program was delivered to physicians in two phases over the span of a month [29]. The first phase focused on SDM knowledge, attitudes and skills using didactic methods (like that used by combining the ODST and skill building workshop). The second phase focused on skill consolidation after physicians have had the opportunity to use their SDM knowledge and skills in clinical practice. However, the impact of this training on SDM use in clinical practice was not evaluated. More research is needed to determine the impact of these capacity building efforts on actual SDM use in clinical practice.

A missing component of programs targeting HCPs, however, is building HCPs' capacity to more equitably redistribute decision making power to the child and parent. Study 1 found that power imbalances were a major barrier to engaging in SDM in the first place. HCPs have difficulty giving up decision making power (Studies 1) even after training (Study 3). At CHEO, the skill building workshop indirectly addressed power relations through decision coaching and PtDA training. Although HCPs reported feeling more confident about their SDM skills [30], they still did not use SDM in their clinical practice (Study 3). Based on findings of this dissertation, pre-existing power relations should be explicitly addressed in HCP capacity building efforts. Although training on how to use SDM clinical tools (e.g., PtDAs) is one good strategy, achieving routine SDM use will likely require supplementary implementation interventions that address pre-existing power differentials between patients and HCPs.

5.3 Implementing Pediatric SDM: A Systems Thinking Lens

Given the complex myriad of factors influencing SDM use in clinical practice (Studies 1 and 3), it is unsurprising that many efforts to implement SDM have been disappointing [31]. Although mapping prospectively assessed barriers to implementation strategies improves uptake of innovations [32], there is no ‘best’ implementation strategy nor is there clear evidence for how, and to what extent, barriers and facilitators should be mapped to interventions [33]. Previous implementation interventions have often been selected to address ‘cherry-picked’ barriers, without sufficient consideration of the context [34]. According to Kitson, implementation efforts that focus specific barriers, without considering their relationships with other factors, are likely to fail [35]. The OMRU, used in several studies to assess barriers and facilitators [36–38], provides a comprehensive approach to identifying multilevel barriers while considering the subsequent phases [39]. However, applying a population health perspective, such as systems thinking, could broaden the conceptualization SDM barriers and facilitators by explicitly considering the interconnectedness of the component parts and approaches to addressing them.

Systems thinking is a philosophy or epistemology that conceptualizes the adaptive, interdependent and interconnected nature of complex environments [40]. This transdisciplinary approach studies influencing factors to predict behavior and inform the development of intervention to produce desired effects within a system. According to Arnold and Wade [41], Systems Thinking includes eight key features: (1) interconnections between system components; (2) feedback loops that positively and negatively impact behavior; (3) a system structure and that affects behavior and visa versa; (4) resources or stocks, change in resources (i.e., flows), and variables or changeable system parts that affect the system; (5) non-linear relationships; (6)

dynamic behavior, including interconnected factors, how they combine into feedback loops and alter resources and result in emergent behavior (intended and unintended); (7) ability to reduce complexity by modelling aspects of the system; and (8) ability to examine various scales of the systems and its systems. Systems thinking also incorporates ecological system concepts, including consideration of the micro, meso, and macro system levels [42]. This is consistent with the interprofessional model of SDM [43] (Appendix A) and a systematic review showing that SDM barriers and facilitators can be identified at the micro, meso, and macro levels [34].

Conceptualizing the pediatric SDM barriers and facilitators identified in this dissertation as part of a system could provide a fresh lens for promoting SDM in pediatrics clinical practice. Systems thinking promotes the evaluation of relationships between system components. Future research can examine the nature of relationships between influential factors and employ concept-mapping studies to demonstrate their influence within a system [42]. This could allow researchers to model, predict, and evaluate multifaceted knowledge translation interventions to promote SDM in pediatric clinical practice.

5.4 Implications for Research, Policy, and Population Health

5.4.1 Research

Based on the contributions of this dissertation and the broader SDM literature, key research priorities include using evidence-based, theory-driven and integrated knowledge translation [44] approaches for developing pediatric SDM implementation interventions. Intervention development informed by barriers and facilitators is a recommended OMRU process, substantiated with research evidence showing that mapping prospectively assessed barriers to implementation strategies improves the uptake of innovations in clinical practice [32, 39]. Interventions should target multiple OMRU levels and be tailored to adopter types (Studies

1 and 3) (Table 5-1). Findings of a Cochrane review suggest that SDM interventions targeting to the interprofessional team as well as those targeting both patients and HCPs could be effective for improving the adoption of SDM in clinical practice [45]. Based on the findings of this dissertation, important research questions include:

(A) Compared to usual care, will pediatric HCPs exposed to a team-based SDM training program demonstrate more SDM behaviours with children and/or parents in clinical practice?

(B) Compared to usual care, will pediatric HCPs of children and parents who were exposed to SDM training and patient-mediated SDM interventions demonstrate more SDM behaviours with children and/or parents in clinical practice?

(C) Compared to usual care and independent use of these interventions, will the combined use of interventions (i.e., targeting HCPs and children/parents) have a greater impact on HCPs' SDM behaviours in pediatric clinical practice?

Table 5-1 Evidence and theory-based implementation interventions corresponding to pediatric SDM barriers and facilitators identified in this dissertation

OMRU levels								
Barriers	**Facilitators**	**Interventions to overcome barriers/ leverage facilitators to promote SDM in pediatric clinical practice**	**Evidence**	**Pediatric Health System level***			**Target**	
Across all OMRU levels				Micro	Meso	Macro	IP - team	Child/ parent
		Use integrated knowledge translation approaches Assess and re-assess local barriers and facilitators, considering relationships between factors Monitor and evaluate barriers and facilitators	[39, 42, 44]	√	√	√	√	√
Innovation								
	Provision of high quality information	Provide HCP training about knowledge translation to patients, SDM, risk communication, and decision support (e.g., ODST) Expose children and families to the AskShareKnow intervention Provide patient decision aids	(Study 2) [19, 46, 47]	√	√	√	√	√
Adopter								
Child's age and competence	Positive attitudes for SDM	Leverage positive attitudes to get SDM buy in and support from HCP, opinion leaders and senior administration Share patient experiences with SDM in audit and feedback approach to changing practice Incentives for HCPs to provide SDM Distinguish between SDM and other health decision making models, focusing on pediatrics, when training adopters	[46, 48–50]	√	√	√	√	√
Relational								
Power imbalances	Invite children/parents to participate in SDM	Organizational policy outlining an expectation of SDM Train HCPs in decision support Provide children/parents with clinical SDM tools Deliver decision support to ensure the child is first to express values and preferences Initiate an AskShareKnow poster campaign Use decision coaching to engage children and parents in a more balanced approach to participating in SDM	[16, 19, 20, 47, 50, 51]	√	√	√	√	√
Practice Environment								

Lack of Time Existing practice and cultural norms	Access to resources	Provide protected and paid time for the IP-team to complete SDM training Reframe the time barrier in HCP training Determine with the IP team where SDM fits into the clinical pathway and roles of the IP team members Make SDM tools and resources available Incorporate SDM into clinical practice guidelines Incorporate SDM into accreditation standards	Study 3 [46, 47, 50, 52, 53]	√	√	√	√	√
Training								
	Educate and train IP teams and children/families	HCPs complete the ODST and a 3 hour SDM skill building workshop with their IP team	Studies 2 and 3 [27, 29]	√	√	√	√	√
	Continuing education	Provide booster sessions						

* IP = interprofessional; Org = Organization; SDM = shared decision making. Of note, barriers and facilitators are listed according to the OMRU levels; however, the strategies to address them may or may not be at another level.

Consistent with the OMRU, implementation interventions should be monitored (e.g., attendance to education and training or distribution of PtDAs) and evaluated for their impact on decision making and use in clinical practice [39]. Evaluation outcomes could include HCP SDM behaviour, HCP reported outcomes (e.g., satisfaction and perceived consultation efficiency), patient and parent reported outcomes (e.g., satisfaction, perceived SDM, decisional conflict, and value-choice agreement), and system level outcomes (e.g., consultation length, costs, health services use).

5.4.2 Policy

SDM has garnered significant attention among health policy makers and researchers [54, 56]; however, its reach is only just extending to pediatrics. A barrier identified in Study 1, is that HCPs and parents were unaware or unclear about policies related to SDM. A recent Canadian Pediatric Society position statement (April 2018) about medical decision making in pediatrics focused on assessing children's capacity for autonomous decision-making [56]. SDM was acknowledged as an approach to deliver patient and family centered care, seemingly if chosen by the HCP. Among the list of recommendations included, "HCPs, patients, and families should work together to reach medical decisions based on the patient's best interest or outcomes" [56]. This position paper is ambiguous regarding the recommended decision making approach to use with children. At the hospital level, an unpublished environmental scan found that 11 of 13 Canadian academic pediatric acute care hospitals' had patient and family centered care statements that articulated the benefit of partnership between children, families, and the interprofessional healthcare teams [63]. Few statements were explicit about using SDM, though most outlines some SDM concepts. This suggests that Canadian regulatory and hospital policies need to improve their messaging about pediatric SDM and dissemination across adopters.

Decision makers should consider the context influencing SDM use in pediatric clinical practice to reduce barriers and leverage facilitators. Pediatric hospitals need to clearly communicate the hospital's direction for SDM, and make this messaging accessible to HCPs, children, and parents. Organizational policies should be designed with the goal of creating supportive environments for HCPs, as well as children and parents, to engage in SDM (Studies 1 and 3). Supportive environments could prioritize patient and family centered care, partnerships with families, team-based care, decision support, decrease pressure for minimum consultation lengths, and incorporate SDM into their clinical practice guidelines and accreditation standards [52, 53, 58]. Pediatric organizations also need to allocate adequate funding, education, and resources to achieve routine SDM use. In doing this, organizations and hospitals can better facilitate the uptake of SDM in pediatric clinical practice.

5.4.3 Population Health

Population health research aims to: improve the health of individuals by reducing inequities in health status between and within populations, study and understand the interrelated and underlying factors that influence health, and develop and evaluate upstream multifaceted interventions that inform evidence-based decision making [12, 59, 60]. My dissertation addresses these population health elements in several ways. First, my studies identified multilevel factors, including the inequitable distribution of power (Study 1), influencing children's access to an evidence-based health intervention (i.e., SDM). Identification of the underlying factors can be used to improve children's access to SDM through the development of knowledge translation interventions. Second, my dissertation affirmed the need to further investigate the relationships between barriers and facilitators influencing pediatric SDM. For example, parents and children described the relationship between receiving an invitation to participate in SDM with high quality information and empowerment (Study 1). ODST learners implied that their motivation for completing the tutorial influenced their satisfaction with the SDM training program (Study 2). HCPs reported positive attitudes about SDM (e.g., it is the right thing to do), but struggled to give up enough control to facilitate SDM (Study 3). Third, my studies promote the use of an upstream evidenced-based intervention with potential to empower and build capacity in a vulnerable population (Study 2) [8]. Dissertation findings can be used to inform evidence-based decision making about strategies to improve the use of SDM in pediatric clinical practice. These contributions to the field of pediatric SDM and population health will help to protect the individual rights of children while promoting the health of pediatric patients by placing them at the center of their care.

5.5 Conclusions

Findings of my dissertation revealed numerous and complex barriers and facilitators influencing adopters' ability to use SDM in pediatric clinical practice. Deep rooted and unresolved power imbalances, which are related to other influencing factors, likely contribute to failed SDM implementation attempts. Carefully planned capacity building efforts, that target the HCP, child, and parent, across the OMRU levels (or system) have potential to improve SDM use in pediatrics. However, capacity building cannot focus on knowledge and skill alone. SDM training can only address a limited number of barriers at the HCP level. Other known barriers and facilitators need to be addressed to improve implementation of SDM in pediatric clinical practice. Such strategies could focus on interprofessional team-based approaches to SDM training, patient and family SDM capacity building, patient targeted interventions that are also known to mediate HCP behaviours (e.g., AskShareKnow, PtDAs, and decision coaching), and policies that support SDM. More research is needed to evaluate such interventions in pediatric clinical practice. These SDM efforts could improve the health of Canadian children by supporting and empowering them to exercise their right to self-determination and build their individual capacity for making high quality decisions that are consistent with their informed values and preferences.

5.6 References

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CHAPTER 6

CONTRIBUTIONS OF COLLABORATORS

6 CONTRIBUTION OF COLLABORATORS

This chapter describes collaborators' contributions and involvement as members of the research team, co-authors of manuscripts, and individuals who contributed to the research process. Authorship decisions were made in accordance with recommendations made by the International Committee of Medical Journal Editors [1].

6.1 Research Team Collaborators

Laura Boland (LB), MSc, SLP-C, PhD(c) conceptualized, led, and participated in all research activities associated with the studies outlined in this dissertation, in partial fulfillment of the requirements of the degree of Doctorate in Philosophy at the University of Ottawa. Collaborators were selected based on their research expertise, potential to use the research findings (i.e., knowledge users), and to enhance the new knowledge resulting from the dissertation with a transdisciplinary perspective. Transdisciplinary thinking incorporates knowledge and perspectives from several disciplines to enhance understanding of complex issues [2].

LB is a Speech-Language Pathologist with expertise in population health, shared decision making (SDM) and related interventions, knowledge translation, and education to healthcare providers (HCPs). In addition to being a doctoral candidate, LB worked as a research assistant at the Ottawa Hospital Research Institute and was a Highly Qualified Personnel working on a grant funded by the Canadian Frailty Network. LB received two Queen Elizabeth II Graduate Scholarship in Sciences and Technology, two Scholarships of Excellence from the University of Ottawa, and a Doctoral Fellowship from the Canadian Institutes of Health Research funded Integrated Knowledge Translation Research Network (CIHR FDN #143237).

6.1.1 Members of the Thesis Committee

Thesis committee members included Professors Dawn Stacey (DS), RN, PhD, Ian D. Graham (IDG), PhD, FCAHS, FNYAM, FRCS, France Légaré (FL), MD, PhD, and Margaret Lawson (ML), MD, MSc, FRCP. Each thesis committee member collaborated in study conceptualization, proposal development, analysis and interpretation of the data, and contributed to the intellectual content of the manuscripts (Table 6-1). All thesis committee members provided consultation throughout the research process.

DS, a registered nurse, was the primary supervisor for this doctoral dissertation. DS holds a Research Chair in Knowledge Translation to Patients, is a Full Professor in the School of Nursing at the University of Ottawa, and a Senior Scientist at the Ottawa Hospital Research Institute. She has expertise is knowledge translation to patients, decision support interventions, interprofessional SDM, oncology nursing, patient centered care, and implementation science.

IDG, a medical sociologist, is a Full Professor at the Department of Epidemiology and Public Health, Senior Scientist at the Ottawa Hospital Research Institute, and Royal Society of Canada Fellow (2017). IDG developed the Ottawa Model of Research Use (OMRU), has research expertise in integrated knowledge translation, evidence-based practice, clinical practice guidelines, and quality appraisal.

FL, a family physician, holds a Tier 1 Canadian Research Chair in SDM and Knowledge Translation, is a Full Professor in the Department of Family Medicine and Emergency Medicine at Laval University, and is the Director of Health and Social Services Systems Knowledge Translation and Implementation Core for the Strategy for Patient Oriented Research in Quebec. FL's research expertise includes SDM, knowledge synthesis and translation, decision support, evidence-based medicine, patient centered care, and dyadic approaches.

ML, a pediatric endocrinologist, is a Full Professor in the Department of Pediatrics at the University of Ottawa, Senior Scientist at the Children's Hospital of Eastern Ontario's (CHEO) Research Institute, and Director of the former CHEO Family Decision Services research program promoting SDM. ML's expertise is in pediatric SDM, type 1 diabetes in children, and interventions for transgender and gender non-binary youth. ML also participated as a knowledge user throughout the dissertation research.

6.1.2 Knowledge Users

My dissertation studies followed an integrated knowledge translation approach by partnering meaningfully with two knowledge users in all phases of the research process [3].
As Director of Family Decision Services, ML was rolling out education and training programs to promote hospital-wide use of SDM at CHEO. This dissertation research was developed in part to inform ongoing efforts to implement SDM at CHEO. Allyson Shephard (AS), RN, was the research associate and coordinator for CHEO's Family Decision Services program while this dissertation research was being conducted. AS's expertise is in pediatric nursing, patient and family centered care, and pediatric SDM. Knowledge users participated in research team meetings, providing feedback about research processes and deliverables, helped to recruit participants and collect data, contributed to interpretation of the findings and dissemination.

6.2 Other Collaborators and Acknowledgements

This section acknowledges other co-authors, research staff, and students who collaborated and contributed to the studies outlined in this dissertation.

6.2.1 Study 1

Krystina Lewis (KL), RN, PhD and Janet Jull (JJ), OT, PhD contributed to this systematic review by screening titles, abstracts, and full texts. Alexandra Davis (AD), BA, MLIS, was the information technologist who designed and ran the search strategy. Audrey Yameogo (AY), MA, Intessar Souli (IS), PhD, and Sophia Siedlikowski (SS), BSc, contributed to the data extraction and appraisal of included studies. Anton Saarimaki, MCS, was the data programmer who designed and administered the title and abstract screening web application. KL, JJ, and AM reviewed and approved the final manuscript.

6.2.2 Study 2

Meg Carley (MC), BSc, is a clinical research coordinator at The Ottawa Hospital and assisted with data management and interpretation. Annette M O'Connor (AMO) PhD FCAHS FRSC, a registered nurse and retired professor, led the development of the original Ottawa Decision Support Tutorial. AMO provided a historical context of the Ottawa Decision Support Tutorial and facilitated with data interpretation. Daniel McIsaac (DM), MD, MPH, FRCPC, provided statistical support. MC and AMO reviewed and approved the final manuscript.

6.2.3 Study 3

Kristin Dorrance (KD), MSc, is a research assistant at the Ottawa Hospital Research Institute and shared her expertise in using Nvivo software and analyzing qualitative data. She was the second coder in this study and assisted in interpreting the results. AS helped to coordinate the launch and distribution of the surveys. Elaine Parker conducted the transcription of all interview data. Yeal Kamil provided support in using the RedCap software program, which served was the platform for the online survey and database. KD and AS reviewed and approved the final manuscript. Finally, I am very appreciative to the healthcare providers who completed the survey and/or participated in the interview process.

Table 6-1 Summary of co-author contributions

	Chapter 1 Introduction	**Chapter 2 (Study 1)**	**Chapter 3 (Study 2)**	**Chapter 4 (Study 3)**	**Chapter 5 Integrated discussion**
Study conceptualization and design	LB	LB DS IDG FL ML	LB DS FL MC	LB DS IDG FL ML	LB
Data collection	LB	LB KL JJ AS AY SI SS	LB DS MC	LB AS ML	LB
Data analysis and interpretation	LB	LB AY DS IDG FL	LB DS MC AMO IDG FL ML	LB KD DS IDG ML FL	LB
Draft manuscripts/chapters	LB	LB	LB	LB	LB
Approval of final manuscript to be published	LB DS IDG FL ML	LB DS IDG FL ML KL JJ AS AY AD	LB DS IDG FL ML AMO MC	LB DS IDG FL ML KD	LB DS IDG FL ML

6.3 References

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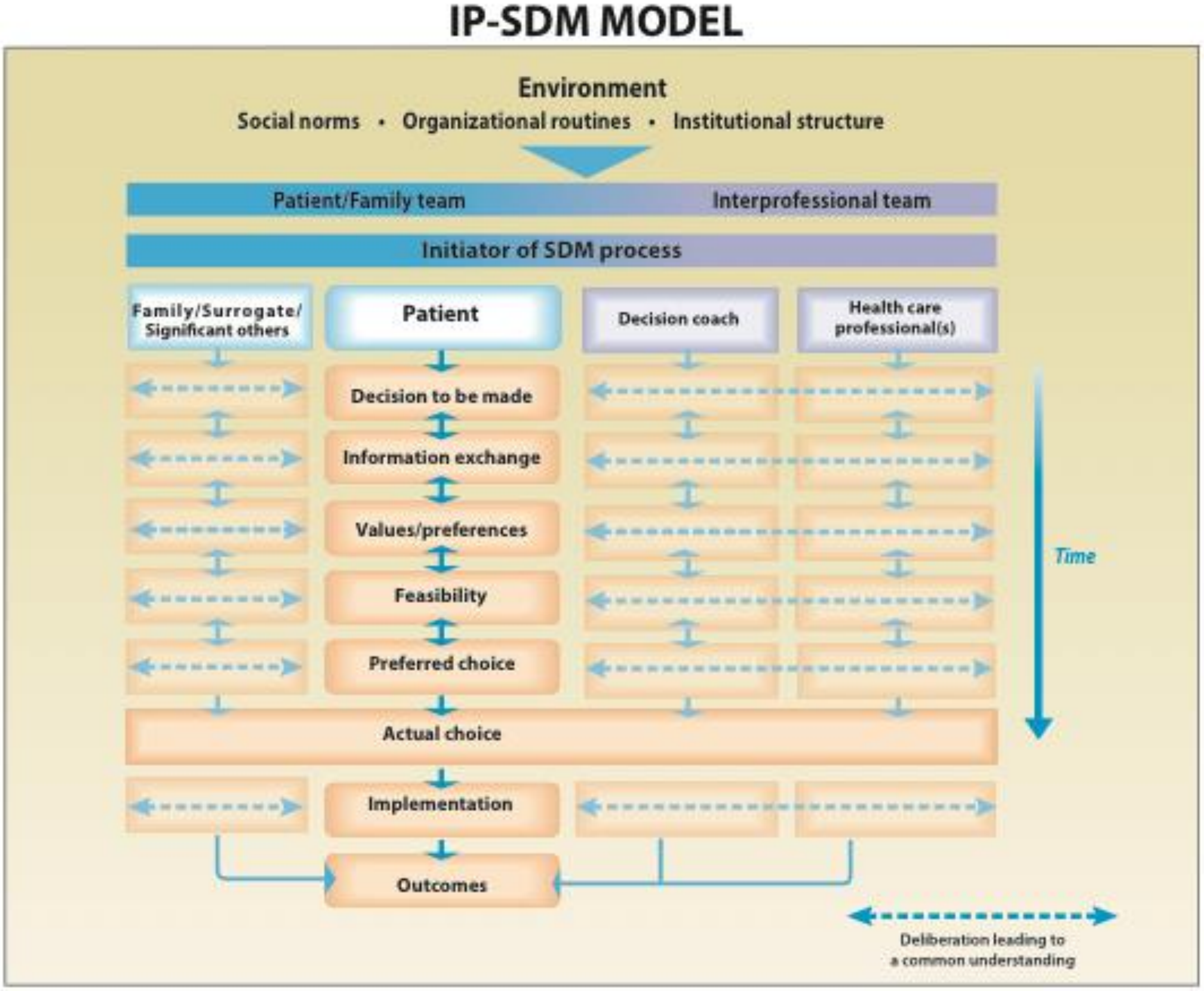
CHAPTER 7

APPENDICES

Appendix A- Interprofessional Shared Decision Making Framework (micro level)
(Légaré, Stacey, & the IP-SDM team, 2010)



© Légaré F, Stacey D, and IP Team, 2010. Available from www.ohri.ca/decisonaid.

At the micro level, interprofessional SDM is a process by which patients, family members, and the healthcare team work through a series of steps to arrive at an informed and high quality decision.

The meso level implicates healthcare team members within an organization in the interprofessional SDM process (e.g., initiating IP-SDM or providing decision coaching).

The macro level highlights the role of health policies and social context, and that interprofessional SDM is not independent of healthcare system.

Appendix B – PRISMA Checklist for systematic review (Study 1)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	4
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5-6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3 and 6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplement 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	8
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	8
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	8

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I2) for each meta-analysis.	8-9

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	10
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	10, figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10, table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	10-11, table 3
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	11-15, Appendix A, table 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	15-16, Table 4, figure 3
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	10-11
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA

DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	16
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	19-20
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	20
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	21

Page numbers correspond to the submitted manuscript.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Page 2 of 2

Appendix C – PROSPERO protocol for systematic review (Study 1)

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

Barriers and facilitators of shared decision making in pediatric clinical practice: a systematic review

Laura Boland, Krystina Lewis, Janet Jull, Allyson Shepard, Anton Saarimaki, Margaret Lawson, France Legare, Ian Graham, Dawn Stacey

Citation

Laura Boland, Krystina Lewis, Janet Jull, Allyson Shepard, Anton Saarimaki, Margaret Lawson, France Legare, Ian Graham, Dawn Stacey. Barriers and facilitators of shared decision making in pediatric clinical practice: a systematic review. PROSPERO 2015 CRD42015020527 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42015020527

Review question

The purpose of this study is to synthesize barriers and facilitators that influence shared decision making implementation in pediatric clinical practice

What are healthcare professionals, parents, and children's perceived barriers and facilitators to pediatric shared decision making implementation?

In the international literature, what are the real or objective barriers and facilitators of pediatric shared decision making implementation?

Searches

An information specialist designed the search strategy and conducted electronic searches specific to each database. The following electronic databases were searched without date limitations: MEDLINE, EMBASE, Cochrane Library, CINAHL, PubMed (not OVID Medline), and PsycINFO.

Types of study to be included

Inclusion: Randomized controlled trial; non-randomized controlled trial; interrupted time series; controlled before and after; and, qualitative, observational, descriptive, and cohort studies.Exclusion: Editorials, commentaries, opinion articles, reviews

Condition or domain being studied

Shared decision making (SDM) is an evidenced-based collaborative health decision making approach between health professionals and patients. Information exchange in SDM involves the health condition, evidence on treatment options including risks and benefits, and patients' personal preferences and values, to determine the best treatment plan. In this review, SDM was defined broadly as a joint approach between one or multiple healthcare team members and parents and/or children for making health decisions, or active participation of the parent, and child/youth patient child in health decision making.

Participants/population

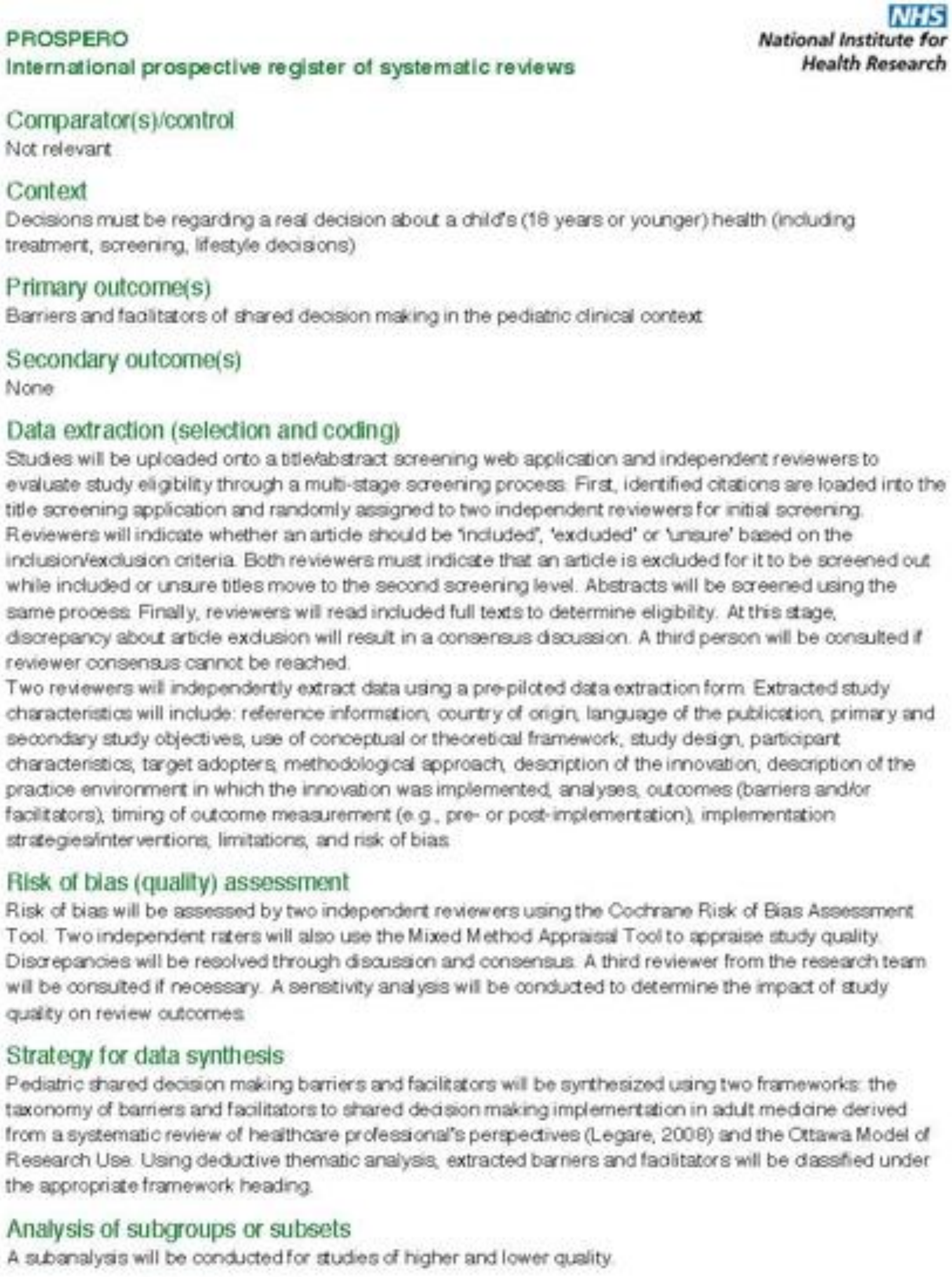
Included participants: healthcare professionals, including frontline staff of any discipline, clinical managers, and administrators; parents, guardians, or surrogate decision makers (any adult who is responsible for providing consent for the child); and, children 18 years of age or younger.

Excluded participants: Adult patients (19 years and older) making a decision about their own health.

Intervention(s), exposure(s)

Inclusion: Shared decision making or an approach consistent with shared decision making about a real health decision, defined broadly as a joint approach between one or multiple healthcare team members and parents and/or children for making health decisions, or active participation of the patient and/or child in health decision makings; studies examining informed consent/assent.

Exclusion: Non-shared decision making interventions; hypothetical decisions; health decisions in a non-clinical setting; decisions about perinatal care (before birth) and participation in health research.



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

Comparator(s)/control

Not relevant

Context

Decisions must be regarding a real decision about a child's (18 years or younger) health (including treatment, screening, lifestyle decisions)

Primary outcome(s)

Barriers and facilitators of shared decision making in the pediatric clinical context

Secondary outcome(s)

None

Data extraction (selection and coding)

Studies will be uploaded onto a title/abstract screening web application and independent reviewers to evaluate study eligibility through a multi-stage screening process. First, identified citations are loaded into the title screening application and randomly assigned to two independent reviewers for initial screening. Reviewers will indicate whether an article should be 'included', 'excluded' or 'unsure' based on the inclusion/exclusion criteria. Both reviewers must indicate that an article is excluded for it to be screened out while included or unsure titles move to the second screening level. Abstracts will be screened using the same process. Finally, reviewers will read included full texts to determine eligibility. At this stage, discrepancy about article exclusion will result in a consensus discussion. A third person will be consulted if reviewer consensus cannot be reached.

Two reviewers will independently extract data using a pre-piloted data extraction form. Extracted study characteristics will include: reference information, country of origin, language of the publication, primary and secondary study objectives, use of conceptual or theoretical framework, study design, participant characteristics, target adopters, methodological approach, description of the innovation, description of the practice environment in which the innovation was implemented, analyses, outcomes (barriers and/or facilitators), timing of outcome measurement (e.g., pre- or post-implementation), implementation strategies/interventions, limitations, and risk of bias.

Risk of bias (quality) assessment

Risk of bias will be assessed by two independent reviewers using the Cochrane Risk of Bias Assessment Tool. Two independent raters will also use the Mixed Method Appraisal Tool to appraise study quality. Discrepancies will be resolved through discussion and consensus. A third reviewer from the research team will be consulted if necessary. A sensitivity analysis will be conducted to determine the impact of study quality on review outcomes.

Strategy for data synthesis

Pediatric shared decision making barriers and facilitators will be synthesized using two frameworks: the taxonomy of barriers and facilitators to shared decision making implementation in adult medicine derived from a systematic review of healthcare professional's perspectives (Legare, 2008) and the Ottawa Model of Research Use. Using deductive thematic analysis, extracted barriers and facilitators will be classified under the appropriate framework heading.

Analysis of subgroups or subsets

A subanalysis will be conducted for studies of higher and lower quality.

https://www.uottawa.ca/en

Review team members and their organisational affiliations

Ms Laura Boland. University of Ottawa
Ms Krystina Lewis. University of Ottawa
Dr Janet Jull. University of Ottawa
Ms Allyson Shepard. Children's Hospital of Eastern Ontario
Mr Anton Saarimaki. Ottawa Hospital Research Institute
Dr Margaret Lawson. Children's Hospital of Eastern Ontario
Dr France Legare. Laval University
Dr Ian Graham. University of Ottawa
Dr Dawn Stacey. University of Ottawa

Collaborators

Dr Daniel McIsaac. The Ottawa Hospital

Anticipated or actual start date

01 May 2015

Anticipated completion date

31 May 2016

Funding sources/sponsors

None

Conflicts of interest

None known

Language

English

Country

Canada

Stage of review

Review_Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Decision Making; Humans; Patient Participation

Date of registration in PROSPERO

13 May 2015

Date of publication of this version

13 May 2015

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	**Started**	**Completed**
Preliminary searches	No	Yes
Piloting of the study selection process	No	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Versions

13 May 2015

Appendix D –Systematic review search strategy for CINAHL (Study 1)

#	Query	Results
S57	S52 AND S56	2,657
S56	S53 OR S54 OR S55	492,243
S55	TI ((infant* or infancy or newborn* or baby or babies or child or children or schoolchild* or "school age" or preschool* or toddler* or adoles* or teen* or boy* or girl* or minors or pediatric* or paediatric*or "nursery school" or kindergar* or "primary school" or "secondary school" or "elementary school" or "high school" or highschool)) OR AB ((infant* or infancy or newborn* or baby or babies or child or children or schoolchild* or school age*or preschool* or toddler* or adoles* or teen* or boy* or girl* or minors or pediatric* or paediatric*or "nursery school" or kindergar* or "primary school" or "secondary school" or "elementary school" or "high school" or highschool))	274,949
S54	(MH "Pediatrics+")	7,810
S53	(MH "Child+") OR (MH "Infant+") OR (MH "Minors (Legal)") OR (MH "Adolescence+")	429,793
S52	S6 OR S49 OR S50 OR S51	13,895
S51	S48 AND (S8 OR S9)	90
S50	S14 AND S39	7,924
S49	S14 AND S31	4,549
S48	S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47	66,091
S47	TI clinician* N4 attitude* OR AB clinician* N4 attitude* OR TI clinician* N4 knowledge OR AB clinician* N4 knowledge OR TI clinician* N4 perspective* OR AB clinician* N4 perspective* OR TI clinician* N4 perception* OR AB clinician* N4 perception*	1,236
S46	TI professional* N4 attitude* OR AB professional* N4 attitude* OR TI professional* N4 knowledge OR AB professional* N4 knowledge OR TI professional* N4 perspective* OR AB professional* N4 perspective* OR TI professional* N4 perception* OR AB professional* N4 perception*	5,850
S45	TI nurse* N4 attitude* OR AB nurse* N4 attitude* OR TI nurse* N4 knowledge OR AB nurse* N4 knowledge OR TI nurse* N4 perspective* OR AB nurse* N4 perspective* OR TI nurse* N4 perception* OR AB nurse* N4 perception*	13,488
S44	TI resident* N4 attitude* OR AB resident* N4 attitude* OR TI resident* N4 knowledge OR AB resident* N4 knowledge OR TI resident* N4 perspective* OR AB resident* N4 perspective* OR TI resident* N4 perception* OR AB resident* N4 perception*	1,190
S43	TI doctor* N4 attitude* OR AB doctor* N4 attitude* OR TI doctor* N4 knowledge OR AB doctor* N4 knowledge OR TI doctor* N4 perspective* OR AB doctor* N4 perspective* OR TI doctor* N4 perception* OR AB doctor* N4 perception*	829

S42	TI physician* N4 attitude* OR AB physician* N4 attitude* OR TI physician* N4 knowledge OR AB physician* N4 knowledge OR TI physician* N4 perspective* OR AB physician* N4 perspective* OR TI physician* N4 perception* OR AB physician* N4 perception*	3,091
S41	TI provider* N4 attitude* OR AB provider* N4 attitude* OR TI provider* N4 knowledge OR AB provider* N4 knowledge OR TI provider* N4 perspective* OR AB provider* N4 perspective* OR TI provider* N4 perception* OR AB provider* N4 perception*	2,361
S40	(MH "Attitude of Health Personnel+")	49,045
S39	S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38	97,913
S38	TI caregiver* N2 clinician* OR AB caregiver* N2 clinician* OR TI caregiver* N2 provider* OR AB caregiver* N2 provider* OR TI caregiver* N2 physician* OR AB caregiver* N2 physician* OR TI caregiver* N2 doctor* OR AB caregiver* N2 doctor* OR TI caregiver* N2 nurse* OR AB caregiver* N2 nurse*	965
S37	TI families N2 clinician* OR AB families N2 clinician* OR TI families N2 provider* OR AB families N2 provider* OR TI families N2 physician* OR AB families N2 physician* OR TI families N2 doctor* OR AB families N2 doctor* OR TI families N2 nurse* OR AB families N2 nurse*	1,566
S36	TI family N2 clinician* OR AB family N2 clinician* OR TI family N2 provider* OR AB family N2 provider* OR TI family N2 physician* OR AB family N2 physician* OR TI family N2 doctor* OR AB family N2 doctor* OR TI family N2 nurse* OR AB family N2 nurse*	6,399
S35	TI parent* N2 clinician* OR AB parent* N2 clinician* OR TI parent* N2 provider* OR AB parent* N2 provider* OR TI parent* N2 physician* OR AB parent* N2 physician* OR TI parent* N2 doctor* OR AB parent* N2 doctor* OR TI parent* N2 nurse* OR AB parent* N2 nurse*	2,074
S34	TI child* N2 clinician* OR AB child* N2 clinician* OR TI child* N2 provider* OR AB child* N2 provider* OR TI child* N2 physician* OR AB child* N2 physician* OR TI child* N2 doctor* OR AB child* N2 doctor* OR TI child* N2 nurse* OR AB child* N2 nurse* OR TI child* N2 professional* OR AB child* N2 professional*	4,273
S33	TI patient* N2 clinician* OR AB patient* N2 clinician* OR TI patient* N2 provider* OR AB patient* N2 provider* OR TI patient* N2 physician* OR AB patient* N2 physician* OR TI patient* N2 doctor* OR AB patient* N2 doctor* OR TI patient* N2 nurse* OR AB patient* N2 nurse* OR TI patient* N2 professional* OR AB patient* N2 professional*	32,821
S32	(MH "Professional-Family Relations") OR (MH "Professional-Patient Relations") OR (MH "Nurse-Patient Relations") OR (MH "Physician-Patient Relations")	61,653
S31	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30	43,067
S30	TI (caregiver* and participat*) OR TI (caregiver* and involv*) OR TI (caregiver* and collaborat*) OR TI (caregiver* and partner*) OR TI (consumer* and participat*) OR TI (consumer* and involv*) OR TI (consumer* and collaborat*) OR TI (consumer* and partner*)	516

S29	TI (parent* and participat*) OR TI (parent* and involv*) OR TI (parent* and collaborat*) OR TI (parent* and partner*) OR TI (relative* and participat*) OR TI (relative* and involv*) OR TI (relative* and collaborat*) OR TI (relative* and partner*)	995
S28	TI (family and participat*) OR TI (family and involv*) OR TI (family and collaborat*) OR TI (family and partner*) OR TI (families and participat*) OR TI (families and involv*) OR TI (families and collaborat*) OR TI (families and partner*)	1,313
S27	TI (child* and participat*) OR TI (child* and involv*) OR TI (child* and collaborat*) OR TI (child* and partner*) OR TI (patient and participat*) OR TI (patient and involv*) OR TI (patient and collaborat*) OR TI (patient and partner*)	3,942
S26	TI consumer* N2 participat* OR AB consumer* N2 participat* OR TI consumer* N2 involv* OR AB consumer* N2 involv* OR TI consumer* N2 collaborat* OR AB consumer* N2 collaborat* OR TI consumer* N2 partner* OR AB consumer* N2 partner*	659
S25	TI caregiver* N2 participat* OR AB caregiver* N2 participat* OR TI caregiver* N2 involv* OR AB caregiver* N2 involv* OR TI caregiver* N2 collaborat* OR AB caregiver* N2 collaborat* OR TI caregiver* N2 partner* OR AB caregiver* N2 partner*	867
S24	TI relative* N2 participat* OR AB relative* N2 participat* OR TI relative* N2 involv* OR AB relative* N2 involv* OR TI relative* N2 collaborat* OR AB relative* N2 collaborat* OR TI relative* N2 partner* OR AB relative* N2 partner*	500
S23	TI parent* N2 participat* OR AB parent* N2 participat* OR TI parent* N2 involv* OR AB parent* N2 involv* OR TI parent* N2 collaborat* OR AB parent* N2 collaborat* OR TI parent* N2 partner* OR AB parent* N2 partner*	2,882
S22	TI families N2 participat* OR AB families N2 participat* OR TI families N2 involv* OR AB families N2 involv* OR TI families N2 collaborat* OR AB families N2 collaborat* OR TI families N2 partner* OR AB families N2 partner*	1,378
S21	TI family N2 participat* OR AB family N2 participat* OR TI family N2 involv* OR AB family N2 involv* OR TI family N2 collaborat* OR AB family N2 collaborat* OR TI family N2 partner* OR AB family N2 partner*	3,109
S20	TI child N2 participat* OR AB child N2 participat* OR TI child N2 involv* OR AB child N2 involv* OR TI child N2 collaborat* OR AB child N2 collaborat* OR TI child N2 partner* OR AB child N2 partner*	1,139
S19	TI patient N2 participat* OR AB patient N2 participat* OR TI patient N2 involv* OR AB patient N2 involv* OR TI patient N2 collaborat* OR AB patient N2 collaborat* OR TI patient N2 partner* OR AB patient N2 partner*	4,305
S18	(MH "Family Centered Care")	4,561
S17	TI patient centered OR AB patient centred OR TI family centered OR AB family centred	3,609
S16	(MH "Patient Centered Care")	13,856
S15	(MH "Consumer Participation")	10,250

S14	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	54,106
S13	TI decision* N1 make OR AB decision* N1 make OR TI decision* N1 making OR AB decision* N1 making	26,364
S12	TI decisionmaking OR AB decisionmaking	334
S11	TI decision support OR AB decision support	1,941
S10	(MH "Decision Support Systems, Clinical")	1,617
S9	TI decision aid* OR AB decision aid*	575
S8	(MH "Decision Support Techniques")	1,760
S7	(MH "Decision Making") OR (MH "Decision Making, Family") OR (MH "Decision Making, Patient")	32,279
S6	S1 OR S2 OR S3 OR S4 OR S5	4,578
S5	TI ((share* or sharing or informed or collaborative)) AND TI ((decision* or choice*))	1,181
S4	(collaborative N2 decid*) OR (collaborative N2 decision*) OR (collaborative N2 choice)	168
S3	(informed N2 decid*) OR (informed N2 decision*) OR (informed N2 choice*)	2,916
S2	(sharing N2 decid*) OR (sharing N2 decision*) OR (sharing N2 choice)	107
S1	(share* N2 decid*) OR (share* N2 decision*) OR (share* N2 choice)	1,420

Appendix E – Standardized data extraction form (Study 1)

Article citation:			
Trial registered/Protocol published:			
Country of origin:			
Language of publication:			
1. Study objectives			Comments
1.1 Primary:		page:	
1.2 Secondary:		page:	
1.3 Tertiary:		page:	
2. Conceptual/theoretical framework/model			
2.1 Did a conceptual or theoretical model/framework guide the study?	Specify:	page:	Comments
Yes			
No			
2.2 Definition of shared decision making approach provided:		page:	Comments
Specify:			
References included:			
3. Methodology			
3.1 Research approach:		page:	Comments

		Check all that apply		
	Experimental (randomized)			
	Quasi-experimental (non-randomized)			
	Observational			
	Descriptive			
	Quantitative			
	Qualitative			
	Mixed methods			
	Prospective			
	Retrospective			
	Multi-center (specify number):			
	Other (specify):			
3.2 Study design:		Check all that apply	page:	Comments
	Randomized controlled trial			
	Pretest			
	Pretest-posttest			
	Posttest			
	Time series			
	Cross sectional			
	Cohort			
	Case control			
	Other (specify):			

3.3 Participants:				page:	Comments
	Who was recruited?		Check all that apply		
		Parents			
		Mother			
		Father			
		Healthcare professional			
		Child			
		Other (specify):			
	Inclusion criteria:				
	Exclusion criteria:				
3.4 Enter available details about the decision (options, considerations, persons involved, etc.)			page:	Comments	
3.5 Describe the setting:			page:	Comments	
3.6 Was a SDM intervention used (e.g., SDM training, patient decision aids, decision cards, decision coaching, etc.)					
No					
Yes					

If yes, describe the intervention:

3.7 Was a barrier and facilitator measurement tool used?

page:

Comments

Yes

No

If yes, describe the tool:

Is this tool validated?

Yes

No

If yes, enter psychometric properties

3.8 Outcomes related to B&F:

3.9 Data collection procedure

page:

Comments

Interviews

Focus groups

Survey

Measurement tool/instrument

Other

When was the data collected?

page:

Comments

No intervention

Pre-intervention

Immediately post-intervention

Follow-up:

How often was data completed?

Single data collection (time 1)

Repeated measures (yes/no?)

page: Comments

3.11 Analysis

Specify:

Qualitative

Quantitative
Mixed
Other

4. Results
4.1 Participant characteristics

page: Comments

Total # Included:

excluded and reasons:

Response rate (if applicable)

Other information (drop out, missing data, etc).

1)
Participant type:
Characteristics:

2)	Participant type: Characteristics:
3)	Participant type: Characteristics:

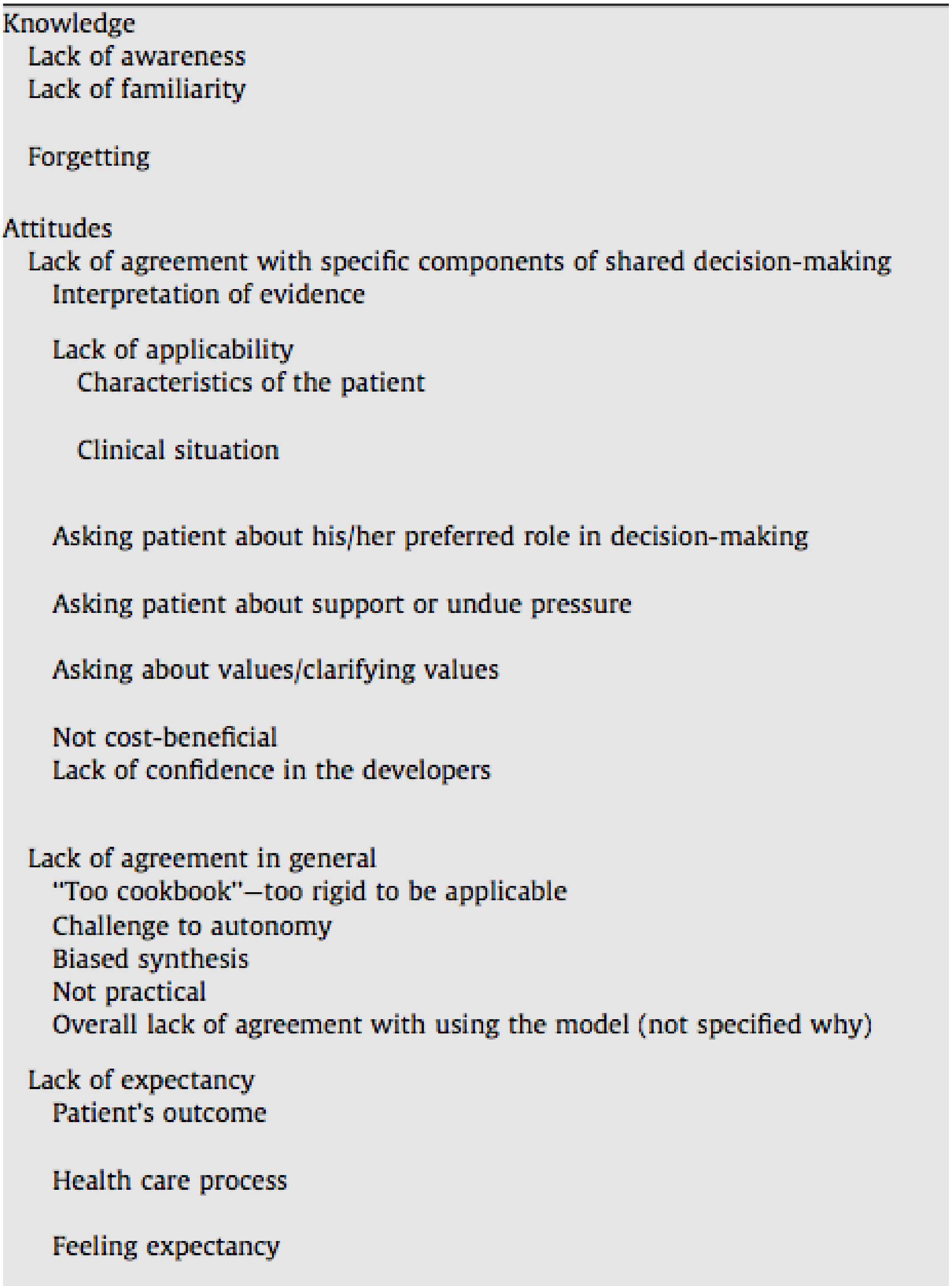
4.2 Characteristics of the child whose health was discussed:	page:	Comments

4.3 Indicate who perceived the B/F (e.g., parent, HCP, child) and what it was:

OMRU level	Items	Barrier	Facilitator	Perceived by who?	sample size	Comments	page
	Decision						
	Innovation						
	Adopters						
	Relational						
	Practice environment						
	Other (specify):						

5. Discussion	
	Summarize findings related to B&F:
	Conclusions (as related to B&F):
5.1 Limitations	
	Explicitly stated:
	Reviewer's judgement:
5.2 Strengths	
	Explicitly stated:
	Reviewer's judgement:
6. Miscellaneous	
	References related to B&F in pediatric SDM approaches?
	Additional comments?

Appendix F – Taxonomy of healthcare professionals perceived SDM barriers and facilitators (Légaré et al., 2008)



- Knowledge
  - Lack of awareness
  - Lack of familiarity

  - Forgetting

- Attitudes
  - Lack of agreement with specific components of shared decision-making
    - Interpretation of evidence

    - Lack of applicability
      - Characteristics of the patient

      - Clinical situation

    - Asking patient about his/her preferred role in decision-making

    - Asking patient about support or undue pressure

    - Asking about values/clarifying values

    - Not cost-beneficial
    - Lack of confidence in the developers

  - Lack of agreement in general
    - "Too cookbook"—too rigid to be applicable
    - Challenge to autonomy
    - Biased synthesis
    - Not practical
    - Overall lack of agreement with using the model (not specified why)

  - Lack of expectancy
    - Patient's outcome

    - Health care process

    - Feeling expectancy

- Behaviour
  - External barriers
    - Factors associated with patient
      - Preferences of patients

    - Factors associated with shared decision-making as an innovation
      - Lack of triability
      - Lack of compatibility
      - Complexity
      - Lack of observability
      - Not communicable

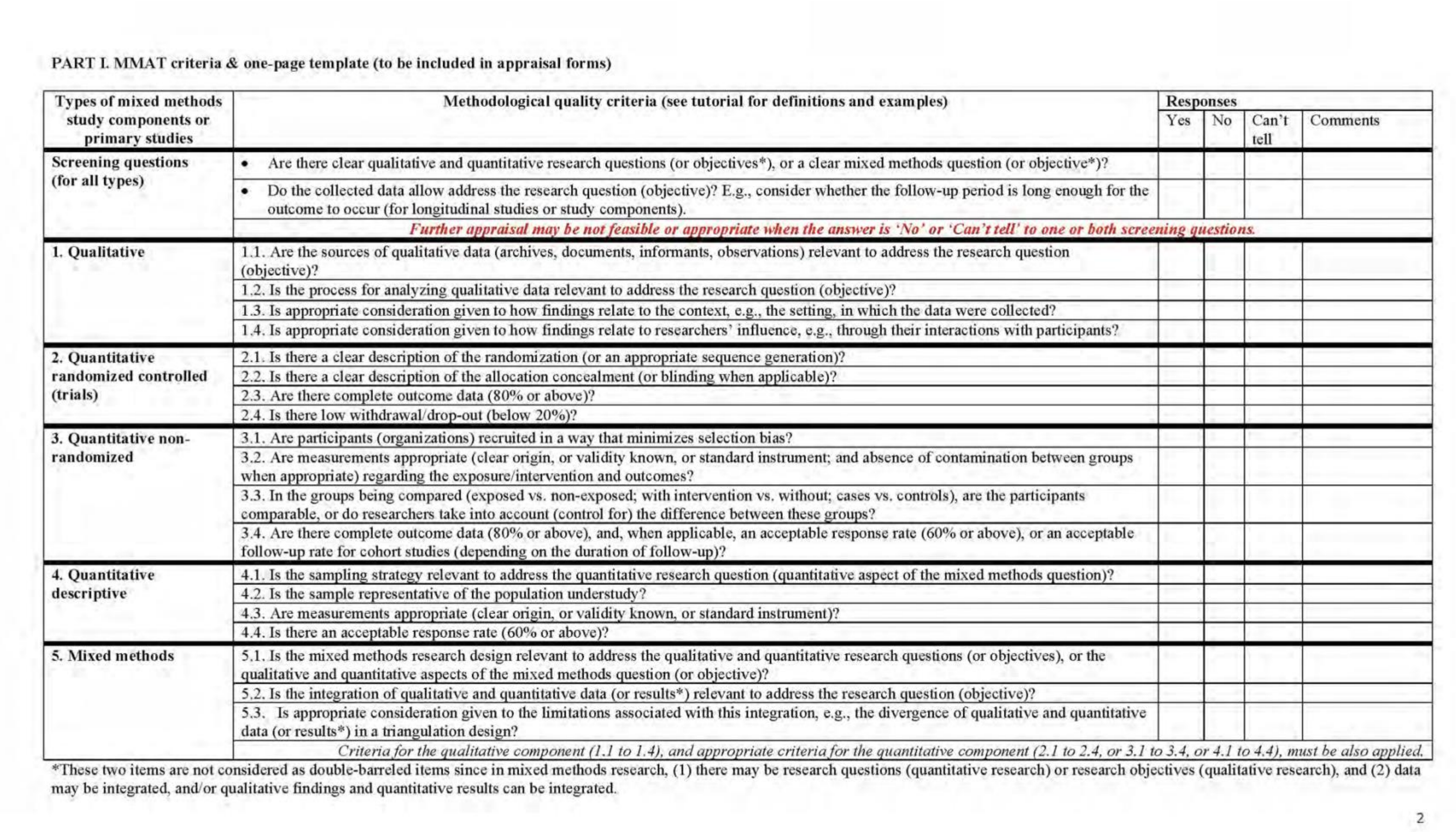
      - Increased uncertainty

      - Not modifiable/way of doing it

    - Factors associated with environmental factors
      - Time pressure
      - Lack of resources
      - Organizational constraints
      - Lack of access to services

      - Lack of reimbursement
      - Perceived increase in malpractice liability
      - Sharing responsibility with patient[a]

Appendix G - The Mixed Method Appraisal Tool (MMAT)
(available at: http://mixedmethodsappraisaltoolpublic.pbworks.com) (Pluye, 2009) (Study 1)



PART I. MMAT criteria & one-page template (to be included in appraisal forms)

Types of mixed methods study components or primary studies	**Methodological quality criteria (see tutorial for definitions and examples)**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	- Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	- Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

Appendix H - University of Ottawa Research Ethics Board application and approval (Study 2)

Secondary use of data is defined as “the use in research of information or human biological materials originally collected for a purpose other than the current research purpose”. The use of these data requires ethics approval, unless the following TCPS 2 articles apply.

Article 2.2 Research that relies exclusively on publicly available information does not require REB review when:
the information is legally accessible to the public and appropriately protected by law; or
the information is publicly accessible and there is no reasonable expectation of privacy.

Article 2.4 REB review is not required for research that relies exclusively on secondary use of anonymous information*, or anonymous human biological materials, so long as the process of data linkage or recording or dissemination of results does not generate identifiable information.

* Information is considered anonymous if it never had identifiers associated with it (e.g., anonymous surveys) and risk of identification of individuals is low. This is different from anonymized information, which is irrevocably stripped of direct identifiers (i.e. no code is kept to allow re-identification) (see TCPS 2, Chapter 5).

Only one copy of this application form and the attachments should be submitted to the Office of Research Ethics and Integrity.

N.B.: All boxes below can expand to accommodate your text.

Principal Investigator Information	
Name:Laura Boland	
Faculty: Health Sciences	E-mail:
Department/School:Population Health	Phone:
Research Team Information	
Name:Dawn Stacey	
Role in the project: ☐ Co-principal investigator ☐ Research coordinator ☒ Supervisor ☐ Co-supervisor ☐ Co-investigator ☐ Collaborator ☐ Researcher assistant ☐ Other:	
Faculty: Health Sciences	E-mail:
Department/School:Nursing	Phone:
Name:Ian Graham	
Role in the project:	

uOttawa

APPLICATION FORM FOR
RESEARCH BASED ON SECONDARY USE OF DATA

☐ Co-principal investigator	☐ Research coordinator
☐ Supervisor	☐ Co-supervisor
☐ Co-investigator	☒ Collaborator
☐ Researcher assistant	☐ Other:
Faculty: Medicine	E-mail:
Department/School: Epidemiology, Public Health and Community Medicine	Phone:

Project Information
Project title: Ottawa Decision Support Tutorial for enhancing understanding of shared decision making: a descriptive study
Is there a pending deadline by which ethics approval is required? ☐ Yes ☒ No If yes, deadline date: If yes, provide reasons for the deadline:
Please provide any additional information that may be relevant for the ethics review of this project. (e.g., relationship to another approved project, etc.).

Type of Project

☐ Professor’s research	☐ Master’s major research paper
☐ Postdoctoral research project	☐ 4th year project
☒ Doctoral thesis	☐ Independent student project
☐ Master’s thesis	☐ Other Specify:

Conflict of Interest Disclosure

Conflicts of interest can arise naturally from a researcher's engagement inside and outside the institution, and the mere existence of a conflict of interest does not necessarily imply wrongdoing on anyone's part. However, conflicts of interest must be recognized, disclosed, and assessed.

Does anyone on the research team have an actual or potential, apparent or perceived conflict of interest (financial, personal or other) in regards to this research project?

☐ Yes ☒ No

If you answered yes, please explain the nature of the conflict of interest and how it will be managed.

Funding Information

Did you receive funding for this project?
☐ Yes ☒ No ☐ Pending

If you answered “yes” or “pending”, indicate the source of funding:
University of Ottawa RE No., Cost Centre or Funding Agency Reference No.:

Project Description

- Describe the purpose and objectives of the current project. Include the research question(s).

Purpose: To evaluate the Ottawa Decision Support Tutorial (ODST). Our research questions are: (1) Do ODST users have improved knowledge after completing the tutorial? (2) Is the ODST an acceptable intervention for learning about shared decision making and decision support?

1.2 - Situate the current project in the scholarly literature and provide the rationale.

Patients should be involved in decisions about their health. Shared decision making (SDM) is an evidenced-based decision making process whereby healthcare providers (HCP), patients, and family members collaborate to make health decisions (Legare, 2011). Decision support strategies, such as patient decision aids, facilitate this process. Patient decision aids provide structured assistance for deliberating about the options and clarifying what is most important to the patient and family. A Cochrane review showed that patient decision aids improved participation in decision making, knowledge, accuracy of risk perceptions, decision quality, and decisional conflict (Stacey, 2017).

Despite high quality evidence underpinning SDM and decision support, many HCPs lack the requisite skills for engaging patients in SDM (Towle, 1999). Indeed, a systematic review showed that HCPs exhibited low levels of patient-involving behaviors in health decisions (Couet, 2013). A Cochrane review that evaluated interventions designed to improve the adoption of SDM suggests HCPs are more likely to share decisions after being exposed to educational interventions (Legare, 2014).

The Ottawa Decision Support Tutorial (ODST) is a theory-based online training designed to develop clinicians’ knowledge about SDM and decision support strategies (O'Connor, 2015). A randomized controlled trial found that nurses exposed to the ODST had improved SDM-related knowledge compared to controls (Stacey, 2006). Subsequent studies have also suggested that the ODST improves users’ knowledge scores when used with undergraduate nursing students (Stacey, 2009). However, the ODST has been used by a much broader range of individuals and there has been no evaluation of ODST outcomes in general including no evaluation since the ODST was updated in 2013 and 2015.

1.3 - Provide references. Include author, year, title, journal, and page numbers.

Légaré F, Stacey D, Gagnon S, Sunn S, Pluye P, Frosch D, Kryworuchko J, Elwyn G, Gagnon MP, Graham ID (2011). "Validating a conceptual model for an interprofessional approach to shared decision making: A mixed methods study." Journal of Evaluation in Clinical Practice 17(4): 554-564.

Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L. (2017). Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews, Issue 4. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub5.

Stacey, D., O'Connor, A. M., Graham, ID., & Pomey, M. P. (2006). Randomized controlled trial of the effectiveness of an intervention to implement evidence-based patient decision support in a nursing call centre. Journal of Telemedicine and Telecare, 12, 410-415.

Towle, A. and W. Godolphin (1999). "Framework for teaching and learning informed shared decision making." Bmj 319(7212): 766-771.

Couet, N., Desroches, S., Robitaille, H., Vaillancourt, H., LeBlanc, A., Turcotte, S., . . . Legare, F. (2013). Assessments of the extent to which health-care providers involve patients in decision making: A systematic review of studies using the OPTION instrument. Health Expectations, epub Jan 2013, 1-20.

Legare, F., Stacey, D., Turcotte, S., Cossi, M. J., Kryworuchko, J., Graham, I. D., . . . Donner-Banzhoff, N. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals (Review). Cochrane Database Syst Rev.(9), 1-166

O'Connor, A. M., Stacey, D., & Boland, L. (2015, 8/05/01/). Ottawa Decision Support Tutorial. from https://decisionaid.ohri.ca/ODST/

Stacey, D., Higuchi, K. A. S., Menard, P., Davies, B., Graham, I. D., & O'Connor, A. M. (2009). Integrating patient decision support in an undergraduate nursing curriculum: An implementation project. International Journal of Nursing Education Scholarship, 6(1), 1-18.

1.4 - Specify the kind of data (e.g., medical files, program evaluation, school or criminal records, interview transcripts, a company's minutes) that you will be using and provide details (e.g., size of the dataset, specific variables).

The ODST was originally developed in 1997 for graduate students based on scientific evidence and the Ottawa Decision Support Framework (O'Connor, 1998), a theoretical framework for guiding patient health decision making. In 2007, the ODST was made publically available online, free of charge (https://decisionaid.ohri.ca/ODST). The webserver is Microsoft IIS, the application was written in PHP and uses a Microsoft SQL Server database to store information. The web server uses https to secure communication between the users browser and the web server. Access to the data is restricted to the system administrator and informtion technologist site manager. The ODST requires a user name and password to access but allows users to pick their own. No data is collected regrading users progress through the ODST. The tutorial was updated in 2013, at which time a French version was added. It was updated again in 2015.

At the end of the tutorial, users are given the option to complete a 12-item acceptability survey. The survey is voluntary and anonymous (no identifiers). Items asked participants why they completed the tutorial (1 item), their profession (1 open ended item), ease and comprehensiveness of the information (2 items), provision of new information (1 item), extent the ODST will help them to support others making difficult decisions (1 item), willingness to tell others about the ODST (1 item), identification of the most helpful module(s) (1 item), ease of navigating through the tutorial web pages (1 item), accreditation options that would best meet their needs (1 item), overall impression of the tutorial (1 item), and suggestions for improvement (1 open ended item).

Users who complete a final quiz at the end of the tutorial can opt to receive a certificate of completion if they score of 75% or higher on the final quiz (10 multiple choice items that review the ODST content). The final quiz provides users with the option of adding their name if they want it displayed on the certificate of completion. The answers to the 10 questions and the final score along with the username, name for the certificate and date-time stamp are stored. Users click buttons to save the survey and final quiz responses. The final quiz can be taken only once per username. However, all identifying data will be removed prior to use for this study.

The sample size is approximately 4000 users. We propose analyzing data from the acceptability survey (no identifying information collected) and final test (some users identified themselves). For this study, ALL data (including the final test scores) will be de-identified.

1.5 - Describe how the data will be analyzed.

After all data is de-identified, raw data will be exported from the server database into Microsoft Excel (Microsoft Corporation, Redmond, WA, U.S.A.) and transferred to Statistical Analysis Software for Windows (version 9.4: SAS, Cary, NC, U.S.A). Missing data will be handled by listwise deletion. We will explore ODST usage by calculating frequency of unique log-ins of users who completed the final test, 2 items on the end-of-tutorial survey (i.e., what is your profession and why did you complete ODST?), and the time-date stamp. To determine temporal trends in ODST use, we will plot user frequency by yearly quarters.
Users' knowledge about SDM and decision support will be evaluated using the final test scores. Acceptability will be evaluated using 10 items from the end-of-tutorial survey.

Descriptive statistics will be calculated for all variables. A generalized linear regression with appropriate response distributions will compare the ODST versions. All p values will be two-sided with statistical significance set at 0.05. Open-ended comments will be analyzed using thematic content analysis.

1.6 - Describe the purpose for which the data were initially collected.

The ODST tutorial was originally developed for use with graduate students and was later incorporated into shared decision making training programs for healthcare professionals. When the ODST went online in 2007, it became accessible to anyone worldwide. The data was originally collected as a component of a student's grade or to determine whether a user was eligible to receive a certificate. The acceptability or satisfaction survey was included for quality assurance and to provide the developers with feedback to improve revisions of the tutorial.

1.7 - Describe the characteristics of the individuals from whom the information was initially collected.

The only demographic characteristics collected were user professions and reason for completing the tutorial. We anticipate that most individuals were graduate students, physicians, nurses, other healthcare professionals; although some will be from the general public. We also hypothesize that their reasons for completing the tutorial include course credit, research study involvement, or professional training.

1.8 - Indicate which organization or individual is providing the data.

Dawn Stacey, professor at the University of Ottawa and the applicant's PhD supervisor, is the director for the Patient Decision Aid research group and helped to develop the ODST. She will be releasing the data, supervising, and co-authoring this study.

1.9 - Is an agreement/permission required for secondary use of these data? (Note: This is usually necessary, unless the data is from a previous project on which you were the principal investigator.)

☒ Yes - please include copies of the relevant documents (e.g., contract, permission letter or email).
☐ No

Additional comments (if applicable)

Please see the attached letter

1.10 - Who will have access to the current dataset?

☒ Principal investigator
☐ Thesis / Project supervisor
☐ Co-researcher
☒ Research assistant
☒ Other Specify: System administrator and IT site manager (already have access, but not for this study).

1.11 - In addition to the research team members identified in this application, there may be other individuals (e.g., research assistants, translators and interpreters) who will have access to the data. Confirm that any such individuals will sign a confidentiality agreement before having access to the data.
☒ I confirm

Privacy and Confidentiality

2.1 - Will any of the following data be obtained as part of the current dataset?

A ☐ Directly identifying information: Information that identifies a specific individual through direct identifiers (e.g., name, email address).
B ☐ Indirectly identifying information: Information that can reasonably be expected to identify an individual through a combination of indirect identifiers (e.g., date of birth, IP address, job title, unique personal characteristic).

If you answered yes to A or B, describe the type of directly or indirectly identifying information that will be obtained as part of the current dataset.

If you answered yes to A or B, describe if and how the identity of the individuals will be safeguarded (e.g., anonymization of data, use of codes or pseudonyms).

2.2 - Describe the physical (e.g., locked filing cabinet) and technical (e.g., encryption) safeguards that will be used to securely store the current dataset (e.g., written records, electronic data, recordings, etc.).

All necessary steps will be taken to protect participants' human rights. The ODST dataset will be transferred electronically in a password protected spreadsheet. This data will be stored on a password protected research computer, with an encrypted file. Identifiable information will not be included.

2.3 - Indicate how long the data for the current project will be conserved.

Data in the excel database will be kept for 5 years after the manuscript is published. At that time, all data will be destroyed (permanent deletion).

Consent

Article 5.5A.d of the TCPS 2 requires that "researchers will comply with any known preferences previously expressed by individuals about any use of their information".

3.1 – Evaluate and comment on the degree of expectations the individuals who provided the information had regarding the confidentiality and secondary use of their data.

People completing the ODST do so voluntarily. the confidentiality statement on the ODST website states: "Any information collected is for the purpose of evaluating the Ottawa Decision Support Tutorial and will be kept confidential. If you are taking this tutorial for credit, your grade on the final quiz could be forwarded to your instructor. Otherwise, you will not be identified in any publications or presentations about the tutorial".

*Please append templates of the consent forms / other documents provided to individuals at the time the information was collected (if possible).

3.2 - Explain if and how informed consent will be sought from the individuals whose data you will be using?
*Please append the consent documents to be used for the current project, if applicable.
Please note that if you will not be seeking consent from participants, all the following conditions must be met (see TCPS 2, Article 5.5):
(a) Identifiable information is essential to the research;
(b) The use of identifiable information without the participants' consent is unlikely to adversely affect the welfare of individuals to whom the information relates;
(c) You will take appropriate measures to protect the privacy of individuals, and to safeguard the identifiable information;
(d) You will comply with any known preferences previously expressed by individuals about any use of their information;
(e) It is impossible or impracticable to seek consent from individuals to whom the information relates; and
(f) You have obtained any other necessary permission for secondary use of information for research purposes.

We will meet the aforelisted conditions.

Risks and Benefits

4.1 - Describe the potential contributions and benefits of the current project.

The ODST has the potential to be a widely used and inexpensive shared decision making training intervention for students, healthcare professionals, and the general public. Analysing the ODST data set will have several benefits. We will gain a better understanding of who is using the tutorial, what users think of it, and their post-tutorial understanding of the content. This information will help us improve uptake among specific stakeholder groups (e.g., physicians and nurses). Our analysis will inform evidence based improvements in tutorial content and educational strategies (e.g., interactive components, performance feedback, etc.). Publication of this study will expose others in the field to the availability and evidence for the ODST.

We do not forsee any risk to the proposed study.

4.2 Could the secondary use of these data lead to any potential harm (e.g., legal, psychological or social)?

☐ Yes ☒ No

If yes, please describe the nature of the potential harms and the measures you will take to minimize these harms.

Documents submitted to the Office of Research Ethics and Integrity for review by the Research Ethics Board:

☒ Application form
☒ Agreement / Permission document (see # 1.9)
☐ Sample consent document(s) (see #3.1 & # 3.2)
☐ Other Specify:

Attestation

I agree to abide by the ethical guidelines and procedures of the University of Ottawa Research Ethics Boards, of the Tri-Council Policy Statement (TCPS 2), of my profession or discipline, as well as of the institution in which the research is undertaken. I am aware of my responsibility to be familiar with these standards. I further agree to notify the appropriate Research Ethics Board of any substantive change in the use of data in this research and to comply with requests made by such REB during the life of this research.

Signature: Date:July 26, 2017
Printed Name: Laura Boland

Signature: Date:July 26, 2017
Printed Name: Dawn Stacey

Signature: Date:July 26, 2017
Printed Name: Ian Graham

Send to:
Office of Research Ethics and Integrity
550 Cumberland, Room 154
University of Ottawa (Tabaret Hall)
Ottawa, Ontario
K1N 6N5, Canada

Email: ethics@uottawa.ca
Phone: (613) 562-5387

Fax: (613) 562-5338

Notice of Collection of Personal Information: Your personal information is collected under the authority of the University of Ottawa Act and is indented to be used for the purpose of and those consistent with the administration and the evaluation of the eligibility of your project for ethics approval. If you have any questions regarding this collection of personal information, please contact us by telephone at (613) 562-5387 or by email at ethics@uOttawa.ca.

File Number: H08-17-10 **Date (mm/dd/yyyy):** 08/09/2017

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Dawn	Stacey	Health Sciences / Nursing	Supervisor
Laura	Boland	Health Sciences / Population Health	Student Researcher
Ian A.	Graham	Medicine / Medicine	Other Collaborator

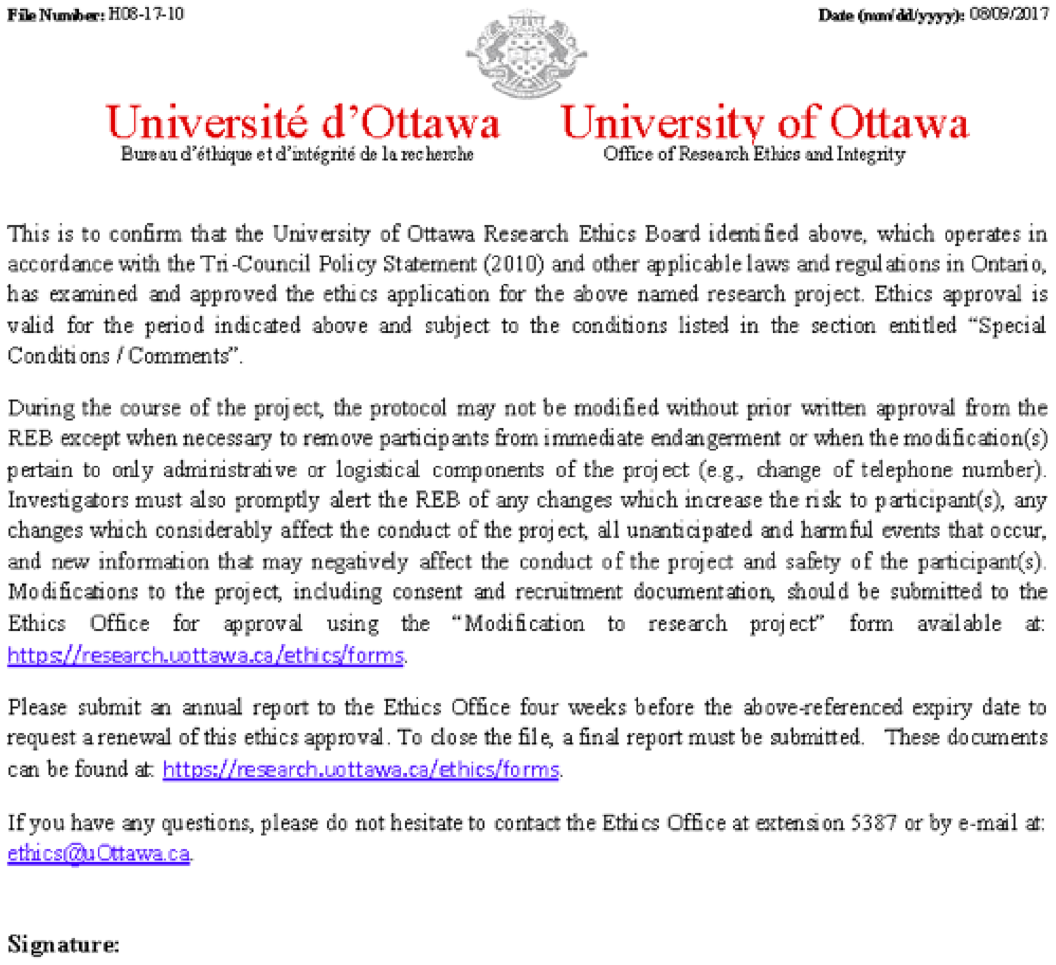
File Number: H08-17-10

Type of Project: PhD Thesis – Secondary Use of Data

Title: Ottawa Decision Support Tutorial for enhancing understanding of shared decision making: a descriptive study

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
08/09/2017	08/08/2018	Approval

Special Conditions / Comments:
N/A



File Number: H08-17-10

Date (mm/dd/yyyy): 08/09/2017

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: https://research.uottawa.ca/ethics/forms.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: https://research.uottawa.ca/ethics/forms.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Appendix I – STROBE reporting guidelines (Study 2)

* Numbers correspond to the manuscript submitted to the journal

STROBE Statement —
Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - Provided, page 3
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found - Provided, page 3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
		- Provided, page 4
Objectives	3	State specific objectives, including any prespecified hypotheses - Provided, page 5
Methods		
Study design	4	Present key elements of study design early in the paper - Provided, page 5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection - Provided, pages 5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants - Provided, page 5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable - Provided, pages 6,7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group - Provided, pages 6-8
Bias	9	Describe any efforts to address potential sources of bias - Provided, page 9
Study size	10	Explain how the study size was arrived at - Provided, page 5

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why - Provided, pages 5, 6
Statistical methods - Provided, pages 10 and 11	12	(a) Describe all statistical methods, including those used to control for confounding (Pages 5, 6)
		(b) Describe any methods used to examine subgroups and interactions (Pages 5, 6)
		(c) Explain how missing data were addressed (Page 9)
		(d) If applicable, describe analytical methods taking account of sampling strategy (NA)
		(e) Describe any sensitivity analyses Page 7
Results		
Participants	13*	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed - Provided, page 9
		(b) Give reasons for non-participation at each stage (NA)
		(c) Consider use of a flow diagram (Figure 1)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders - Provided, page 9
		(b) Indicate number of participants with missing data for each variable of interest - Provided, Tables page 9 and Table 2
Outcome data	15*	Report numbers of outcome events or summary measures - Provided, pages 9, 10
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included - Provided, pages 9-11; Tables 2, 3, 4
		(b) Report category boundaries when continuous variables were categorized - Provided, pages 14
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period (Page 10; Figure 3)

Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (Page 11; Table 4)
Discussion		
Key results	18	Summarise key results with reference to study objectives - Provided, page 11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias - Provided, pages 14-15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence - Provided, page 11-13
Generalisability	21	Discuss the generalisability (external validity) of the study results - Provided, page 14
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - Provided, page 2

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix J – Ottawa Decision Support Tutorial acceptability survey (Study 2)

ODST Satisfaction Survey

Before proceeding to the final quiz, please take a moment to answer the following survey questions about this tutorial. Please do not complete the survey until after you have completed all of the tutorial. Your responses will help us refine the tutorial to better meet the learning needs of people like you. Your responses will be completely anonymous.

1. Why did you complete this tutorial?
    a. I am completing it as part of a course.
    b. I am completing it to obtain Continuing Education credits.
    c. A colleague told me about it.
    d. I am just curious.
2. What is your overall impression of the tutorial?
    a. Excellent
    b. Good
    c. Fair
    d. Poor
3. How easy is it to understand the information presented in the tutorial?
    a. Very easy
    b. Somewhat easy
    c. Not very easy
    d. Not at all easy
4. How comprehensive is the information in the tutorial?
    a. Very comprehensive
    b. Somewhat comprehensive
    c. Not very comprehensive
    d. Not at all comprehensive

5. Did the tutorial provide you with new or additional information about decision support?
    a. Yes
    b. No
    c. Unsure
6. Do you think that the tutorial will help you in supporting individuals making difficult decisions in your practice?
    a. Yes
    b. No
    c. Unsure
    d. Not applicable
7. Will you share this information with others or tell them about the tutorial?
    a. Yes
    b. No
    c. Unsure
    d. Not applicable
8. Which sections of the tutorial were most helpful. (Choose all that apply.)
    1. Decision Support and Shared Decision Making (SDM)
    2. Conceptual Foundation: The Ottawa Decision Support Framework
    3. Clarify the Decision
    4. Decisional Conflict and Characteristics of the Decision and Participants
    5. Knowledge and Expectations
    6. Personal Values
    7. Support and Resources
    8. Monitor and Facilitate Progress
    9. Methods of Delivering Decision Support
    10. Case Study: Decision Support Using a Patient Decision Aid
9. How easy was it to navigate through the web pages of the tutorial?
    a. Very easy
    b. Somewhat easy
    c. Not very easy
    d. Not at all easy
10. What are your suggestions for improving the tutorial? (255 character limit)
11. What is your profession? (e.g., Nurse, Social Worker, Physician, Pharmacist, Nutritionist, etc.)

12. This tutorial provides a Certificate of Completion for participants who obtain a score of 75% or above on the Final Quiz. Which of the following accreditation options would best meet your needs?
    a. Proof of Completion and Medical Education Credits
    b. Proof of Completion and Education Credits for another discipline.
    c. The current Certificate of Completion meets my needs.

Appendix K –Children's Hospital of Eastern Ontario (CHEO) Research Ethics Board application and approval (Study 3)

RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

Prospective Studies Involving Minimal Risk (old form)

Project Info.

File No: 20150131
Project Title: CHEOREB# 15/42X - Factors influencing implementation of shared decision making in pediatric clinical practice: a mixed methods study
Principal Investigator: Dr. Margaret Lawson (Clinical Research\Endocrinology)
Start Date: 2015/12/02
End Date: 2018/04/13
Keywords: Shared decision making, pediatrics, barriers, facilitators, mixed methods, healthcare professionals, family centred care

Project Team Info.

Principal Investigator

Prefix: Dr.
Last Name: Lawson
First Name: Margaret
Affiliation: Clinical Research\Endocrinology
Rank: Senior Scientist
Email: lawson@cheo.on.ca
Phone1: 613-737-7600 x2113
Phone2:
Fax:
Primary Address: 401 Smyth Road, Ottawa, Ontario, K1H 8L1
Institution: CHEO Research Institute
Country: Canada
Comments: Full Professor

Other Project Team Members

Prefix	Last Name	First Name	Affiliation	Role In Project	Email
Ms.	Shephard	Allyson	Clinical Research\Endocrinology	Research Coordinator	shephard@cheo.on.ca

Dr.	Legare	France	Clinical Research\Other	Co-Investigator	france.legare@mfa.ulaval.ca
Dr.	Graham	Ian	Clinical Research\Epidemiology	Co-Investigator	igraham@ohri.ca
Ms.	Stacey	Dawn	Clinical Research\Nursing	Co-Investigator	dstacey@uottawa.ca
Ms.	Boland	Laura	Clinical Research\Endocrinology	Co-Investigator	lbola072@uottawa.ca

Common Questions

1. Conflict of Interest Statement

#	Question	Answer
1.1	Function as advisors, employees, directors or consultants for the sponsor?	No
1.2	Has direct or indirect financial interest in the drug, device or technology employed (including patents or stocks) in this research study?	No
1.3	Will receive honoraria or other benefits from sponsor (apart from fees for service)?	No
1.4	If Yes, to any of the above, describe how the potential conflict of interest is being managed to ensure that research is conducted in a way to maintain the independence and integrity of the research process; for example, the participant's rights and welfare.	
1.5	I will notify the REB if my contract with the study sponsor changes in any way or if any changes are made that could be perceived as a conflict of interest.	Yes

2. Nature of Project

#	Question	Answer
2.1	Please indicate the nature of the project below	Studies involving Staff or Physicians

3.1	Provide a synopsis and description of the ethical considerations as well a brief description of the proposed research.	Rationale and HypothesesShared decision making (SDM) is a collaborative decision making approach between the patient, family, and healthcare team that improves patient participation, knowledge, and decision quality. SDM is rarely implemented in pediatric clinical practice and little is known about the barriers and facilitators of pediatric SDM implementation. Consideration of barriers and facilitators is essential for promoting health intervention implementation in clinical practice. We hypothesize that healthcare professionals can identify modifiable barriers of implementing SDM in pediatric clinical practice to help researchers tailor SDM interventions and chose evidence-based knowledge translation strategies for promoting SDM uptake.Study Design and MethodsA sequential exploratory study using mixed-methods with triangulation of data sources will identify what health professionals with SDM training perceive as barriers to SDM in pediatric practice. First, semi-structured interviews will be conducted with pediatric healthcare professionals trained in SDM. Then, a validated SDM barriers survey will be tailored based on interview responses and distributed to SDM trained pediatric healthcare professionals. Participant SelectionAll pediatric health professionals who have completed the SDM training through CHEO Family Decision Services (http://www.cheo.on.ca/en/DecisionServices) will be eligible to participate in the interviews and survey. As of January 2015, 138 individuals (n = 66 from CHEO; n = 73 from Ottawa Children's Treatment Center (OCTC) were eligible. Healthcare professionals will be excluded if they are no longer CHEO or OCTC employees/consultants, or are on extended

		leave (e.g., disability or parental). Interview participants (n=10-14) will be purposefully recruited from both CHEO and OCTC. The Medical Director of Family Decision Services (Margaret Lawson; co-investigator) will invite interviewees via email. The researcher (Laura Boland) will approach interested individuals to obtain informed consent and conduct the interview. A short survey (i.e., 10-15 minutes for completion) will be administered used the Dillman's Tailored Mixed Mode Survey Guidelines [2014]. First, online surveys will be distributed to eligible participants via the REDcap program. A paper copy will follow for non-respondents. Outcomes and AnalysesThe primary outcomes are healthcare professionals' perceived barriers and facilitators of implementing SDM in pediatric clinical practice. Two coders will analyze interviews using thematic content analyses. Univariate descriptive statistics will be calculated for all quantitative (survey) data. Open-ended responses will be analyzed thematically and triangulated with interview data and quantitative survey responses. Healthcare professional demographic data information will also be collected.Ethical ConsiderationsAll necessary steps will be taken to protect participants' human rights and will be in accordance with the TCPS 2. After CHEO Research Ethics Board approval, OCTC Research Review Committee and University of Ottawa' REB approval will also be sought (in accordance with the CHEO REB and UofO REB agreement). All interviewees will provide informed signed consent (Appended) and a consent page will be attached to the survey (Appended). Returned surveys to the researchers will be considered provision of consent.

		Interviewee transcripts and surveys will be assigned identification numbers to protect confidentiality. Digital recordings of interviews will be password protected and encrypted and stored on a computer in the CHEO Research Institute. Data from online surveys will be stored in REDcap and paper surveys will be stored in a locked cabinet in a locked research office at the CHEO Research Instutute. Survey respondents' anonymity will be protected by assigning an identification code to the survey, associated with an email list on REDcap. Once the survey is returned, the email address is deleted from the system. Paper surveys will be sent to non-respondents and coded with an ID number. Data from returned paper surveys will inputted into the REDcap system resulting in the deletion of the associated email address. When the study is complete, there will be no association between participants email addresses and their survey ID. No patient information or identifiers are being collected.

4. Funding or Sponsoring Agency

#	Question	Answer
4.1	Study both funded and initiated by an Industry (Pharmaceutical or other)	No
4.2	Specify Company Name	
4.3	Provide name and address of contact person.	
4.4	Study funded by CHEO Internal Cost Centre (either research or hospital-based)	No
4.5	Study funded by External Granting Agency	No
4.6	If yes, please indicate name of agency	
4.7	Study will be carried out without additional expenditure	Yes

5. Multi-Site Research

#	Question	Answer
5.1	Is this a multi-centre study?	Yes
5.2	How many sites are involved?	2

5.3	Which other Canadian pediatric sites are participating in the study (select all that apply)	
5.4	Are there any other Canadian (adult) sites participating in the study?	No
5.5	Specify the name and contact information for the primary coordinating site.	CHEO Research InstituteResearch Building II401 Smyth Road Ottawa, ON K1H 8L1
5.6	Are there any sites outside Canada participating in the study?	No
5.7	If yes, specify below	
5.8	Is a network of sites participating in the study?	No
5.9	If yes, specify below (eg. C-17, COG, POGO)	

6. Data Sharing Agreements/Additional Contracts

#	Question	Answer
6.1	Is this a multi-site study?	Yes
6.2	Is there information data being transferred outside the institution?	Yes
6.3	Is the data identified or de-identified?	De-Identified
6.4	If yes, what is the modality of transfer? (paper, electronic transfer (i.e., email, database), electronic device.	No data will be transferred outside of CHEO. However, data from OCTC will be transfered to a research office at CHEO (Research Building II). This data may be electronic (digital interview recordings) formats and in paper format (survey). The researcher will carry the digital interview recordings directly from OCTC to the CHEO RI office by foot immediately after the interview was completed. Completed paper surveys will be mailed to the CHEO RI office. The researcher will make data sharing agreements with between CHEO and OCTC once the OCTC Ethics Review Committee has reviewed this study.
6.5	What safeguards will be used? (of note, paper transfer should be via courier, and electronic data should be password protected, and encrypted)	Due to resource limitations, surveys cannot be couriered and will be returned using regular mail service. However all surveys are coded with ID numbers and no personal information is included. Digital interview recordings will be password protected and encrypted.

7. Data Safe Guards and Retention

#	Question	Answer
7.1	All data will be safeguarded and stored in accordance with the general safeguards for the storage of research data	
7.2	Please select the data retention period	
7.3	If "other" specify below	

8. Checklist

#	Question	Answer
8.1	Check all that apply (NOTE: This is not a comprehensive list and some may not be applicable to your study).	Protocol / SynopsisIConsent FormIAssent FormIStudy Questionnaires/SurveysIRecruitment MaterialsISignature Page (signed by the PI, Division Head and the Department Head) {Note: If the division head is PI, They cannot sign as division head; the authorization of the next appropriate person within the division should be obtained}I

Attachments

Doc / Agreement	Version Date	File Name	Description
Consent Form	2015/11/13	FINAL Clean Consent pilot survey ped SDM amendment2 _annual renewal 2017.docx	15/42X - Lawson - Consent - English - version 2 - November 13 2015
French Consent Form	2015/11/13	Final French consent and survey - version 1- Nov 3 2015_annual renewal 2017.docx	15/42X - Lawson - Consent form - French - version 1 - November 13 2015
Protocol	2015/04/29	Final Protocol Ped SDM amendment1 version2 clean_annual renewal 2017.docx	15/42X - Lawson - Protocol - version 2 - April 29 2015
Signature Page	2018/04/10	Study Closure Report_Signature Page_ML Lawson.pdf	REB 15/42X_Study Closure Report_PI Lawson_ Signature Page_April 10 2018

Signature Page	2016/03/10	Signature page_Minor Admin Change_ MLawson_March 10, 2016.pdf	Signature Page - Minor Admin Change - MLawson - March 10, 2016
Signature Page	2016/03/10	Signature page_Annual Renewal_MLawson_ March 10,2016.pdf	Signature Page - Annual Renewal - MLawson - March 10, 2016
Signature Page	2017/03/09	Signature Page_ML Lawson_Annual Renewal 2017.pdf	Signature page_ML Lawson_March 9 2017
TCPS Certification	2015/03/25	Legare TCPS module3 Ped SDM amended0 version1.pdf	Legare TCPS module3 Ped SDM amendment0 version1
TCPS Certification	2015/03/25	Legare TCPS2 Ped SDM amendment0 version1.pdf	Legare TCPS2 Ped SDM amendment0 version1
TCPS Certification	2015/03/25	Legare TCPS1 Ped SDM amendment0 version1.pdf	Legare TCPS1 Ped SDM amendment0 version1
TCPS Certification	2009/11/27	Lawson TCPS Ped SDM amendment0 version1.pdf	Lawson TCPS 2009/11/27
TCPS Certification	2007/10/17	Stacey TCPS ped SDM amendment0 version1.pdf	Stacey TCPS 2001/10/17
TCPS Certification	2015/02/24	Boland TCPS Ped SDM amendment0 version1.pdf	Boland TCPS 2015/02/24
TCPS Certification	2012/01/16	Graham_tcps2 ped SDM amendment0 version1.pdf	Graham TCPS 2012/01/16
TCPS Certification		Biomedical Research Ethics Tutorial March 2015AS.pdf	TCPS_Allyson Shephard

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CHEO Research Ethics Board
Approval - Delegated Review

Principal Investigator: Dr. Margaret Lawson
REB Protocol No: 15/42X
Romeo File No: 20150131
Project Title: CHEOREB# 15/42X - Factors influencing implementation of shared decision making in pediatric clinical practice: a mixed methods study
Primary Affiliation: Clinical Research\Endocrinology
Protocol Status: Active
Approval Date: December 02, 2015
Valid Until: April 15, 2016
Annual Renewal Submission Deadline: March 15, 2016

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Protocol	Final Protocol Ped SDM Amendment 1 Version 2 Clean	2015/07/16
Consent Form	Consent - Clean - Version #3	2015/11/19
Consent Form	Consent Form Ped SDM Amendment 1 Version 2 Clean	2015/07/16
Recruitment Materials	Final Recruitment Interview Email Ped SDM Amendment 1 Version 2 clean	2015/07/16
Questionnaire/Survey	Final Survey Ped SDM Amendment 1 Version 2 clean	2015/07/16
Questionnaire/Survey	Interview Guide Ped SDM Amendment 1 Version 2 clean	2015/07/16
Questionnaire/Survey	REB 15/42X - Example of SDM barriers survey that will be further tailored to reflect interview results Amendment0 Version2	2015/10/14
French Consent Form	REB 15/42X - Lettre d'information et formulaire de consentement - Clean	2015/10/14

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed under the delegated review stream, which is reserved for projects that involve no more than minimal risk to human subjects.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.
2. Investigators must submit an annual renewal report to the REB 30 days prior to the expiration date stated above.
3. The investigator must not implement any deviation from, or changes to, the protocol, consents or assents without the approval of the REB.
4. The investigator must, prior to use, submit to the Board changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.
5. Investigators must provide the Board with French versions of the consent form using the 'translated study documents' event, unless a waiver has been granted. An interpreter should be offered to participants as required or at the request of the participant throughout the course of research.

Appendix L – Participant consent form an interview (Study 3)

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Letter of Information and Consent Form

Assessment of Pediatric Shared Decision Making Barriers and Facilitators

Principal Investigator:
Laura Boland, MSc, SLP-C, PhD(c)
University of Ottawa, Institute of Population Health

Co-investigators:
Margaret Lawson, MD, MSc, FRCP, Dawn Stacey, RN, MScN, PhD, France Légaré, MD, PhD, Ian Graham, PhD

You being asked to take part in a study aimed at exploring shared decision making barriers and facilitators in pediatric health care. Please read this information and review it with the research assistant to help you decide if you would like to participate in this study.

Why is this study being done?

Children benefit from being involved in health decisions. Shared decision making is an evidence based collaborative approach to health decision making improves that adult patient participation, knowledge, and decision quality. Studies show that shared decision making is rarely used in pediatric health care. The purpose of this study is to explore the barriers of implementing shared decision making in a pediatric tertiary care center.

You are eligible to participate in this study if:
You are a pediatric health professional, clinical manager, or administration at the Children's Hospital of Eastern Ontario (CHEO) or the Ottawa Children's Treatment Center (OCTC).
You have completed the shared decision making training provided by CHEO Family Decision Services.

What does study participation involve?
You will be asked to attend one interview (approximately 20-30 minutes in duration) with the researcher. All discussions will be audio recorded for later transcription and analysis.

What are the risks of this study and how are the risks different from the standard of care?

There is minimal risk to you for participating in this study. Some questions may make you uncomfortable. You can opt to not answer any question or terminate your participation in this study at anytime. Whether or not you participate in this study will have no impact on your current or future employment.

What are the benefits to taking part in the study?

The findings will help identify the barriers of using shared decision making in pediatrics, thus potentially improving children and families access to shared decision making interventions.

If I chose, can I withdraw from the study?

Participation in this study is voluntary. You may withdraw at any time without penalty. Your decision about participating in this study will in no way affect your employment status at CHEO/OCTC.

What about confidentiality and privacy?

All information discussed during the study will be kept strictly confidential except as required by law (e.g., child abuse and neglect). Your names will not be written on study forms. If your employment position or title is identifying, you will be asked to identify yourself more broadly (e.g., manager or administrator). We will not publish any information that may identify you. Participants will be categorized according to their discipline (e.g., physician, nurse) or role (e.g., manager, administrator). Members of the CHEO Research Ethics Board may have access to your study forms to ensure we followed the approved procedures. All digital recordings, transcripts, and paper forms will be kept in a locked research office in a locked cabinet at CHEO. Digital recordings will be password protected, encrypted and only accessible to the researchers responsible for the study.

Compensation

Participants will be offered a $10 Starbucks gift card for their participation

Other Information

We will inform you of any new information that might influence your decision to participate in this research project. At your request, you can receive a copy of the study results once it has been concluded. You will be given a copy of your signed consent form.

For more information concerning this study, please contact, Laura Boland, PhD(c)

Consent form

I have been informed about the nature of the study and the way it will be conducted.

I have read the consent form and I have been given a copy.
I have been able to ask questions pertaining to the study and they have been answered.
After thoughtful consideration, I agree that I will participate in this research study.

__________________________ ______________________________ ______________

Participant Name Signature Date
(Printed)

I have explained all aspect of this study explained to the participant and I have answered the questions he/she had asked me. I have indicated to the above signed that participation in the study is voluntary and that their may withdrawal from participating at any time.

__________________________ ______________________________ ______________

Name of the person who has Signature Date
obtained the consent
(Printed)

Commitment for the researcher or his/her delegate

The research project and participation requirements must be explained in full to the participant. A member of the research team must answer questions and must specify that participation in the project is voluntary. The research team will respect the terms of the consent form.

__________________________ ______________________________ ______________

Name of the researcher Signature Date
(Printed)

CHEO Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Lettre d'information et formulaire de consentement

Évaluation des barrières de la prise de décision partagée en pédiatrie

Chercheur principal:
Margaret Lawson, MD, MSc, FRCP
Centre hospitalier pour enfants de l'est de l'Ontario
401 chemin Smyth, Ottawa, ON

Chercheurs associés:
Laura Boland, MSc, SLP-C, PhD(c), Dawn Stacey, RN, MScN, PhD, France Légaré, MD, PhD, Ian Graham, PhD

Vous êtes invité à participer à une étude visant à explorer les barrières de la prise de décision partagée dans les soins de santé pédiatriques. Veuillez lire cette information pour vous aider à décider si vous souhaitez participer à cette étude.

Pourquoi faisons-nous cette étude?

Dans une certaine mesure, toutes les familles veulent être impliquées dans les décisions concernant la santé de leur enfant. Quand une famille et l'équipe soignante prennent des décisions ensemble, c'est ce qu'on appelle la prise de décision partagée (PDP). Des études montrent que la PDP est rarement utilisée dans les soins de santé pédiatriques. Le but de cette étude est d'explorer les barrières de la PDP dans un centre pédiatrique.

Qui peut participer?
Vous pouvez participer à cette étude si:
Vous êtes un professionnel de la santé pédiatrique, gestionnaire clinique, ou de l'administration du Centre hospitalier pour enfants de l'est de l'Ontario (CHEO) ou le Centre de traitement pour enfants d'Ottawa (CTEO).
Vous avez terminé la formation de la PDP fournie par le groupe, Services d'aide à la prise de décisions de CHEO.

Que va-t-on me demander de faire?
Vous serez invité à signer le formulaire de consentement.
Vous serez invité à assister à une entrevue (environ 20 à 30 minutes) avec le chercheur.
Toutes les discussions seront audio enregistré pour la transcription et l'analysé plus tard.

Quels sont les risques ou les inconvénients de participer à cette étude?

Il n'y a pas de risques connus pour vous de prendre part à cette étude.
Que vous participiez ou non dans cette étude n'aura aucun impact sur votre emploi.

Quels sont les avantages de participer à l'étude ?

Il n'y a pas d'avantages directs pour vous à prendre part à cette étude. Cependant, les résultats de cette étude nous aideront à identifier les obstacles d'utiliser la prise de décision partagée en pédiatrie. Cela pourrait donc améliorer l'accès aux interventions de PDP pour les enfants et les familles.

Comment pourrais-je me retirer de l'étude?

Prendre part à cette étude est votre décision. Vous pouvez vous en retirer à n'importe quel moment et il n'y aura pas de pénalité. Votre décision de participer à cette étude n'affectera en aucune façon votre situation d'emploi au CHEO ou CTEO.

Comment la confidentialité est-elle assurée?

Les renseignements qui vous concernent seront protégés et demeureront confidentiels. Votre nom ne sera pas écrit sur les formulaires d'étude. Toutes les données seront codées de sorte que vous ne puissent pas être connus par votre nom. Toute l'information recueillie lors de cette étude sera gardée dans des classeurs verrouillés ou des fichiers électroniques protégés par un mot de passe. Seuls les chercheurs directement impliqués dans l'étude ou les représentants du comité d'éthique de la recherche au CHEO ou CTEO auront accès aux renseignements qui vous concernent. Les représentants du comité d'éthique de la recherche au CHEO ou CTEO peuvent avoir accès à l'information, s'ils le souhaitent afin de confirmer que nous avons suivi les procédures approuvées.

Les résultats de cette étude peuvent être publiés et présentés lors de réunions scientifiques. Cependant, on ne pourra pas vous identifier dans aucune publication ou présentation relative à cette étude.

Compensation

Pour vous compenser pour le temps supplémentaire impliqué dans l'étude, nous vous fournirons une carte de Starbucks (10$).

Informations supplémentaires
Nous vous tiendrons informés de toute nouvelle information qui pourrait influencer votre décision de continuer de participer à ce projet de recherche. Si vous en faites la demande, vous pourrez recevoir une copie des résultats de cette étude à la fin de l'étude.

Si vous aimeriez avoir plus d’information avant de prendre votre décision, s'il vous plaît contacter : Dr. Margaret Lawson.

Cette étude a été examinée et approuvée par le Comité d’éthique de la recherche (CER) du CHEO. Le CER du CHEO est un comité composé de personnes venant de divers horizons professionnels. Le CER étudie tous les projets de recherche effectués à l’Hôpital. Son objectif est de veiller à la protection des droits et du bien-être des personnes qui y participent. Le travail du Comité ne vise pas à remplacer le jugement des parents ou de l’enfant concernant les décisions et les choix qui sont les meilleurs pour eux. Vous pouvez communiquer avec la présidente du CER pour obtenir des renseignements sur les droits des patients dans le cadre de projets de recherche en composant le 613-737-7600, poste 3272, mais cette personne ne sera pas en mesure de fournir des informations médicales.

FORMULAIRE DE CONSENTEMENT

J’ai été informé sur la nature de l'étude et la façon dont elle sera menée.

J’ai lu le formulaire de consentement et j’ai reçu une copie.
J’ai été en mesure de poser des questions relatives à l'étude et qu'ils ont été exaucés.
Après réflexion, je suis d'accord que je vais participer à cette étude de recherche.

______________________________ __________________________________ ________________

Nom du participant Signature Date
(imprimé)

J’ai expliqué tous les aspects de cette étude au participant et j’ai répondu aux questions qu'il/elle m’avait demandées. J'ai indiqué ci-dessus que la participation à l'étude est volontaire et qu’il/elle peut retraiter à tout moment.

______________________________ __________________________________ ________________

Nom de la personne qui a
obtenu le consentement Signature Date
(imprimé)

Formulaire d'engagement pour le chercheur ou son / sa délégué

Le projet de recherche et les conditions de participation doivent être expliquées en pleine au participant. Un membre de l'équipe de recherche doit répondre aux questions et doit préciser que la participation au projet est volontaire. L'équipe de recherche doit respecter les termes de la forme de consentement.

______________________________ __________________________________ ________________

Nom de le chercheur Signature Date
(imprimé)

Appendix M – STROBE guidelines with page numbers corresponding to the submitted manuscript (Study 3)

STROBE Statement —
Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - Provided, page 1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found - Provided, page 2, 3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
		- Provided, pages 4, 5
Objectives	3	State specific objectives, including any prespecified hypotheses - Provided, page 5
Methods		
Study design	4	Present key elements of study design early in the paper - Provided, page 5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection - Provided, page 5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants - Provided, pages 5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable - Provided, pages 5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group - Provided, pages 7
Bias	9	Describe any efforts to address potential sources of bias - Provided, page 16
Study size	10	Explain how the study size was arrived at - Provided, page 5

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why - Provided, page 8
Statistical methods - Provided, pages 10 and 11	12	(a) Describe all statistical methods, including those used to control for confounding - Provided, page 8
		(b) Describe any methods used to examine subgroups and interactions - Provided, page 8
		(c) Explain how missing data were addressed - Provided, page 8
		(d) If applicable, describe analytical methods taking account of sampling strategy (NA)
		(e) Describe any sensitivity analyses (NA)
Results		
Participants	13*	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed - Provided, page 9
		(b) Give reasons for non-participation at each stage (NA)
		(c) Consider use of a flow diagram (NA)
Descriptive data	14*	(a) Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders - Provided, page 9; Table 1
		(b) Indicate number of participants with missing data for each variable of interest - Provided, Tables 2-5
Outcome data	15*	Report numbers of outcome events or summary measures - Provided, pages 9-13, Tables 2-5
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included - Provided, pages 9, Table 2
		(b) Report category boundaries when continuous variables were categorized - Provided, page 9
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period (NA)
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (NA)

Discussion		
Key results	18	Summarise key results with reference to study objectives - Provided, page 14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias - Provided, pages 16
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence - Provided, page 14, 15
Generalisability	21	Discuss the generalisability (external validity) of the study results - Provided, page 16
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - Provided, page 1

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix N – Introduction letter for the survey (Study 3)

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Dear Pediatric Healthcare Professional,

You are being invited to complete a short survey led by Dr. Margaret Lawson because you have completed the shared decision making/decision coaching training program offered by CHEO Family Decision Services.

The purpose of our survey is to identify barriers of using shared decision making in pediatric clinical practice.

In the next few days, you will receive an email link to access the survey.

This survey will ask about your thoughts and experiences with shared decision making and it will take approximately 10-15 minutes to complete. You may not directly benefit from this research; however, your participation may improve knowledge about using shared decision making in pediatrics. Your participation is completely voluntary and you can withdraw at any time. Your current or future employment will in no way be jeopardized if you choose not to participate. To the best of our ability your answers in this study will remain confidential by not associating identifying information to your survey responses and keeping completed surveys in a locked research cabinet in a locked office at the CHEO Research Institute.
If you have questions about this project or if you have a research-related problem, you may contact the researcher, Margaret Lawson, MD or the CHEO Research Ethics Board at 613-737-7600 ext. 3350.
Please find enclosed $5 as a token of appreciation for your participation in this survey.

Thank you for considering participation in this study.

Margaret Lawson

Margaret Lawson, MD, MSc, FRCP, Pediatric Endocrinologist, Division of Endocrinology and Metabolism, Medical Director, Family Decision Services, Professor, Department of Pediatrics, University of Ottawa, Children's Hospital of Eastern Ontario (CHEO), 401 Smyth Road Ottawa, ON K1H 8L1, Tel: (613) 737-2411 | Fax: (613) 738-4215 | lawson@cheo.on.ca

Appendix O – Survey consent form (Study 3)

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Consent Form

You are being invited to participate in a survey for a research study titled "Factors influencing implementation of shared decision making in pediatric clinical practice: a mixed methods study". This study is being done by:

Margaret Lawson, MD, MSc, from the Children's Hospital of Eastern Ontario
Laura Boland, MSc, PhD(c) from the University of Ottawa
France Légaré MD, PhD from Université de Laval
Ian Graham, PhD from the University of Ottawa
Dawn Stacey, PhD from the University of Ottawa

You are being asked to participate in this pilot survey because you completed the shared decision making/decision coaching training program offered by CHEO Family Decision Services.

The purpose of this pilot study is to test and obtain feedback on the survey we developed to identify barriers of using shared decision making in pediatric clinical practice. If you agree to take part, you will be asked to complete the enclosed pilot survey asking about your thoughts and experiences with shared decision making. It will take approximately 10-15 minutes to complete.

You may not directly benefit from this research; however, your participation may improve our survey seeking to gain knowledge about using shared decision making in pediatrics. Your participation is completely voluntary and you can withdraw at any time. Your current or future employment will in no way be jeopardized if you choose not to participate.

To the best of our ability your answers in this study will remain confidential by not associating identifying information to your survey responses and keeping completed surveys in a locked research cabinet in a locked office at the CHEO Research Institute.

This project has been reviewed and approved by the CHEO Research Ethics Board.
If you have questions about this project, you may contact the researcher, Laura Boland, PhD(c).

By proceeding to the pilot survey you are indicating that you have read and understood this consent form and agree to participate in this study. Please keep this page for your records and return the survey to the researchers. Please DO NOT write your name on the survey.

Best regards,

Margaret Lawson, MD, MSc, FRCP Pediatric Endocrinologist, Division of Endocrinology and Metabolism, Medical Director, Family Decision Services, Professor, Department of Pediatrics, University of Ottawa Children's Hospital of Eastern Ontario (CHEO) 401 Smyth Road Ottawa.

CHEO Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Lettre d'information et formulaire de consentement

Vous êtes invité à participer à un sondage visant à explorer les barrières de la prise de décision partagée dans les soins de santé pédiatriques. Les chercheurs sont:

Margaret Lawson, MD, MSc, CHEO
Laura Boland, MSc, PhD(c) Université d'Ottawa
France Légaré, MD, PhD Université Laval
Ian Graham, PhD Université d'Ottawa
Dawn Stacey, PhD Université d'Ottawa

Vous êtes invité à participer à ce sondage (environ 10 à 15 minutes) parce que vous avez terminé la formation sur la prise de décision partagée donnée par les Services d'aide à la prise de décisions du CHEO.

Il n'y aura pour vous pas d'avantages directs à participer à cette étude. Cependant, les résultats nous aideront à améliorer nos connaissances sur la prise de décision partagée et sur le processus décisionnel en lien avec les soins pédiatriques chez les enfants et les familles.

Votre participation à cette étude est volontaire, vous êtes libre de vous en retirer à tout moment et sans aucun préjudice. Votre décision de participer à cette étude n'affectera en aucune façon votre situation d'emploi au CHEO.

Les renseignements qui vous concernent seront protégés et demeureront confidentiels. Votre nom n'apparaîtra pas sur le sondage. Toutes les données seront codées de sorte que vous ne puissiez pas être reconnu. Toute l'information recueillie lors de cette étude sera gardée dans des classeurs verrouillés ou des fichiers électroniques protégés par un mot de passe.

Cette étude a été évaluée et approuvée par le Comité d'éthique de la recherche (CER) du CHEO. Si vous désirez avoir plus d'information, s'il vous plaît contacter : Dr. Margaret Lawson au 613-737-7600, Ext 2113.

En participant à ce sondage, vous indiquez avoir lu et compris le formulaire de consentement et que vous êtes d'accord pour y participer.

Merci,

Margaret Lawson, MD, MSc, FRCP, Tel: (613) 737-2411 | lawson@cheo.on.ca

Appendix P – Non-respondent reminder letter about the survey (Study 3)

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Dear Pediatric Healthcare Professional,

Approximately 3 weeks ago, you were invited to complete a short survey led by Dr. Margaret Lawson because you have completed the shared decision making/decision coaching training program offered by CHEO Family Decision Services.

The purpose of our survey is to identify barriers of using shared decision making in pediatric clinical practice. For your convenience, we have enclosed a paper-based survey here. If you chose to complete the survey, please return in in the addressed envelope provided through the CHEO inter-mail system.

Alternatively, you can complete the survey online. The link was sent to you via email on February 17th and 24th 2016. Or, you may open the survey in your web browser by using the following link: https://redcap.cheori.org/surveys/?s=F3ADHNP8K3

This survey asks about your thoughts and experiences with shared decision making and it will take approximately 10-15 minutes to complete.

Your participation is completely voluntary and you can withdraw at any time. Your current or future employment will in no way be jeopardized if you choose not to participate. To the best of our ability your answers in this study will remain confidential by not associating identifying information to your survey responses and keeping completed surveys in a locked research cabinet in a locked office at the CHEO Research Institute.

This project has been reviewed and approved by the CHEO Research Ethics Board, REB Protocol No 15/42X. If you have questions about this project or if you have a research-related problem, you may contact the researcher, Margaret Lawson, MD or the CHEO Research Ethics Board at 613-737-7600 ext. 3350.

Thank you for considering participation in this survey study.

Margaret Lawson

Margaret Lawson, MD, MSc, FRCP, Pediatric Endocrinologist, Division of Endocrinology and Metabolism, Medical Director, Family Decision Services, Professor, Department of Pediatrics, University of Ottawa, Children's Hospital of Eastern Ontario (CHEO), 401 Smyth Road Ottawa, ON K1H 8L1.

Appendix Q – Barrier and facilitator survey (Study 3)

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Pediatric Healthcare Professionals Perceptions of Barriers to Shared Decision Making: A Survey

Shared decision making is when healthcare providers, patients, and/or parents collaborate in decision making by exchanging medical information and the patient's values and preferences. Together they determine the best treatment decision for the patient.

Please tell us about your experience with shared decision making:

1.	Did you complete the shared decision making/decision coaching training provided by CHEO Family Decision Services? If yes, in what year?	☐ Yes ☐ No
	If yes, what components? Online decision coaching tutorial	☐ Yes ☐ No ☐ Unsure
	Decision coaching workshop	☐ Yes ☐ No ☐ Unsure
	If no, please do not complete the survey	
2.	Have you completed any refresher sessions since the original training?	☐ Yes ☐ No ☐ Unsure
3.	Have there been changes in leadership that has affected your work since you completed the training?	☐ Yes ☐ No ☐ Unsure
4.	About how many patient health decisions have you been involved with in the last 2 weeks?	☐ None ☐ 1-2 ☐ 3-5 ☐ 5-10 ☐ >10 ☐ Unsure
5.	About how often have you used shared decision making with patients and/or families in the last 2 weeks?	☐ Not at all ☐ 1-2 times ☐ 3-5 times ☐ 5-10 times ☐ >10 times

		☐ Unsure
6.	How often have you used decision coaching skills with patients and/or family members in the last 2 weeks?	☐ Not at all ☐ 1-2 times ☐ 3-5 times ☐ 5-10 times ☐ >10 times ☐ Unsure
7.	How often have you used a patient decision aid (e.g., Ottawa Family Decision Guide) with patients and/or family members in the last 2 weeks?	☐ Not at all ☐ 1-2 times ☐ 3-5 times ☐ 5-10 times ☐ >10 times ☐ Unsure
8.	Do you document that shared decision making has occurred? If yes, how? ____	☐ Yes ☐ No ☐ Unsure

Please answer each of the following questions by indicating the number that best describes your opinion. Some questions may seem similar, but they measure different aspects of shared decision making.		
9.	Most parents prefer shared decision making	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
10.	Most competent children prefer shared decision making	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
11.	I believe that I will use shared decision making	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
12.	I have the ability to use shared decision making	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
13.	I am confident that I could use shared decision making if I wanted to	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
14.	For me, shared decision making would be:	Extremely difficult Extremely easy 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
15.	To the best of my knowledge, the percentage of my colleagues who used shared decision making is:	0-20% 21-40% 41-60% 61-80% 81-100% ☐ ☐ ☐ ☐ ☐
16.	Think about a co-worker whom you respect as a professional. In your opinion, does he/she use shared decision making?	Never Always 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐

17.	Most of my professional role models use shared decision making.	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
18.	I intend to use shared decision making.	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
19.	Shared decision making is an ethical thing to do.	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
20.	It is acceptable at my work place to use shared decision making.	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
21.	Overall, I shared decision making would be:	Extremely Useless Extremely Useful 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
22.	I plan to use shared decision making	Strongly disagree Strongly agree 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
23.	Overall, I think that for me, shared decision making would be:	Harmful Beneficial 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐

Item	Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	I can't say
24.	Shared decision making improves parents' involvement in health decision making						
25.	Shared decision making improves children's involvement in health decision making						
26.	Most trained healthcare providers are able to engage parents in shared decision making						
27.	Most trained healthcare providers are able to engage children in shared decision making						
28.	Most trained healthcare providers are using shared decision making with parents						
29.	Most trained healthcare providers using shared decision making with children						
30.	I have adequate access to the resources needed to use shared decision making (e.g., patient decision aids, evidence-based information)						
31.	I have the time required to engage use shared decision making						
32.	Additional training would improve my ability use shared decision making						
33.	My colleagues support me in using shared decision making						

34.	My manager supports me in using shared decision making						
35.	My organization supports me in using shared decision making						
36.	I believe parents think shared decision making is acceptable						
37.	I believe children think shared decision making is acceptable						

38. Please list 3 main barriers for healthcare professionals to use shared decision making and rate the level of importance.

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

39. Please list 3 main barriers for parents and children to use shared decision making and rate the level of importance.

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

40. Please list 3 factors that make easier for you to use shared decision making and rate the level of importance.

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Very important Very unimportant
1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

41. Do you have any further comments, questions or suggestions? Please do not include information that could identify you (your name, address, identifying aspects of your unique circumstance, or your patients, etc.)

Please tell us about yourself

Where do you work?

Your profession/specialty:

Your role on the team:

How many years of healthcare experience do you have?
< 1 year
1-5 years
6-10 years
11-19 years
20+ years

Do you work?
Full time
Part time
Casual

What is your age range?
20-25
26-30
30-40
41-50
51-60
61+
I prefer not to disclose

What is your gender?
Man
Woman
Transsexual or transgender
I prefer not to disclose

What is your highest grade or level of education completed?
High school
College degree
University degree
Post graduate
Other (please indicate):
____

Thank you very much for your participation in this study!

Children's Hospital of Eastern Ontario
Centre hospitalier pour enfants de l'est de l'Ontario

Perception des professionnels de la santé pédiatrique face aux obstacles qui entravent la prise de décisions partagée

On parle de prise de décision partagée lorsque les professionnels de la santé, les patients et les parents collaborent à la prise de décision en échangeant des informations médicales et en mettant en évidence les valeurs personnelles et les préférences des patients. Ils choisissent ainsi les meilleurs traitements à administrer aux patients.

Veuillez nous décrire votre expérience de la prise de décisions partagée :

Quand avez-vous suivi la formation et l'encadrement sur la prise de décision partagée au Service des décisions axées sur la famille du CHEO?
Année _________
Je ne me souviens pas

Quels éléments avez-vous suivis?

Tutoriel de soutien à la décision d'Ottawa
Atelier de renforcement des compétences en prise de décision partagée
(Decision coaching skill building workshop)
Pas certain

2.	Avez-vous suivi des cours de formation continue depuis votre formation initiale?	☐ Oui ☐ Non ☐ Pas certain
3.	Y a-t-il eu des changements de leadership qui ont affecté vos capacités à fournir la prise de décision partagée depuis que vous avez terminé la formation?	☐ Oui ☐ Non ☐ Pas certain
4.	À environ combien de prises de décisions avez-vous participé au cours de ces 3 dernières semaines?	☐ Aucun ☐ 1-2 ☐ 3-5 ☐ 6-10 ☐ >10 ☐ Pas certain
5.	Avec quelle fréquence avez-vous utilisé la prise de décision partagée avec des patients et leurs familles au cours de ces 3 dernières semaines?	☐ Aucun ☐ 1-2 fois

		☐ 3-5 fois ☐ 6-10 fois ☐ >10 fois ☐ Pas certain
6.	Avec quelle fréquence avez-vous utilisé vos compétences d’encadrement à la prise de décision (decision coaching) auprès de patients et de membres de leurs familles au cours de ces 3 dernières semaines?	☐ Aucun ☐ 1-2 fois ☐ 3-5 fois ☐ 6-10 fois ☐ >10 fois ☐ Pas certain
7.	Avec quelle fréquence avez-vous utilisé un outil d’aide à la prise de décision (p. ex., Le guide familial d’aide à la décision ou autre) auprès de patients et de membres de leurs familles au cours de ces 3 dernières semaines?	☐ Aucun ☐ 1-2 fois ☐ 3-5 fois ☐ 6-10 fois ☐ >10 fois ☐ Pas certain
8.	Documentez-vous les occasions où vous appliquez la prise de décision partagée? Si oui, comment? ____	Toujours Occasionnellement Jamais Pas certain

SVP répondre à chacune des questions suivantes en indiquant le numéro qui correspond le mieux à votre opinion. Certaines questions peuvent vous sembler similaires, mais elles mesurent des aspects différents du comportement énoncé.		
9.	La plupart des parents préfèrent partager la prise de décision.	1, Fortement en désaccord 2, En désaccord 3, Plutôt en désaccord 4, Neutre 5, Plutôt d'accord 6, En accord 7, Fortement en accord
10.	La plupart des enfants préfèrent partager la prise de décision.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
11.	Je crois que je vais utiliser la prise de décision partagée dans ma pratique pédiatrique.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
12.	Je suis capable d’utiliser la prise de décision partagée.	F Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐

13.	Je suis confiant que je pourrais utiliser la prise de décision partagée si je le voulais.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
14.	Pour moi, la prise de décision partagée serait:	1, Extrêmement difficile 2, Difficile 3, Plutôt difficile 4, Neutre 5, Plutôt facile 6, Facile 7, Extrêmement facile
15.	Au meilleur de ma connaissance, la proportion de mes collègues qui utilisent la prise de décision partagée est de:	0-20% 21-40% 41-60% 61-80% 81-100% ☐ ☐ ☐ ☐ ☐
16.	Pensez maintenant à un collègue de travail que vous respectez comme professionnel. À votre avis, utilise-t-il la prise de décision partagée?	0, Jamais 1, Rarement 2, De temps en temps 3, Parfois 4, Fréquemment 5, Habituellement 6, Toujours
17.	La plupart des personnes importantes pour moi dans ma profession utilisent la prise de décision partagée.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
18.	J’ai l’intention d’utiliser la prise de décision partagée.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
19.	Il est éthique d’utiliser la prise de décision partagée.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
20.	Il est acceptable d’utiliser la prise de décision partagée.	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
21.	De façon générale, je pense que la prise de décision partagée serait:	Très inutile Très utile 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
22.	Je planifie d'utiliser la prise de décision partagée au cours des 3 prochaines semaines?	Fortement en désaccord Fortement en accord 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐
23.	De façon générale, je pense que la prise de décision partagée serait pour moi:	Très néfaste Très bénéfique 1 2 3 4 5 6 7 ☐ ☐ ☐ ☐ ☐ ☐ ☐

Question	Énoncé	Pas du tout d’accord	Pas d’accord	Neutre	D’accord	Tout à fait d’accord	Je ne sais pas
24.	L’approche de la prise de décision partagée améliore la participation des parents à la prise de décision en matière de santé.						
25.	L’approche de la prise de décision partagée améliore la participation des enfants à la prise de décision en matière de santé.						
26.	La plupart des professionnels de la santé formés sont en mesure de faire participer les parents à la prise de décision partagée.						
27.	La plupart des professionnels de la santé formés sont en mesure de faire participer les enfants à la prise de décision partagée.						
28.	La plupart des professionnels de la santé formés utilisent la prise de décision partagée avec les parents.						
29.	La plupart des professionnels de la santé formés utilisent la prise de décision partagée avec les enfants.						
30.	J’ai accès à toutes les ressources nécessaires pour utiliser la prise de décision partagée (p. ex., fiches d’aide à la prise de décision pour les patients, information fondée sur des données probantes).						
31.	Je dispose de tout le temps nécessaire pour utiliser la prise de décision partagée.						
32.	Si je suis encore plus de formation, j’utiliserai mieux la prise de décision partagée.						
33.	Mes collègues appuient mon choix d’utiliser la prise de décision partagée.						
34.	Mon gestionnaire appuie mon choix d’utiliser la prise de décision partagée.						
35.	L’établissement où je travaille appuie mon choix d’utiliser la prise de décision partagée.						
36.	Je crois que les parents acceptent bien la prise de décision partagée.						
37.	Je crois que les enfants acceptent bien la prise de décision partagée.						

38. Veuillez inscrire jusqu'à 3 obstacles qui empêchent l'application de la prise de décision partagée et indiquer leur importance. SVP noter, il n'est pas nécessaire de les classer par ordre d'importance vous signalez seulement l'importance que vous accordez à chaque obstacle.

Obstacle #1	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important
Obstacle #2	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important
Obstacle #3	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important

39. Veuillez inscrire jusqu'à 3 facteurs qui facilitent votre utilisation de la prise de décision partagée et les classer par ordre d'importance.

Facteur qui facilite #1	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important
Facteur qui facilite #2	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important
Facteur qui facilite #3	1, Très peu d'importance 2, Peu d'importance 3, Neutre 4, Important 5, Très important

Avez-vous d’autres commentaires, questions ou suggestions? Nous vous prions de ne pas inscrire de détails qui peuvent vous identifier (comme votre nom, votre adresse, des aspects d’une situation particulière où vous ou vos patients vous trouvez, etc.).

Merci beaucoup d’avoir participé à ce sondage!

Parlez-nous un peu de vous.

Où travaillez-vous?

Quelle est votre profession?

- Médecin
- Infirmière
- Orthophoniste
- Ergothérapeute
- Physiothérapeute
- Travailleurs sociaux
- Spécialiste du milieu de l'enfant
- Consultant en comportement
- Autre

Si autre, veuillez spécifier

Quelle est votre spécialité?

Quelle est votre rôle dans l’équipe?

- Professionnel de la santé
- Gestionnaire
- Administrateur
- Personnel de soutien
- Autre

Si autre, veuillez spécifier

Combien d’années d’expérience en soins de santé avez-vous accumulées?
< 1 an
1-5 ans
6-10 ans
11-19 ans
20+ ans

Vous travaillez :
À temps plein
À temps partiel
Occasionnellement
Autre

Quel âge avez-vous?
20-25
26-30
31-40
41-50
51-60
61+
Je préfère ne pas répondre.

Vous êtes :
Un homme
Une femme
Transsexuel ou transgenre
Je préfère ne pas répondre.

Quel est votre plus haut niveau de scolarité obtenu?
Secondaire
Collégial
1er cycle universitaire
2e cycle universitaire
Diplôme professionnel
Je préfère ne pas répondre.
Autre (veuillez spécifier): _________________

Appendix R - Semi-structured interview guide (Study 3)

Semi-structured interview guide

Introduce self and project

Demographic information: *To begin, I would like to ask a few demographic questions to get a better sense of the type of work that you do.*

1) What is your profession?
2) Where do you work (clinic, other organizations)?
3) Do you work in multiple clinics?
4) How often are you in clinic seeing patients?
5) May you describe some characteristics of the children you typically work with?
    a. *Probe: demographics, conditions, types of decisions, who is making decision with them?*
6) Who do you usually report to?
7) When did you complete the shared decision making training/workshop?
8) Have there been organizational changes that have affected your work since you completed the shared decision making training?
9) Who usually leads the process of change within your clinical practice?

Involving children and parents in decisions: *Now I'd like to explore your perceptions of involving children and parents in decision making.*

10) How important do you think it is to involve children and parents in decision making?
11) How often would you say you engage parents and children in decisions about their health (percentage)?
12) What kinds of things do you do to involve children and families in decision making?
13) In your own words, how would you describe shared decision making?
    a. *Describe the main elements of shared decision making, if required*

14) How do you see your role in shared decision making?
15) How have you used your shared decision making skills with patients and families?
    a. *Probe: Decision coaching skills and patient decision aid/Ottawa Family Decision Guide.*

Barriers and Facilitators: *Now I would like to discuss things that make it easy or hard to involve children and parents in decisions about the child's health*

16) What helps you involve children and families in decision making?
    a. *Probe: What would be required to get health professionals to use shared decision making with all patients and families?*
    b. *Probe: What support, resources or changes do you have or need to involve patients and families in decision making?*
17) Please describe a situation where you thought shared decision making children and parents went really well.
18) What gets in the way of you involving children and families in decision making?
19) Please describe a situation when you thought shared decision making or involving parents and children in the decision making process went poorly.
20) Does your clinical practice or organization support you in using shared decision making with children and families?

1. Thank you for your participation!