DEVELOPMENT OF A

SHARED DECISION-MAKING PROGRAM THEORY:

A REALIST SYNTHESIS EXAMINING CONTEXTS AND

MECHANISMS TO ENGAGEMENT

A Thesis Submitted to the College of
Graduate and Postdoctoral Studies
In Partial Fulfillment of the Requirements
For the Degree of Master of Science
In the Department of Community Health and Epidemiology
University of Saskatchewan
Saskatoon

By TAMARA WALDRON

PERMISSION TO USE

In presenting this thesis/dissertation in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis/dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis/dissertation work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis/dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis/dissertation.

DISCLAIMER

The contents of this thesis were exclusively created to meet the thesis requirements for the degree of Master of Science in Community Health and Epidemiology at the University of Saskatchewan. Reference in this thesis/dissertation to any specific commercial products, process, or service by trade name, trademark, manufacturer, or otherwise, does not constitute or imply its endorsement, recommendation, or favoring by the University of Saskatchewan. The views and opinions of the author expressed herein do not state or reflect those of the University of Saskatchewan, and shall not be used for advertising or product endorsement purposes.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Head of the Department of Community Health and Epidemiology
107 Wiggins Road
University of Saskatchewan
Saskatoon, Saskatchewan S7N 5E5
Canada
OR
Dean
College of Graduate and Postdoctoral Studies
University of Saskatchewan
116 Thorvaldson Building, 110 Science Place
Saskatoon, Saskatchewan S7N 5C9
Canada

ABSTRACT

Purpose: Shared Decision-making (SDM) is a style of medical decision-making that focuses on balancing the relationship between patients, physicians, and other key players. SDM is purported to improve patient and system outcomes; however, the potential effectiveness is challenged in part due to gaps in the current literature between theory and implementation. With my team, I conducted a realist synthesis of SDM literature to identify "In which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved patient-centered decisions?" Method: We conducted a seven step iterative process, including: preliminary theory development, establishment of a search strategy, selection and appraisal of literature, data extraction, identification of formal theories, analysis and synthesis of extracted results from literature, and formation of a revised program theory with the input of patients, physicians, nurse navigators, and policy makers from a stakeholder session **Results:** We developed a program theory comprised of eight complex, interrelated mechanisms, three contexts, and a single outcome of engagement in SDM. Conclusion: Our realist synthesis produced a program theory for SDM through the identification of mechanisms which shape the characteristics of when, how, and why SDM will, and will not, work. This research hypothesizes that by facilitating high engagement of SDM, medical consultations will lead to informed, patient-centered decisions.

Acknowledgements

It is of the utmost importance to me to thank the guidance I received from my supervisor, Dr. Gary Groot, and for his continued support throughout the duration of this project. I would further thank my Advisory Committee members, Dr. Linda McMullen and Dr. Nazeem Muhajarine, for their directional assistance throughout my project.

I would further like to acknowledge the support of the Department of Community Health and Epidemiology in providing financial assistance, in the form of a tuition scholarship, for my academic year of 2016 to 2017.

Last, but certainly not least, I would like to thank the support of my research team from the induction of this project through completion. These individuals include: Dr. Gary Groot, Dr. Tracey Carr, Dr. Linda McMullen, Dr. Gill Westhorp, Lori Ann Bandura, Shelley-May Neufeld, and Vicky Duncan. Your assistance and guidance in this project was vital to my success in this project.

Dedication

To my family who always support, always love, and always walk beside me while I work toward my dreams. Thank you for your never-ending belief in me. My ability to achieve my goals is a reflection of your presence in my life.

Love always,

Tami

TABLE OF CONTENTS

LIST OF ABBREVIATIONS	ix
CHAPTER ONE INTRODUCTION	1
1.1: Statement of the Problem	1
1.2: Research Question	2
1.3: Purpose of the Study	2
1.4: Theoretical and Analytic Perspective	2
1.5: Definition of Terms	3
1.6: Chapter Summary	4
CHAPTER TWO BACKGROUND LITERATURE	6
2.1: Shared Decision-making	6
2.2: SDM in Cancer Care	8
2.3: SDM Definitions	9
Table 1: Definitions of SDM.	10
2.4: Models of SDM	10
2.4.1: "Choice Talk, Option Talk, Decision Talk"	10
2.4.2: Ottawa Decision Support Framework (ODSF)	11
2.4.3: Interprofessional Shared Decision-Making Framework (IP-SDM)	11
2.5: Facilitators of SDM	13
Table 2: Facilitators for SDM Implementation	13
2.6: Barriers to SDM Implementation	16
Table 3: Barriers to SDM Implementation	16
2.7: Substantive Theories Supporting Shared Decision-Making	20
2.7.1: The Theory of Planned Behaviour	20
2.7.2: Feeling of Rightness (Dual-Process Theory of Decision-Making)	24
2.7.3: Normative Expected Utility Theory	26
2.8: Chapter Summary	27
CHAPTER THREE THEORETICAL FRAMEWORK	29
3.1: Realist Philosophy	29
3.1.1: Critical and Scientific Realism	31
3.2: Chapter Summary	34
CHAPTER FOUR ANALYTICAL FRAMEWORK	35
4.1: Realist Syntheses	35

	Figure 6: Process for Conducting a Realist Synthesis (179).	40
	4.2: Chapter Summary	41
Cŀ	HAPTER FIVE METHODS	42
	5.1: Chapter Introduction	42
	5.2: Methods Overview	42
	Figure 7: Realist Synthesis Process (18).	43
	5.3: Preliminary Program Theory Development	43
	5.4: Search Strategy Development	44
	Figure 8: Initial Medline Search Strategy.	45
	Figure 9: Secondary Medline Search Strategy.	46
	5.5: Literature Selection and Appraisal	47
	5.6: Data Extraction	48
	5.7: Identification of Substantive Theories	48
	5.8: Analysis and Synthesis Process	48
	5.9: Stakeholder Input and Dissemination of Revised Program Theory	49
5.	10: Revised Program Theory Refinement	52
5.	11: Chapter Summary	52
Cŀ	HAPTER SIX RESULTS	54
	6.1: Chapter Introduction	54
	6.2: Preliminary Program Theory Development	54
	6.3: Search Results and Selection and Appraisal of Documents	54
	Figure 11: Screening and Mechanism Formation Process.	55
	6.4: Data Extraction	55
	6.5: Identification of Substantive Theory	56
	6.6: Analysis and Synthesis	56
	Table 4: Initial Key Mechanisms	58
	Figure 12: Initial Program Theory.	59
	6.7: Expert Consultation and Stakeholder Session	59
	6.8.1: Expert Consultation	59
	6.8.2: Stakeholder Session	60
	6.8: Revised Program Theory	60
	Figure 13: Revised Program Theory.	61
	Figure 14: Revised Focused IP-SDM Mechanisms Map.	62

Table 5: Definition of Concepts in the Revised Program Theory	63
Table 6: Descriptions of Key Mechanisms in the Revised Program Theory	66
Table 7: Substantive Theories Underpinning the Revised Program Theory	72
6.9: Chapter Summary	73
CHAPTER SEVEN DISCUSSION OF RESULTS	74
7.1: Discussion of Results	74
7.1.1: Key Mechanism Sets in Relation to SDM	76
Table 8: Connecting Processes between Mechanism Sets and IP-SDM Steps	77
7.1.2: Formation of Testable Hypotheses	78
7.1.3: Support of Substantive Theories	78
7.1.4: Comparison of Findings to Current Literature	79
7.2: Limitations	80
7.3: Future Implications	81
7.4: Future Research	81
7.5: Chapter Summary	83
CHAPTER EIGHT REFERENCES	84
CHAPTER NINE APPENDICES	97
9.1: A: Preliminary Program Theory	97
9.2: B: All Articles Used for Synthesis	97
9.3: C: All EA statements	105
9.4: D: EA Thematic Groups by Category	131
9.5: E: Theories Identified in SDM Literature Review	134
9.6: F: All Identified Mechanisms	136
9.7: G: Expanded IP-SDM Mechanism Man	140

LIST OF ABBREVIATIONS

C: Context

CMO: Context- Mechanism-Outcome

CMOC: Context-Mechanism-Outcome Configuration

EA: Explanatory Account

FOR: Feeling of Rightness

HCP: Health Care Professional

IP-SDM: Interprofessional Shared Decision-making

M: Mechanism

O: Outcome

ODSF: Ottawa Decision Support Framework

RAMESES: Realist and Meta-narrative Evidence Syntheses: Evolving Standards

SDM: Shared Decision-making

ToPB: Theory of Planned Behaviour

CHAPTER ONE INTRODUCTION

1.1: Statement of the Problem

Historically patients have often been excluded from the treatment decision-making process. Until the end of the 1970s, patients routinely experienced the paternalistic decision-making style dominant at the time (1, 2). However, paternalistic decision-making, which gives decision power to the physician without consideration of patient values or preferences (3, 4), did not meet the decisional needs of patients (5, 6). Paternalistic decision-making has been increasingly seen as inappropriate for use in medical decision-making due to historical abuse of power by physicians combined with increased patient access to information, which created a social movement of distrust towards physicians (5). Shared Decision-Making (SDM) was introduced as an alternative style of decision-making in the 1980s to 1990s with the aim of creating a structure for facilitating patient-centered decisions, as it focuses on the sharing of power and values between all parties involved (1, 6).

SDM has been implemented and analyzed globally and research has indicated that patients experience improved outcomes when SDM is applied (7, 8). Such improvements include increased satisfaction (9, 10), improved affective-cognitive outcomes (11), and reduced decisional conflict/anxiety (12, 13). However, many gaps still exist in the field of SDM, as conceptual development (i.e., descriptive frameworks and models) and empirical testing exist separately from one another rather than informing each other. This has created a disparity between theoretical understandings and practice. Furthermore, research has not linked *how* facilitators and barriers affect patient engagement in SDM, for *whom*, in *what circumstances*, or *why*. A successful, implementable model of SDM requires that research be done to identify the nuances of SDM, identifying *what works*, for *whom*, in *which circumstances*, and *why*. Accordingly, we have adopted a realist approach to this project, with the primary goal of building theory around these questions.

1.2: Research Question

The primary research question guiding this work was:

"In which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved patient-centered decisions?"

The research question was broken down into three sub questions that aimed to unpack the nuances of SDM:

- 1. What mechanisms facilitate or hinder patient and health care provider engagement in SDM?
- 2. What contexts can affect the expression of the identified mechanisms?
- 3. What are the outcomes that form between identified contexts and mechanisms?

1.3: Purpose of the Study

The purpose of this study was to conduct a realist synthesis to identify contexts (C), mechanisms (M), and outcomes (O) within SDM literature as they relate to engagement within SDM. SDM engagement was chosen as the focal outcome, as this project serves as the first step towards understanding how SDM works. We believe that an understanding of engagement is a prerequisite for assessment of further outcomes. A program theory for SDM was developed as the result of this project in order to create a refined theory of how SDM can be successfully implemented during medical consultations. Using stakeholder input, we formed a program theory based on the literature and supported by real-life users, describing *how* SDM does or does not *work*, as well as in which *situations* and *why*.

1.4: Theoretical and Analytic Perspective

Realist philosophy acknowledges that the world is real but individual perceptions of the world shift based on interpretations and social nuances (14-18). Rooted in realist philosophy, realist research is an emerging methodology that can be applied to both qualitative and quantitative inquiry. Although popularized in the field of program evaluation (16) realist inquiry has spread into many fields, including health research (19-22).

As a developing methodology, researchers must understand the historical philosophy of the approach if they are to produce high-quality findings. Realist methodology stems from its philosophical backgrounds, including critical and scientific realism (further discussed in chapter three) (16, 23). Researchers may ground themselves in any realist philosophical background but must clearly identify the one to which they adhere, ensuring that users of their work will interpret information through the appropriate lens.

1.5: Definition of Terms

The following operational definitions are used throughout this research project:

<u>Context (C):</u> A pre-existing factor that, when interacting with a mechanism, can influence a specific event. Contexts can influence the level a mechanism may be expressed.

<u>CMOCs:</u> The configuration of a context, mechanism, and outcome to form a testable hypothesis.

<u>Critical Realism:</u> The acceptance of "... a real world that exists independently of our perceptions, theories, and constructions [...] while accepting ... [that] our *understandings* of this world is inevitably a construction from our own perspectives and standpoint" (24).

<u>Health Care Provider (HCP):</u> Any health service provider involved in the SDM process, including, but not limited to, physicians, nurses, physical therapists, dietitians, and social workers.

Mechanism (M): An invisible factor (such as a psychological construct) that often displays itself in a gradient nature such that it can present differently in each encounter. These agents of change create regularity for a process which cannot be directly observed (15). For example, a dimmer switch may cause low light or bright light, depending on how high the switch is turned on.

<u>Mechanism Set:</u> A label applied to mechanisms relating to the same concept but displaying in varying manners (for example, high versus low anxiety).

<u>Middle-Range Theory:</u> A level of theory abstraction describing uniformities of social behaviour that can be expanded to form testable hypotheses by configuring features of an intervention together.

Outcome (O): The product of an interaction between a context and a mechanism.

<u>Program Theory:</u> A theory describing how a program or intervention is hypothesized to work, including the description of contexts, mechanisms, and outcomes (15). This can exist in multiple forms: preliminary program theory (initial rough understanding) and revised program theory (refined theory following a realist synthesis).

<u>Realist Evaluation:</u> The testing of realist hypotheses (i.e., CMOCs) by iterative analysis and refining in order to gain a clearer understanding of how contexts and mechanisms interact to create relevant outcomes.

<u>Realist Synthesis (Realist Review):</u> An examination of literature intended to determine nuances of a program by unpacking the reasoning(s) and contexts for successful or unsuccessful implementation.

Retroduction: The process of extracting empirical knowledge to identify theoretical patterns, which can aid the conceptualization of patterns in data, thereby combining deductive and inductive reasoning (25). Retroduction links evidence to social theory in an iterative fashion to combine both theoretical and empirical observations (25).

<u>Shared Decision-Making (SDM):</u> A style of decision-making that balances the power between health care providers and patients with a focus on creating a treatment decision that both parties agree on and that centres around the values and preferences of the patient.

<u>Scientific Realism:</u> The "view that theories refer to the real features of the world... refer[ring] to whatever it is in the universe ... that causes the phenomena we perceive with our senses" (24).

<u>Substantive Theory (or formal theory):</u> Formal theories that have been previously established in literature and that are descriptive of the underlying reasoning or causation of an action or process.

1.6: Chapter Summary

The objective of this research project was to identify the contexts, mechanisms, and outcomes that influence SDM engagement between health care providers (HCPs) and patients.

To better understand these nuances, we employed realist research methods to identify CMOCs in

literature. The following chapters outline the background of SDM and realism, describe the study methods, present our results, and discuss our findings.

CHAPTER TWO

BACKGROUND LITERATURE

2.1: Shared Decision-making

Shared Decision-Making (SDM) is a form of decision-making that focuses on creating a balanced relationship between patients and physicians to help them arrive at a mutually agreed-upon medical treatment decision (1, 26). While previous works have extensively examined SDM, successful systematic integration is uncommon (27-29). Contexts affecting the SDM process are often unspecified or poorly described (30), and mechanisms often do not exist in literature.

Although a fair amount is known about SDM, the relevant literature is limited to describing its conceptual properties (31-33) or empirical implementation (34, 35). Empirical literature has begun to identify promoting and inhibiting factors that affect SDM implementation, establishing subsets of patients who are more likely to prefer the use of SDM, including females (32, 36, 37), younger individuals (32, 36, 38), and those who have a severe diagnosis (32, 39). Literature has yet to examine *how* these factors act to inhibit or promote SDM, as they do not connect back to the conceptual literature. Conceptual literature is also often not applied to implementation strategies in empirical studies, resulting in SDM implementations that are not theoretically supported. As the first step to further understanding how SDM works, we have focused this synthesis on the main outcome of patient and HCP engagement. We do believe that further outcomes exist beyond this, but exploration of the facilitators and inhibitors of engagement is needed for any determination of how to bring about successful SDM implementation.

No standardized strategy or set of requirements indicates how to implement SDM, but several consistently acknowledged key attributes of SDM include the following:

- definition and explanation of the decision that needs addressing (32, 40, 41),
- presentation of option(s) (1, 40, 42, 43),
- information and preference exchange (40, 44-46),
- discussion of pros and cons (40, 47, 48),
- discussion of risks (1, 6, 49, 50),
- patient values and preferences elicited with physician knowledge and recommendations (40, 41, 51-54),
- checks for understanding throughout the process (40),
- the reaching of a mutual decision (1), and
- the fostering of trust in the patient–physician dyad (55-57).

The individuals involved in these discussions vary; many sources focus solely on the patient–physician dyad (6, 58-61), but recent literature has included other HCPs and patient supports (such as family and friends) (31, 62). SDM is known to increase patient satisfaction (32) and treatment adherence (45, 63) when properly implemented.

Research has established that the majority of patients prefer SDM in their decision-making process (38, 64-66). In one cohort surveyed for their involvement preferences, nearly all patients (96%) indicated that they wished to have all options presented from their physicians and in relation to their preferences (37). This desire coincides with a key tenet of SDM – knowledge and preference exchange (40, 41, 51, 53, 67). Despite these findings, previous studies indicate that SDM is implemented in approximately a third of consultations (65), significantly less often than patients desire (68).

When HCPs implement SDM, they should assess the patient's desired level of involvement. Previous studies indicate that preference mismatch is likely to occur when HCPs do not explicitly inquire about patient preferences (5, 65, 69). Patients may also have a preferred level of involvement for their families. Evidence shows that patient involvement preferences may vary depending on disease severity (51, 56, 70). Some patients desire high family involvement, whereas others prefer to make their decision alone (32, 39, 71). Patients may have different preferences with a less serious disease than they would with an advanced disease (39, 72, 73). HCPs should thus continually check patient preferences throughout their decision-

making process. Preference matching is known to decrease anxiety (8) and create higher satisfaction with treatment (8) and in life after disease (7). Conversely, research shows that patients who do not have matched preferences are actively dissatisfied with their care (51, 74).

Although many HCPs support SDM use (52, 75), implementation does not necessarily correlate to their support level (27, 28, 32). HCPs who choose to implement SDM believe that it leads to improved clinical outcomes (27, 76, 77), such as increased treatment adherence (63, 78). Those who do not employ SDM in their consultations often cite fear of malpractice (77) and extended time requirements as barriers (27, 52, 79). In practice, SDM's effect on HCP time is uncertain, with some HCPs indicating that time increases when practicing SDM (63, 80) but others indicating no change (81). Studies have found that the amount of information exchange increases as a direct correlation with consultations' length (82). HCPs who practice SDM and those that do not have both indicated that training may be necessary for proper implementation (52, 80, 83).

2.2: SDM in Cancer Care

SDM is also useful in complex care, as its emphasis on value and preference exchange can help determine the best course of treatment for a patient. Cancer care is often used as an exemplar of the value of SDM in treating complex diseases, particularly because of the complexity stemming from having a variety of options (84) with a lack of clear evidence, potentially high risks, and the multidisciplinary nature of oncology care (85). Patients' need to make multiple decisions throughout the process can be overwhelming (84). As technology continues to progress and new treatments develop, patients are given an increasing number of options, corresponding with an increased level of decisional conflict and anxiety (4, 18). The use of SDM can allow patients and HCPs to openly discuss these potential options and how they fit with a patient's preferences and values, leading to an informed patient-centered decision.

The natural fit between SDM and oncologic care has resulted in a body of SDM literature specific to cancer. One study examined the perspectives of cancer patients regarding their care, satisfaction, and treatment experience (86). 48% of patients did not feel satisfied with the amount of information they received about their disease and potential options, and a quarter felt as if they had no options for treatment (86). Notably, 90% of surveyed patients desired written information yet were not given this option (86). Scarcity of information has been echoed in other studies of a

variety of cancer cohorts (51, 87). Some oncology patients report long-term deficits, such as chronically reduced energy levels (95%) and development of secondary cancers, cardiovascular complications, and infertility (32%), as a result of their treatment (86). Considering the possibility of such deficits from treatment, it is important that patients be well informed so that they can make the best decision for their circumstance.

Slight incongruities have been shown to exist between how patients and HCPs perceive provided care. Patients often feel that their informational and decisional needs are unmet by their HCP. Correspondingly, only 56% of oncologists and 69% of surgeons report using SDM in their typical practice regime (27). Although these self-reported rates are slightly higher than patients perceive, nearly 90% of both oncologists and surgeons report that they are comfortable implementing SDM in cancer care (27). This indicates the existence of additional HCP barriers to SDM implementation.

Examination of complex decisions, such as those stemming from a cancer diagnosis, along with variability on the HCP level, can help us begin to understand engagement within SDM. Although this project uses oncologic decision-making as a distinct example of use within SDM, we also explore decisions outside oncology, such as mental health diagnoses and coronary care.

2.3: SDM Definitions

Definitions of SDM vary widely (1, 26, 88); however, consistent themes appear, including patient autonomy, dynamic/interactive exchange between at least two people, discussion of preferences and values, discussion of options, and mutual consensus. For this project, I have chosen to define SDM as the style of decision-making that balances the power between health care providers and patients with the aim of creating a treatment decision that both parties agree on and that centres on the values and preferences of the patient. Table 1 outlines selected definitions found within the literature, chosen to highlight the similarities and differences that exist among descriptions of SDM.

Table 1: Definitions of SDM.

This table outlines the various definitions of SDM found during the literature review conducted for this project.

Definitions of SDM

- (3) "Patient and physician interact at all stages of the decision-making process. Patient brings intimate knowledge of health history, illness experiences, tolerance for pain, lifestyle, personal values and benefits, etc., while physician presents information regarding the history of the disease and risks and benefits."
- (26) "Simultaneous interactive process between the physician and patient involving information exchange, deliberation of treatment preferences and determination of treatment through consensus."
- (1) "Involve at least two people (physician and patient) with family and friends playing a variety of roles within the medical decision process."
- (64) "Patient engagement in decision-making, use of patient decision aids, and the need to ensure patients' understanding of the seriousness of the diseases and available treatment alternatives (e.g. risks, benefits, and uncertainties)."
- (5) "Process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision board based on mutual agreement."

2.4: Models of SDM

No universally accepted, standardized, and implementable model of SDM is available (31-33). However, three commonly used models are the Interprofessional Shared Decision-Making Model (IP-SDM) (cited 1,063 times) (89-92), the Ottawa Decision Support Framework (ODSF) (cited 477 times) (9) and "Choice Talk, Option Talk, Decision Talk" (original article cited 941 times) (29). These three models are discussed further hereafter.

2.4.1: "Choice Talk, Option Talk, Decision Talk"

"Choice Talk, Option Talk, Decision Talk" simplifies the SDM process to an easily accessible three-stage model (29, 93-95). The first stage, choice talk, requires awareness that a choice exists, elaboration of treatment options, and justification of each option. This stage also emphasizes patient values and preferences and explores decisional uncertainty for each option

(29). Option talk, the second stage, includes the checking of patient and physician knowledge, discussion of options with focus on harms and benefits, and provision of any decision support necessary or available to the patient (29). The final stage, decision talk, is focused on the final decision, including the elicitation of an agreed-upon preference with the opportunity for the patient to review the options further (29, 93-95). The largest drawback to this model is the sole focus on the patient–physician dyad. It also does not acknowledge facilitators or inhibitors of SDM.

2.4.2: Ottawa Decision Support Framework (ODSF)

The ODSF helps guide the development of interventions seeking to support patients and HCPs and prepare them for an SDM experience (83, 96, 97). ODSF focuses on the decisional needs of a patient and emphasizes the need for decisional quality (32). To achieve a high-quality decision, ODSF argues, SDM should address decisional conflict, patient knowledge, patient values, available supports, decision type, and any patient characteristics that might affect a decision (32). This model is often adapted for use under specific conditions, such as cardiovascular disease (97). However, the ODSF is weakened by its limited inclusion of supports.

2.4.3: Interprofessional Shared Decision-Making Framework (IP-SDM)

IP-SDM is innovative in its emphasis on including individuals outside the patient—physician dyad (41, 67, 92, 98, 99) (Figure 1). IP-SDM depicts the iterative process of decision—making, focusing as it does on the development of a patient-centered outcome, and clearly outlines common tenets of SDM: decision to be made, information exchange, values/preferences exchange, feasibility, preferred choice, actual choice, and implementation (67). The iterative nature of IP-SDM replicates the natural progression of a decision-making process.

Figure 1: IP-SDM (67).

This extracted diagram outlines the IP-SDM model as designed by Légaré and colleagues in 2010.

Environment Social norms · Organizational routines · Institutional structure Patient/Family team Interprofessional team Initiator of SDM process Family/Surrogate/ Significant others Decision to be made Information exchange Values/preferences Feasibility Preferred choice Actual choice Implementation Outcomes Deliberation leading to a common understanding

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

IP-SDM is strengthened by the incorporation of social supports (67, 98). This may increase the cultural appropriateness of this model, as certain communities emphasize the inclusion of family (100). Social supports may also assist in situations in which a patient has limited capacity to participate (26), such as in end-of-life care (36).

Attempts have been made to implement IP-SDM in health systems around the world, but a review of IP-SDM implementation concluded that this model is hindered by several barriers. One clear barrier was the absence of theory underpinning the model: "[Researchers] identified 15 unique frameworks, none of which described in any detail how teams of health professionals shared in decision making with a patient" (101). However, this team did acknowledge that

conceptual building blocks exist and explicitly highlighted the opportunity to refine IP-SDM to include theory. One aim of this research is to meet this challenge.

2.5: Facilitators of SDM

SDM literature has explored variables that appear to affect the success of SDM. Facilitators of the process are noted less frequently than barriers, a fact which may stem from a lack of use of implementation theory. Many identified facilitators are not fully explored for *how*, *why*, and for *whom* they affect the SDM process, which has created a disparity in understanding between available literature and successful implementation of SDM. Regardless of the depth of exploration currently available, generalized facilitators mentioned in the literature are noted in Table 2:

Table 2: Facilitators for SDM Implementation
Identified facilitators based on the current status of literature

Facilitators fo	r SDM Implementation
Age	(5, 32, 36-38, 66, 102-106)
	Younger individuals are more likely to prefer
	SDM.
Breast cancer diagnosis	(32)
	Breast cancer patients have been shown to
	prefer SDM.
Ethics	(52, 99, 107-111)
	Professional ethics may encourage HCP use
	of SDM.
Education	(72, 103, 104)
	Those who have a higher level of education
	are more likely to prefer SDM.
Family / friends / external support	(27, 32, 60, 112, 113)
	The ability to involve patient supports when
	preferred can improve the likelihood of
	patients' preferring SDM use.

Increase focus on patient-physician	(6, 7, 32, 56, 58, 59, 61, 103, 112)
balance relationship	The shared power is likely to facilitate SDM
	implementation for patients.
Multiple options	(32)
	Having multiple options is likely to facilitate
	SDM implementation, there being a more
	pressing need to explore each option
	thoroughly.
Perception of positive effect on patient	(110, 114)
outcomes	
Reduced resentment	(26)
Higher patient satisfaction with	(8, 9, 26, 43, 111, 115-117)
decisions	
Reduced decision conflict	(9, 97, 116, 118-120)
Increased patient knowledge	(1, 26, 37, 40, 41, 44-46, 54, 56, 57, 110, 121
	123)
Physician ambivalence about treatment	
type	A physician who does not have a preference
	is more likely to implement SDM to
	determine patient preference.
Positive effect on clinical process	(29, 43, 112, 114, 124)
	An HCP who believes that there are positive
	outcomes of SDM is more likely to facilitate
	the intervention.
Potential cost savings after SDM	(95)
implementation	A system that views SDM as a source of cost
	savings is more likely to implement the
	intervention.

Provider motivation	(112, 114, 125)
	An HCP who is motivated to implement SDM
	is more likely to implement SDM.
Reduction of the opportunity for	(52, 109, 110, 126, 127)
malpractice	An HCP who believes that SDM can reduce
	the likelihood of being sued is more likely to
	implement the intervention.
Severe diseases	(32)
	Severe diseases that have the potential for
	longer-term effects on the patient increase the
	likelihood of SDM implementation for both
	the patient and the HCP.
Smoking status	(105)
	Individuals who smoke are more likely to
	prefer to use SDM.
Social class	(105)
	Higher social class corresponds to increased
	preference for SDM.
Specialty	(79)
	Oncologic, obstetric, and gynecologic
	physicians prefer SDM implementation.
Trust between physician and patient	(27, 43, 54, 61, 79, 118, 128-130)
	When trust is established, both parties are
	more likely to want to engage in SDM.

2.6: Barriers to SDM Implementation

Significantly more implementation barriers are described in the literature compared to facilitators, yet information is lacking that could lead to an understanding of *how* barriers affect the SDM process, as well as for *whom*, *why*, and *in what circumstances*. Table 3 provides a comprehensive listing of barriers to SDM implementation that have been found in the current literature:

Table 3: Barriers to SDM Implementation Identified barriers based on a review of the literature.

Cognitive bias	(131)
	The first option presented might seem
	best regardless of what it is, limiting
	SDM implementation.
Comorbidity	(27, 36, 77)
	Having multiple diseases may make it
	more difficult for a patient to engage
	due to the need to manage multiple
	outcome factors.
Concern about bad outcomes	(64, 77, 132)
	An HCP who is concerned about
	negative professional outcomes (such
	as malpractice) is less likely to
	implement SDM.
Education	(2, 52, 79, 131)
	Lower education status reduces the
	likelihood of successful SDM
	implementation.
Funding	(3, 109, 133)
	Publicly funded health care systems
	are pressured to remain economical.

Health care provider	bias	(77, 118, 134)
	Drive to conduct	(3, 63)
	procedure for	
	remuneration	
	Use of power to	(55, 135)
	persuade patient	
	Reluctance to	(135)
	divulge certain	
	treatment options	
	Physician bias	(111)
	against nurses	
	Willingness to	(111)
	withdraw life	
	support	
High clinic volume		(32, 79, 136)
		An HCP at a busy clinic may think
		time lacking for implementation of
		SDM.
Lack of applicability	due to clinical situation	(32, 82, 114)
		An HCP who does not think a
		situation is appropriate for SDM will
		not implement the intervention.
Lack of applicability	due to patient	(7, 27, 32, 53, 77, 114, 118, 133)
characteristics		An HCP who does not believe that a
		patient is able to engage in SDM will
		not implement the intervention.
Lack of measurement	ts with which to	(1, 95)
determine implement	ation success	Lack of clear evidence for how to
		successfully implement SDM can

	reduce the likelihood of implementing
	the intervention.
Lack of physicians' knowing patients	(79)
	In the absence of a pre-existing
	relationship, an HCP may feel
	uncomfortable engaging with the
	patient and implementing SDM.
Lack of training	(27, 32, 52, 54, 124, 127, 132, 137,
	138)
	An HCP who is not trained in how to
	implement SDM is less likely to use
	the intervention.
Language barriers	(77, 79, 100)
	When the HCP and patient are
	separated by a language barrier, SDM
	is less likely to be used.
Lower socioeconomic	(5, 47)
	Patients who have a lower
	socioeconomic status are less likely to
	experience successful SDM
	implementation.
Older age	(52, 79, 127)
	Older patients are more likely to
	desire paternalistic decision-making,
	believing that the HCP has the most
	appropriate knowledge of what will
	be best for them.
Patient desire to be a "good" patient	(113, 128, 134)
	If a patient wants to be viewed by the
	HCP as an "easy" patient or fears

		being viewed as a nuisance, SDM is
		less likely to be successfully
		implemented.
Patient illness symptom	s	
	Nausea can decrease	SDM (86, 138)
	participation.	
	Extremely severe	(103)
	symptoms.	
Patient role uncertainty		(113, 124)
		When a patient is uncertain how
		much he or she is "allowed" to
		participate in the process, SDM is les
		likely to be successfully
		implemented.
Perception of patient co	gnitive ability	(27, 79, 134, 138, 139)
		An HCP who perceives that the
		patient is not cognitively capable of
		engaging in SDM is less likely to
		implement the intervention.
Physician	(106)	
characteristics	An HCP who wishes	s to perform surgery is more likely to
	recommend surgical	options, thereby frustrating true SDM
	implementation.	
Physician-patient	(131)	
power imbalance	When an HCP does	not share decision power with the patient
		ntation will not occur.

Specialties			
	Cardiologists are less (136)	
	likely to implement SDM.		
	Radiation oncologists and (140, 141)	
	urologists differ in		
	opinions but often have to		
	work together, reducing		
	successful SDM		
	implementation.		
Time constraints	(1, 2, 2	7, 32, 47, 52, 54, 64, 79, 80,	
	82, 87,	109, 114, 118, 127, 134, 142-	
	144)	An HCP who believes that SDM	
	An HC		
	takes lo	onger to implement than	
	current	practice is less likely to	
	implem	nent the intervention.	

2.7: Substantive Theories Supporting Shared Decision-Making

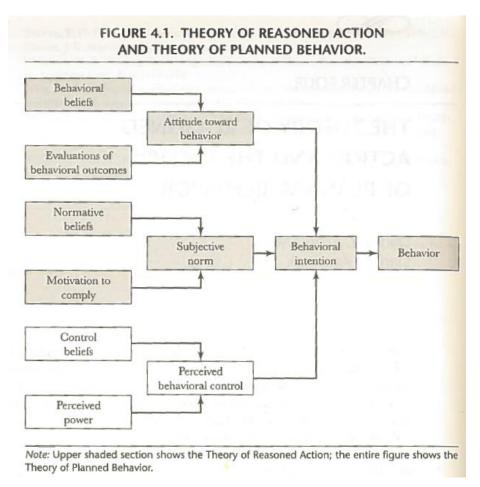
Previous research has identified substantive theories which may underpin SDM. Substantive theories are theories that have already been significantly developed, often acting as grand psychological theories, and that can aid understanding of how key factors work. We have identified three substantive theories that are potentially relevant to SDM: the Theory of Planned Behaviour (ToPB), Feeling of Rightness (FOR), and Normative Expected Utility Theory.

2.7.1: The Theory of Planned Behaviour

The Theory of Planned Behaviour (ToPB) is an extended version of the Theory of Reasoned Action, both developed by Icek Ajzen (145, 146). Both theories are formulated as a way of predicting individual behaviours, but the ToPB extends the Theory of Reasoned Action by including the perception of control over a certain behaviour (146). Thus the ToPB incorporates an individual's perception of whether he or she truly has the power and control needed to engage in a behaviour.

The ToPB postulates that three factors are required for an appropriate and accurate prediction of whether an individual will engage in a certain behaviour: *behavioural beliefs*, *normative beliefs*, and *control beliefs* (145, 146). These three belief categories interact with intent and perception to form *attitude towards behaviour*, *subjective norm*, and *perceived behavioural control* (147) (Figure 2). At its core, the ToPB is designed to predict an individual's behaviour based on that individual's beliefs, applied social pressures, and level of control within a given situation. Knowing these three influences on an individual can inform predictions of whether the individual will enact a behaviour and what that behaviour might be.

Figure 2: The Theory of Reasoned Action and Theory of Planned Behaviour (147). The entirety of this extracted diagram depicts the Theory of Planned Behaviour.



Attitude towards behaviour: The attitude an individual holds towards a behaviour is determined by behavioural beliefs and evaluation of behavioural outcomes (145). Behavioural beliefs are the opinions a person has of a certain behaviour (146). These combine with the individual's assessment of expected outcomes if he or she chooses to enact the behaviour within the current context. Together, these form a context-specific attitude towards the behaviour that can be thought of as the individual's beliefs about and assessment of the potential effect of his or her beliefs given the situation.

Subjective norm: Subjective norms are informed by an individual's *normative beliefs* and his or her *motivation to comply*. Normative beliefs are the expectations of individuals other than the patient (145), paired with the level of motivation to comply with the beliefs held by others (145, 146). The resulting subjective norm is the combination of the applied social pressure and the impetus the individual has to adhere to this pressure.

Perceived behavioural control: The level of control that an individual believes he or she holds is determined by the combination of *control beliefs* and *perceived power*. Control beliefs are those existing factors that an individual believes could facilitate or hinder the performance of a specific behaviour and are paired with the perceived power of said factors (145-147). Explicitly, if an individual strongly believes that an existing factor will inhibit him or her from performing a behaviour, then the perceived power of his or her control would decrease. The perceived behavioural control is thus determined by the combination of these levels of actual and perceived control.

<u>Behavioural intention:</u> Combining attitude towards behaviour, subjective norms, and perceived behavioural control, an individual subconsciously forms his or her intentions to engage in the behaviour in question. This process leads to the actual behaviour engaged in by the individual (145). This can include choosing not to perform a specific behaviour.

2.7.1.1 Application of the ToPB in SDM

The ToPB has been applied to many different areas, including two applications within SDM. One study examined how family physicians intend to use SDM based on their attitudes, subjective norms, and perceived behavioural control, as measured by a questionnaire (148). The authors sought to identify facilitating factors of physician interest in attending SDM continuing professional development programs (148). This study is weakened by the lack of integrating findings into SDM. Although the authors assessed physician intent to implement SDM in the consultation, physician understanding of SDM and its facilitators were not evaluated. Even though this research is useful for promoting a professional development program, researchers must gain a deeper understanding of how facilitators work, as well as in which situations and why, to further the understanding of SDM.

A second study used the Theory of Reasoned Action, the pre-cursor to the ToPB, to understand SDM. The authors used the Theory of Reasoned Action to assist in the identification and validation of norms, beliefs, and behavioural intent with a view to understanding the reasons men engage with SDM during medically uncertain situations (57). This article identified factors necessary for an individual to participate in SDM, such as a positive relationship with the HCP. However, failed to explore how these factors works, as well as in which situations and why.

Also, the authors did not link the factors back to a framework of SDM to create an applicable theory within this area.

2.7.2: Feeling of Rightness (Dual-Process Theory of Decision-Making)

A Feeling of Rightness (FOR) is a metacognitive process formulated based on a heuristic response that results in an analytic process (Figure 3) (149). This response is a construct that is introduced within a dual-process theories to decision-making. Dual-process theories postulate that two types of systems are involved in decision-making: system one (heuristic response) and system two (rationality) (150). The FOR would be an example of system one reasoning, with the output of the formed heuristic resulting in the necessity for system two reasoning. An individual will make an assessment about what feels right based on his or her intuition, which will create a FOR that can be either strong or weak.

Figure 3: Feeling of Rightness (149).

This extracted diagram explains how an individual develops a feeling of rightness and the resulting outcomes and responses.

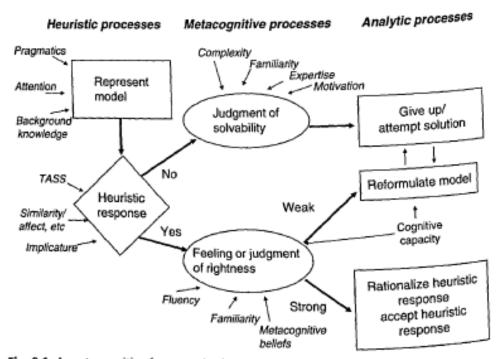


Fig. 8.1 A metacognitive framework of reasoning.

Forming a heuristic response: The formation of a heuristic response is done as a *natural* assessment to a stimuli and is completed without any voluntary control – assessments are made implicitly and automatically (149, 151). These natural assessments are formed by initial impressions of the stimuli, which can include physical and abstract properties (such as affective valence, level of expectancy, and level of familiarity) (151, 152). These natural assessments are also influenced by the individual's reasoning skills, by how a problem is framed, and by the level of priming that has occurred (149, 151).

Forming a Feeling of Rightness: The strength of an individual's FOR is formed by the initial heuristic response. However, additional determinants assist in the formation of a strong or weak FOR. The strength of the FOR is dependent on how easily the heuristic response is accessed or processed by the individual (149, 153). Specifically, those who experience an easily processed heuristic response will accept it – correctly or incorrectly – without further assessment (149). A weak FOR may result if an individual has little familiarity with the situation or stimuli, creating a more difficult retrieval process for the heuristic response. This will create a more difficult retrieval process and likely result in the individual's rejecting the assessment.

<u>FOR informing action:</u> Once an individual has formed a FOR, regardless of strength, it can affect the individual's action in four ways (149):

- 1) Acceptance of heuristic with minimal analysis: If the individual forms a heuristic that he or she believes meets the needs of the situation, he or she is likely to experience a strong FOR and will not assess the situation further. Similarly, if the heuristic response results in a strong FOR that an action will not adequately meet the needs of the situation, the individual will abandon the process without further analysis (149).
- 2) Rationalization or justification of heuristic: This result often obtains when the individual is given more time to understand and analyze his or her initial heuristic response (149), regardless of strength of FOR. However, it is unlikely to produce a different result than a less analyzed process (i.e., example number one) (149, 154, 155), as the individual is simply reasoning that his or her initial heuristic response is accurate (154).

- 3) Reformulation of initial model: When an individual does not trust his or her FOR (low strength FOR), he or she might aim to reformulate his or her initial model with the intent of finding a new heuristic response (149). This often takes a large amount of effort and a high cognitive ability and is less likely to be chosen (149, 156, 157).
- 4) Failed reformulation and acceptance of initial response: When an individual engages in the effort to reformulate his or her initial model but the resulting heuristic is less plausible than the original, the individual will likely accept his or her initial response (149).

How an individual interprets a heuristic response, and how the resulting FOR forms, varies depending on the problem presented to the individual. How familiar and how quickly an individual forms a heuristic is likely to determine the resulting actions of that individual. Accordingly, this theory can help predict the behaviour of an individual – but its application in medical decision-making has yet to be explored.

2.7.3: Normative Expected Utility Theory

The Normative Expected Utility Theory has yet to be linked to SDM, but it has been connected to general health decision-making literature (158, 159). This theory is often applied as a means of analyzing decision-making in uncertain situations (159). The Normative Expected Utility Theory relies on determination of an individual's preferred course of action dependent on *transitivity* and *independence*, which together form the perceived *utility* of a decision (159):

<u>Transitivity</u>: The transitivity between multiple options can be comparative. If an individual prefers option one to option two and option two to option three, then we can conclude that option one is preferred to option three (159).

<u>Independence</u>: Independence will result in an individual's having a greater preference for option one, given a certain probability against option three, than for option two given the same probability against option three (see Figure 4). Thus option one will be selected regardless of the probabilities of likeliness.

Figure 4: Expected Utility Theory: Independence Principle (159).

This extracted diagram demonstrates that given a preference for option a, option a will continue to be selected over option b, regardless of probabilities between the three options.

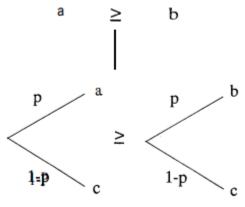


FIGURE 1. The independence principle.

<u>Utility:</u> The utility of an outcome is an individual's preferences together with the perceived usefulness that any given outcome will have if chosen. These utilities can be assessed with reference to the individual's preferences (158, 159).

While these examples paint an image of concise decision-making, uncertainty of outcome can add complexity to the decision process. Individuals might, for example, choose a less preferential option to avoid risk (160). As diagnosis complexity increases, uncertainty raises correspondingly, reducing preference rankings. Thorough exploration of the options that exist thus becomes important, as is their connection to the individual's preference for treatment options. It is important to note that this theory has been contested in literature as a normative theory, amid some belief that it does not contain enough detail to be a descriptive theory (160).

2.8: Chapter Summary

This chapter summarized the literature background of SDM. It covered broad understandings and definitions of SDM, reviewed factors that facilitate and hinder implementation of SDM, and explored potential substantive theories to underpin SDM. Certain frameworks were introduced, including the IP-SDM model. This chapter highlighted the

disconnect found between conceptual models and empirical implementation and the resulting lack of understanding of *how* SDM works, as well as for *whom*, in which *situations*, and *why*. Without an understanding of the nuances of SDM, it is impossible to form a model that can be adapted to allow for true patient-centered, informed care.

CHAPTER THREE

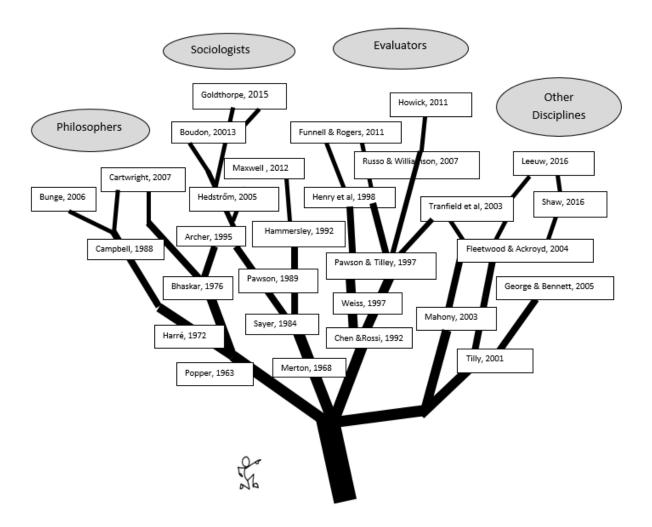
THEORETICAL FRAMEWORK

3.1: Realist Philosophy

Realist philosophy, which provides the grounding for this work, is notable for its amalgamation of positivist and constructivist thinking, which allows users to acknowledge that although truth does exist in the world, perceptions of this truth vary as a result of social and cultural effects (16). Within SDM, every decision process varies for each individual and indeed can vary within individuals from day to day. Using realist philosophy, we can understand the individual-level interpretation of influencing factors (contexts and mechanisms) and thus come to an understanding of how different individuals may or may not engage within SDM. This approach strengthens the contending positivist (which holds that one final level of knowledge is achievable) and constructivist (which holds that every individual constructs his or her own meaning) views by encapsulating the individualistic nature that creates a common outcome among multiple people. That is, it allows for recognition of the individual level of meaning while accepting a group understanding of a tangible outcome.

Realist philosophy dates to the 1500s, when Francis Bacon first challenged Aristotelian philosophy, thinking it adequate for discussion but not suited for interventions (161). Throughout his life, Bacon continued to contest the (then) modern Aristotelian philosophy, in the process giving rise to the notion of realist philosophy (161, 162). In the 1960s, realist philosophy began to gain momentum, branching into four key streams (Figure 5). Ray Pawson and Nick Tilley, the modern-day grandfathers of realist research, have devoted their careers to the debate and advancement of realist research methodology (15, 16, 84). Furthered by the RAMESES project, which aims to create publication standards, training manuals, and guidelines for researchers (15, 163, 164), realist research is only just gaining recognition as a research philosophy and tool.

Figure 5: A Realist Family Tree as Depicted by Ray Pawson (165). This diagram shows the evolution of realist philosophy since the early 1960s.



The development of realist philosophy has created a diverse understanding of what this philosophy entails that nonetheless has a consistently agreed-upon base. Realism bridges the polarizing epistemologies of positivism and constructivism (16). Like positivism, realist epistemology sees the world as real; however, it also encompasses individual perceptions of the world, as constructivism does (84). Realist philosophy merges these epistemologies and states that there is no source of final knowledge: we can only continue to build our understanding of different perceptions of the world.

3.1.1: Critical and Scientific Realism

Although several streams of realist philosophy exist, scientific and critical realism are most commonly referenced. Scientific realism (realist philosophy as described by Dr. Ray Pawson) has been defined as the "view that theories refer to the real features of the world ... refer[ring] to whatever it is in the universe ... that causes the phenomena we perceive with our senses" (24). This is contrasted by Roy Bhaskar's critical realism (166), which purports that "... there is a real world that exists independently of our perceptions, theories, and constructions ... while accepting ... [that] our *understandings* of this world is inevitably a construction from our own perspectives and standpoint" (24). These two philosophical backgrounds are separated by the level of information they explore, with critical realism focusing on macro-level social structures in the hope of understanding what exists (167) whereas scientific realist research examining micro-level functioning within social structures (168). Researchers should locate themselves in the philosophical background for their project to help readers understand the reasoning used in their research.

Before delving into what separates critical and scientific realism, it is important to clarify what ontology and epistemology are within research. Ontology is the exploration of what exists based on perceived reality (169). It involves exploration of existing items or structures based on an individual's philosophical background. Epistemology builds on this by exploring how we come to know information (169). It then seeks to uncover how we understand information about our world and surroundings. To link these two concepts, researchers may explore questions of whether something exists (exploring the ontology of the item), then follow this up by examining how we can come to understand that the item exists (the epistemology of how we understand the ontology). Realist ontology is recursive to reality in that we continually interact with reality (15, 170). Realist epistemology indicates that reality constructs and constrains our interpretation of reality (15, 170).

Confusion and debate are often sparked in the realist community over these philosophical backgrounds. Critical realism focuses on the ontological roots of knowing, whereas scientific realism emphasizes the empirical testing of epistemological knowledge (24, 171). Critical realism describes our way of knowing compared to scientific realism's description of how we obtain knowledge, focusing on analytical perspectives and examining the power relationships

within society with a partisan frame (170). Scientific realism follows a more traditional focus in relation to scientific process, requiring the formation of hypotheses which are tested through empirical observation and generalizations for the formation of a theory which can be analyzed retroductively through new hypotheses (170). Exploration of mechanisms allows us to explore the ontology level of our reality, constrained as it is through epistemological contexts. Table 4 outlines popularly referenced definitions of and assumptions about both philosophies of realism.

Table 4: Critical and Scientific Realism Comparison

This table presents definitions of and key assumptions concerning both critical and scientific realism.

	Critical Realism	Scientific Realism
Definition	"Critical realist philosophy of sciences	"Principles of our best scientific
	starts with the assumption that reality	theories are true and we are
	exists independently of human observers.	warranted in accepting the entities
	Critical realism sees this as the	they postulate Scientific realism
	fundamental justification of the practice	is, therefore, a philosophical
	of science It emphasises that causes	position. In the simplest sense,
	always exist in open systems where	realism means a belief in the
	multiple causal forces interact and	independent existence of reality"
	counteract in complex ways and where	(171).
	individual causes cannot be isolated as in	
	a laboratory experiment" (172).	

Table 4 Continued: Critical and Scientific Realism Comparison

	Critical Realism	Scientific Realism
Core assumptions	"1. Causes exist as (ontologically) real forces in the world around us and causes	"1. "Theoretical terms" in scientific theories (i.e., non-observational terms) should be thought of as putatively
	are ubiquitous ('nothing comes from nothing').	referring expressions; scientific theories should be interpreted "realistically".
	 Many causes are unobservable and the empiricist observation-based approach to causal analysis is problematic. Causes do not work in "when A, then B" manner and always exist in complex causal contexts where multiple causes interact and counteract with each other. Social causes are of many kinds: from reasons and norms to discourses and social structures. Interpretation is central to causal analysis in social science" (172). 	2. Scientific theories, interpreted realistically, are confirmable and in fact often confirmed as approximately true by ordinary scientific evidence interpreted in accordance with ordinary methodological standards. 3. The historical progress of mature sciences is largely a matter of successively more accurate approximations to the truth about both observable and unobservable phenomena. Later theories typically build upon the (observational and theoretical) knowledge embodied in previous theories. 4. The reality which scientific theories describe is largely independent of our thoughts or theoretical commitments" (168).

Faced with this philosophical dichotomy, I adopted a scientific lens for this project, believing that there is a level of truth in the world but that how we perceive and make sense of truth is what results in our knowledge. For example, one may believe that a chair exists while acknowledging that perceptions of its use are developed through social constructs. As this project focuses on the formation of a theory through testable hypotheses which can be evaluated through empirical observations, scientific philosophy seemed to align most with its goals.

3.2: Chapter Summary

This chapter outlined the philosophical background of realist research, including the historical development of this epistemology, and summarized the current divide within the realist community between critical and scientific realism. The following chapter discusses how this philosophy formed into an analytical framework, as well as the methodologies possible under the umbrella of realist research.

CHAPTER FOUR

ANALYTICAL FRAMEWORK

Two main methodologies of realist research exist: realist synthesis and realist evaluation (15, 16, 24, 84). As described by Ray Pawson, "Realism is a methodological orientation, or a broad logic of inquiry that is grounded in the philosophy of science and social science" (173). The best practice for conducting realist research begins with a synthesis and builds towards evaluation of the developed program theory in specific contexts with a view to testing hypotheses (164). Faced with constraints of time and feasibility constrictions most researchers select one type (i.e., synthesis or evaluation) as part of their larger research program (20, 21, 174, 175). This project uses a realist synthesis to build an initial understanding of *how* SDM works, as well as for *whom*, in *which situations*, and *why*. A realist synthesis is the appropriate approach because no true SDM theory has yet been formed. This program theory may later be tested through evaluation projects. This chapter will focus on the methodology (realist synthesis) used in this project.

4.1: Realist Syntheses

Realist syntheses, also known as realist reviews, are used as a method for reviewing current literature in the field of interest. Realist syntheses explain how a program works by unpacking how complex programs are successful or unsuccessful and how varying contexts may affect program success (84). The product of a realist synthesis, the program theory, is formed with testable hypotheses that allow researchers to identify *how*, for *whom*, and in *which contexts* a program is understood to work (16-18, 173).

Realist syntheses extend their use beyond a traditional literature review in several ways. First, and most relevant, realist syntheses explore causal factors rather than limiting themselves to contextual factors and their corresponding outcomes. That is, realists extend the traditional linear thinking of "A = B" to "A = B because of C". Such an approach allows a significantly deeper exploration and understanding of how programs and interventions works, allowing determination of the *why* and *how*. This, in turn, allows the formation of program theories

derived of testable hypotheses, whereas a traditional review may only speculate at contexts of certain outcomes. Secondly, realist syntheses incorporate the use of grey literature (literature outside peer-reviewed articles) and assess rigour and relevancy when judging the quality and nature of a source rather than using stringent criteria by which systematic or Cochrane reviews are bound. Furthermore, realist syntheses encourage the use of stakeholders in an active phase of the research process in which to confirm, refine, or refute analysis.

The backbones of realist research are contexts (C), mechanisms (M), and outcomes (O). Realist researchers use realist syntheses to identify specific Cs (pre-existing factors) that interact with Ms (often invisible factors) to trigger an O (a product modified by the presence of certain contexts and mechanisms). When put together in the configuration of $C + M \rightarrow O$ (CMOC), hypotheses are formed to explain a certain piece of a project that can later be tested. CMOCs are often identified to understand the facilitators and barriers for program success (15, 84). To assess a program, realist questions are formed in a specific fashion to uncover *in which situations*, *who*, *how, and why (or why not) a program works*.

Guided by realist epistemology, realist research uses hypotheses to build and evaluate realist program theories. These are similar to frameworks and allow program users to understand how different outcomes are generated for different groups in specific circumstances. Currently, two factions exist in the realist community regarding how program theories are conceptualized (16, 175, 176). The first holds that each body of research can produce multiple program theories, with each depicting a single hypothesis of how the program at hand works. Explicitly, a program theory consists of one CMOC. The opposing side interprets the program theory as a complete view of all hypotheses of the program. Specifically, all CMOCs are included in one all-encompassing program theory. Researchers must locate themselves in one of the foregoing early in their research, for a reader who assumes that a manuscript follows the "one CMOC, one program theory" formula might then be expecting multiple program theories to appear within a paper. I adopt the second explanation, with program theories encompassing all CMOCs of a project.

Ideally, a program theory fills the specified scope and depth of the research question at hand (15). Program theories should clearly outline CMOCs that the synthesis has indicated promote or inhibit a specific intervention. Each CMOC can lend itself to becoming a hypothesis for future studies, leading to further refinement of the program theory. Contexts, mechanisms, and outcomes within these CMOCs are further able to adapt within different situations: a mechanism in one situation may act as a context in a second situation, creating a "ripple effect" (175). Mechanisms can express strongly or weakly depending on preceding contexts, forming a potential gradient nature.

Realist researchers use CMOCs abstracted at the middle-range theory level. Middle-range theories articulate regularities of behaviour in a form that allows for testable hypotheses and causative explanation of an intervention (16, 18). As defined by sociologist Robert Merton, middle-range theories are abstracted only to the point at which they are still able to be observed and at which they can still be incorporated into propositions (177). Identifying and building on middle-range theories will assist in ascertaining the nuances necessary to improve quality of care (177) and is critical for broad, effective SDM implementation.

The Realist and Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) project was initiated to ensure that realist researchers adhere to a standard of quality and rigour (15, 163, 164, 178). The standards defined by RAMESES outline seven key areas that researchers should consider when conducting their research (15, 163, 164):

1) The research problem:

The research problem must be oriented around the essential philosophical elements of realism: *what works*, *how*, *why*, for *whom*, to *what extent*, and in *what context* (15). Furthermore, researchers are strongly encouraged to explain their justification for choosing a realist synthesis to answer their research question.

2) Understanding and applying the underpinning principles of realist syntheses:
Once researchers have framed their question(s), they should apply realist synthesis principles (15). To do so, researchers must undertake an iterative review that allows for testing and refinement during the analytic process.

3) Focusing the synthesis:

Researchers must be purposeful when focusing the breadth and depth of their synthesis. Refining the review scope is critical, as the philosophy of realism indicates that no knowledge is final, and thus an infinite number of CMOCs can be formed (16, 84, 173). Without focusing the synthesis, there is likely to be far too much to cover, blocking necessary detail from being uncovered.

4) Constructing and refining a realist program theory:

Researchers must then develop the initial program theory, which can follow a realist program theory structure (i.e., CMOCs) but is not restricted to doing so.

5) Developing a search strategy:

This standard introduces one of the differences between traditional systematic reviews and realist syntheses: realist syntheses encourage the consideration of non–peer-reviewed articles (19, 163, 175). Documents may be taken from a broad range of locations, often even outside traditional review boundaries. Sources other than peer-reviewed journals, referred to as grey literature, can include internal documents, blogs, and other non-traditional sources.

6) Selection and appraisal of documents:

Realist syntheses use two conditions to appraise a document, regardless of whether they are traditionally sourced or grey literature: relevance and rigour (164). Rigour refers to the credibility and trustworthiness of a source, whereas relevance is in relation to the synthesis topic.

7) Data extraction:

Data extraction includes identifying Cs, Ms, and Os as well as demi-regularities in the data and middle-range theories (15, 23).

8) Reporting:

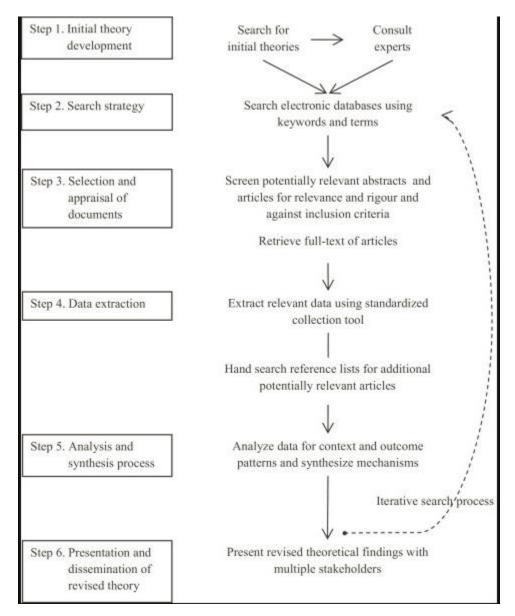
Researchers may report findings in a variety of venues (e.g., reports, articles, websites) but should do so according to RAMESES syntheses publication guidelines to ensure the plausibility and coherence of findings (163, 164).

Although RAMESES provides a clear idea of what is required to produce a high-quality realist synthesis product, it does not describe specific methods for reaching these objectives. For example, the authors briefly discuss data extraction (15) without detailing information regarding

how this should be completed. Accordingly, many researchers have taken these guidelines and adapted them into working models with which to conduct realist syntheses. Using such protocols requires researchers to critically appraise the proposed steps with relation to the RAMESES guidelines to ensure their consistency and quality.

One excellent example of adapting the RAMESES guidelines and following Pawson's depiction of realist syntheses (84) is Molnar and colleague's 2015 work examining the effect of unemployment insurance on health and poverty status (179). Molnar et al. begin their paper by justifying the fit of a realist synthesis with their research question and developing an initial program theory. The article's main strength is the logic flow chart developed to guide their work (179) (Figure 6). This chart not only outlines their six-step process (initial theory development, search strategy, selection and appraisal of documents, data extraction, analysis and synthesis process, presentation and dissemination of a revised theory) but also further expands to include the methods for each step in their iterative process (179). The authors outline their data extraction tool in sufficient detail for others to adapt it for their own projects, laying out clear steps that link extracted data with synthesized CMOCs to provide the utmost transparency in their findings – important in this developing field as a way of ensuring that researchers external to the realist community can interpret and appraise the quality of research.

Figure 6: Process for Conducting a Realist Synthesis (179). This figure outlines Molnar and colleagues' recommended procedure for conducting a realist synthesis.



Following these steps, research complies with both RAMESES guidelines and Pawson's original depiction of the process. This should assist in the formation of a strong theory-based program theory. Researchers can then continue to test the resulting program theory to confirm, refine, or refute findings in varying circumstances.

4.2: Chapter Summary

This chapter outlined the current understanding of realist syntheses and presented a framework for performing a successful synthesis. Furthermore, it outlined the RAMESES guidelines for a successful synthesis, used to guide researchers' efforts to ensure the quality of research projects. The following chapters describe our application of realist philosophy and synthesis methodology to conduct our own synthesis and form a program theory for SDM. This will include slight adaptations to Molnar's process outlined above.

CHAPTER FIVE METHODS

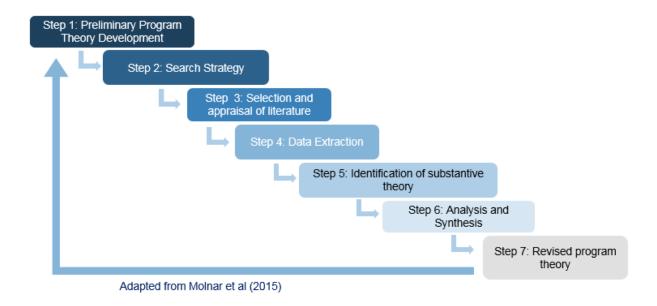
5.1: Chapter Introduction

The research team comprised clinicians (a surgical oncologist and a psychologist) (GG and LM), content specialists (TW [thesis author], TC, and LB), methodology specialists (GW), a health sciences librarian (VD), and other researchers (SN). Our study protocol has been published separately in the journal *Systematic Reviews* (18). Some excerpts of that paper have been used within this chapter and are referenced accordingly. While allowing publication in this thesis format, the authors still maintain the copyright of this document.

5.2: Methods Overview

We followed Molnar's interpretation of Pawson's realist synthesis process (84, 179), adapting it to incorporate participatory involvement (176) (Figure 7) and RAMESES realist synthesis training guidelines for an "excellent" program theory (15, 163, 164). This adaptation resulted in the following steps: 1) preliminary program theory development, 2) search strategy development, 3) selection and appraisal of literature in accordance with realist methodology (15, 164), 4) data extraction, 5) identification of substantive theory, 6) data analysis and synthesis, and 7) formation of a revised program theory with the input of stakeholders (18). As part of our seventh step, we consulted with stakeholders to ensure that the program theory accurately reflected real experiences with the consultation process.

Figure 7: Realist Synthesis Process (18). This figure depicts the seven-step iterative process we undertook to conduct this realist synthesis.



5.3: Preliminary Program Theory Development

TW developed a preliminary program theory after conducting a scoping literature review (180). A scoping review targets specific bodies of literature and in this case was used to arrive at an initial understanding of literature. This outlined the outcomes of SDM implementation based on an overview of the literature (appendix A). We developed our study hypotheses and an indepth search strategy using this preliminary program theory. Our team decided to use IP-SDM as the conceptual basis of our research, as it incorporates HCPs beyond the physician and states that others can, and indeed should, be involved in the decision-making process. Dr. Gill Westhorp, an internationally recognized realist expert, assisted in hypothesis formation from this preliminary program theory. Following this collaboration, we were able to refine our search strategy. However, without conducting a full review, we were unable to fully understand *how* SDM worked.

5.4: Search Strategy Development

We developed a search strategy designed to encompass SDM literature since its popularity of the 1980s. In doing so, we began with a purposive search conducted using Medline and Google Scholar, so defined because we targeted articles focused on SDM and looked for those sources providing the most valuable information. Our search terms included *shared*, *collaborative*, *decision-making*, *informed*, *oncology*, *cancer*, *treatment*, *patient*(*s*), *physician*(*s*), *clinician*(*s*), *theory*, *development*, *model*(*s*), and *framework*(*s*) (Figure 8). TW and VD completed a secondary search through Medline using an adapted search strategy. These expanded terms included *choice behavior*, *decision making*, *decision*, *choic* or preference**, *patients*, *or inpatients*, *or outpatients*, *patient dropouts*, *or exp survivors*, *consumer participation*, *consume**, *conceptual framework*, *framework**, *decision theory*, and *model** (Figure 9). We targeted cancer decision-making for its known applicability to complex decision-making but did not exclude decision-making outside this context. All identified sources were stored within EndNoteTM (Clarivate Analytics).

Figure 8: Initial Medline Search Strategy. Extended search strategy conducted using Medline.

- 1. Choice Behavior/
- 2. Decision Making/
- decision*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- (choic* or preference*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 5. patients/ or inpatients/ or outpatients/ or patient dropouts/ or exp survivors/
- 6. exp Consumer Participation/
- consumer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 8. patient*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 9. or/5-8
- 10. "conceptual framework*".mp.
- 11. framework*.mp.
- 12. Decision Theory/
- model".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 14. health personnel/ or exp allied health personnel/ or caregivers/ or faculty, medical/ or faculty, nursing/ or health educators/ or medical staff/ or exp nurses/ or exp nursing staff/ or personnel, hospital/ or exp pharmacists/ or exp physicians/
- 15. 1 or 2 or 3 or 4
- 16. 10 or 11 or 12 or 13
- 17. 9 and 14 and 15 and 16
- 18. limit 17 to (english language and humans and yr="1980 -Current" and "all adult (19 plus years)")

Figure 9: Secondary Medline Search Strategy.
Search strategy conducted for scoping review using Medline.

- shared.mp.
- 2. collaborative.mp.
- Informed consent/ or informed.mp.
- Decision Making/
- Oncology Nursing/ or Surgical Oncology/ or Medical Oncology/ or Radiation Oncology/ or Oncology Service, Hospital/ or oncology.mp.
- 6. cancer.mp. or Neoplasms/
- 7. Therapeutics/
- 8. treatment.mp.
- 9. Patients/
- 10. Physician-Patient Relations/
- 11. Physicians/
- 12. clinician*.mp.
- 13. theory.mp.
- 14. theory development.mp. Or Research/
- 15. model*.mp.
- 16. Models, Psychological/ or Models, Nursing/
- 17. framework*.mp.
- 18. 1 or 2 or 3
- 19.5 or 6
- 20. 7 or 8
- 21. 10 or 11 or 12
- 22. 13 or 14 or 15 or 16 or 17
- 23. 4 and 18
- 24. 4 and 19
- 25. 4 and 20
- 26. 4 and 22
- 27. 9 and 23 and 24 and 25 and 26
- 28. Limit 27 to (English language and yr="1980-Current")

TW performed snowball sampling techniques to extend the reach of our literature search. Snowball sampling includes examination of documents based on key authors in the field, such as Drs. France Légaré and Dawn Stacey, as well as examination of highly cited sources (181). This method of secondary sampling, which allows researchers to capitalize on expert knowledge that may be missed in the primary search (181), ensured that we examined leading papers in the SDM field.

In accordance with RAMESES guidelines, we incorporated grey literature into our search. Grey literature was sought from North American health jurisdictions, including our local provincial health region. The benefit of using grey literature is the ability to see the inner workings and current use of interventions in a level of detail not often covered in academic sources (173).

5.5: Literature Selection and Appraisal

Literature selection and appraisal was conducted by TW and TC. Involvement of a second reviewer reduces the potential of selection bias. Selection criteria included: "1) exchange between a patient and/or patient's family and a health care provider; 2) a clinical situation where the patient is legally competent to make their own decision; 3) adult patients (18 years or older) making decisions about their own medical situation; 4) sources from 1980 to present; 5) English-language sources only (due to the language constraints of our team)" (18). We excluded sources that focused on situations in which a patient would be unable to participate in his or her own decision-making process, including, but not limited to, end-of-life care, pediatric decision-making, reduced competency, and dementia, all of which situations require a surrogate decision-maker.

In addition to the above selection criteria, reviewers also examined the relevancy and rigour of each source. This was accomplished through the use of a realist resource – Pawson's criteria of relevance – able to guide researchers in their assessment of quality (15). Relevance was determined by the applicability of the source in relation to the research question at hand. Rigour was defined as methodological appropriateness chosen to assess the source's research question (15). We applied RAMESES guidelines for conducting a realist synthesis, following the requirements for an "excellent" product (15, 164).

We completed screening in an iterative fashion that allowed for refinement throughout the process. Our first round included title and abstract review, followed by full text review. Grey literature files were reviewed in full, there being no abstract to review. When disagreements arose between reviewers, the source was sent to a third reviewer (GG) to determine source inclusion.

5.6: Data Extraction

Data extraction was completed by TW and TC to ensure that no extraction bias occurred. Each source was independently read in full by each member, who identified and extracted all relevant outcomes. We identified contributing factors (contexts and mechanisms) for each outcome in the form of explanatory accounts (EA), or "if—then" statements phrased as follows: if "x" occurs, then "y" results (18, 174, 182). Although this structure can result in a positivist result ("A = B"), we strived to include mechanisms when possible ("A + C = B"). EA statements may or may not contain all three aspects of a CMO configuration. Extraction of EA statements allowed a close examination into the causal forces and corresponding contexts to determine each outcome.

Each extracted EA statement was inserted into an extraction template. Information gathered in the extraction template included "1) article bibliographic information; 2) relevant study/document notes (its relevance to the program theory); 3) country of study/document; 4) focus/sample of study/document (including if the focus is on patients, health care provider, both, or systematic factors); [and] 5) if a research article was empirical or theoretical..." (18). Relevant middle-range theories existing within the literature but outside a CMOC were extracted as EA statements as well. The extraction template was managed using Microsoft Excel.

5.7: Identification of Substantive Theories

TW and TC identified substantive theories from literature as they were noted throughout the data extraction phase. This was achieved by noting any substantive theory sources linked to SDM. Literature on substantive theories of decision-making was also sought by TW to determine other possible theories that had yet to be linked to the SDM literature. This method of substantive theory identification aligns with RAMESES realist synthesis guidelines (176). Each substantive theory was examined to determine fit once the revised program theory was developed.

5.8: Analysis and Synthesis Process

Demi-regularities within the EAs were identified with the intent of forming thematic groupings. Demi-regularities are sequences that hold truthful meaning over a certain scenario or period of time but that do not hold true under other situations (183, 184). These could be on the context, mechanism, or outcome level. Identifying such regularities in the data is important for a

realist synthesis, as it assists in the identification of mechanisms that predict successful, or unsuccessful, outcomes (179). Researchers (TW and TC) identified these demi-regularities and formed thematic groups. Each EA statement was sorted into relevant thematic groups, creating a consolidated account of EA statements. When more than one relevant thematic group was identified, the EA was sorted into both. Thematic groups were further classified to determine whether they acted on patients, on HCPs, and/or at a system level. Retroductive analysis of these groups allowed us to identify key mechanisms within the literature, using EA as our extraction tool.

Researchers retroductively synthesized thematic groupings into CMOCs to determine how the procedural steps of IP-SDM (67) work. We identified mechanisms that affect SDM, the variability in their expression, and the relevant contexts that change how a mechanism unfolds. Upon completion of this process, our team used content expertise to determine which mechanisms were considered "key" to our final outcome of *engagement of SDM*. Key mechanisms are those that strongly affect the process and that may promote or hinder the process depending on the consultation (18). Key CMOCs were used to revise the program theory in order to assess its accuracy with stakeholders.

5.9: Stakeholder Input and Dissemination of Revised Program Theory

Upon completion of the initial revisions to the program theory, we consulted two internationally recognized content experts – Dr. Gill Westhorp and Dr. France Légaré – to ensure that the program theory aligned with both realist and SDM standards. Dr. Westhorp was consulted during a week-long intensive in which the research team collectively worked through the program theory to ensure that it adhered to RAMESES guidelines and presented a full program theory with appropriate contexts, mechanisms, and outcomes. We further consulted with Dr. Légaré, the Canadian Chair of Shared Decision-making, during a one-day meeting in Quebec City that included Dr. Légaré, her team members, and consultants from Denmark. During this meeting, Dr. Légaré's team reviewed the program theory and offered feedback on the SDM processes. Notably, Dr. Légaré is one of the co-developers of IP-SDM.

Following expert consultation, we conducted a stakeholder group targeting those potentially affected by SDM, including two representatives from each of the following categories: oncology patients, nurse navigators, policy-makers, physicians (an oncologist and a

family physician). While realist syntheses do not require researchers to conduct stakeholder sessions, we believed that it necessary to consult with individuals who had experience in the medical decision-making process and who thus could provide preliminary verification of our findings. A previous study identified that the addition of such knowledge users was able to assist in: 1) identification of active components within an intervention, 2) a full description of how interactions influence success of an intervention, 3) location of areas where the literature is inadequate or inaccurate, 4) identification of immediate outcomes, and 5) differentiation of levels of a given context in relation to the intervention (185). Accordingly, we believe that this added strength to the overall product of our realist synthesis.

Ethical approval was sought and granted from the University of Saskatchewan Behavioural Research Ethics Board (BEH # 16-456) prior to the conducting of stakeholder sessions. This included approval of participant recruitment, data collection methods, participant compensation, participant data security and storage, acknowledgement of potential harms and mitigation strategies, transcript release forms, consent forms, and the stakeholder guide. Patient participants were compensated \$100 for their time, but HCPs and policymakers were not financially compensated, for accepting compensation would have conflicted with their professional contracts. All participants were provided dinner.

The stakeholder session was audio-recorded and conducted through a semi-structured guide. Prior to the beginning of the session, three members of the research team (TW, GG, and TC) gave a twenty-minute lay presentation on the topic of realist research and our program theory. We then began the formal session, which explored topics ranging from program theory completeness and appropriateness to language used (Figure 10). We encouraged open conversations between stakeholders and allowed the discussions to flow organically, interjecting only when clarification was needed. We probed further, if necessary, only after stakeholders had fully discussed their opinions on a topic. Stakeholders were given the opportunity to comment on the overall program theory if they had thoughts that had gone unaddressed during the session. All stakeholders were encouraged to contact TW if they had additional thoughts after the formal closure of the session; however, no stakeholders took the opportunity to do so.

Figure 10: Semi-structured Stakeholder Guide.

This figure depicts the complete stakeholder guide used for the stakeholder session.



Stakeholder guide

Development of program theory for Shared Decision Making: A realist review protocol

Thank you for joining us today to talk about how decisions are made for medical treatments. Before we begin let's go around the table and introduce ourselves and briefly describe the type of experience we have for decision making in the health care system, be it a patient, health care provider, or on the policy side. I'll begin,

[Introductions]

Thank you everyone for introducing yourselves. The first thing do is review an image of how our team believes decision making might work. We are aiming to create an improved model of Shared Decision Making. This means that the patient and the health care provider team exchange knowledge, values and preferences to make a decision that is informed and patient centered. So far our team has gone through literature on Shared Decision Making and through review have created this model to explain how we believe it might work. We would like you to tell us your initial reactions, whatever comes to mind first. [Show and explain model]

[Discussion about initial reactions]

Now we want to discuss if you think that this model shows how the decision process works

- How does the model match what you have experienced?
 - O How do you see yourself fitting into the model? Does it change based on if you view it as a patient or as a health care provider (if relevant)?
 - o In what ways is the model different from your experience?
- Do you feel like this is what you would want to see in the decision process?
 - o What do you think should be added?
 - o Are there things that are included that should be removed?
- Are the influencing factors that we have outlined representative of factors that may strongly impact the decision process?
 - o What do you think about the factors identified?
- Does the terminology resonate with you?
 - o How would you define the influencing factors?
 - Would you recommend different language to be used?

The session transcript was transcribed by the University of Saskatchewan's Social Science Research Laboratory (SSRL). TW reviewed the transcript for accuracy. All data were imported into NVivo 11 and were coded as confirming, refining, or refuting the program theory. "Confirm" was used for opinions that were in agreement with the proposed definition, existence of the CM/O, placement of the CM/O, and/or adequacy of description. "Refine" was applied when stakeholders indicated partial agreement but suggested slight modification (e.g., reclassification or adjustment of a definition). "Refute" was used when stakeholder(s) did not

believe that a specific part of the program theory was appropriate and preferred full removal of the item. Stakeholder recommendation for a new aspect was coded as "refine: overall program theory", while any other aspect was coded with direct correlation to the aspect of the program theory being discussed (e.g. "Confirm – Trust").

All coding followed retroductive techniques, consistent with realist evaluative processes (32). Retroductive techniques differ from the processes and outcomes that researchers expect from either an inductive or a deductive approach. Retroductive analysis requires researchers to approach the data with assumptions while seeking to identify the contexts that satisfy or dissatisfy the assumption (186, 187). Using theoretical inferences researchers are able to form a priori knowledge about their preceding assumptions, allowing the formation of a theoretical framework development (186). The code manual was approved by senior researchers on the team (GG, LM, and TC), and the full results were discussed as a collective. At this time, stakeholder feedback was integrated into the program theory. This was completed by TW and was followed by team verification.

5.10: Revised Program Theory Refinement

The initial revision of the program theory was created through development of CMOCs and the gaining of understanding of these processes. The initial revised program theory was created by TW and was iteratively reviewed until it was believed to adequately and succinctly reflect the current standing in literature, based on our analysis. The program theory was then graphically created in Microsoft PowerPoint by TW. This version was refined by our team for graphic clarity. At this point, the majority of revisions were aesthetic (e.g., colour changes). Further revisions underwent the same process and were also created using Microsoft PowerPoint.

5.11: Chapter Summary

This chapter summarized the methods undertaken to answer the thesis question: "In which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved patient-centered decisions?" The seven-step iterative realist synthesis process allowed us to form a program theory for SDM and a preliminary test with stakeholders to confirm, refine, or refute our analysis based on current literature. The formation of this Revised Program Theory required us to draw on a wide base of literature, content experts, and ongoing

retroductive analysis. The following chapter will outline the results of this process, ending with the *Revised Program Theory*.

CHAPTER SIX

RESULTS

6.1: Chapter Introduction

This chapter details the results of the seven-step development process undertaken to form a *Revised Program Theory* of SDM. The results of this project have been submitted for publication in a separate manuscript in *Health Services Research* but have yet to be accepted at the time of this thesis's publication.

6.2: Preliminary Program Theory Development

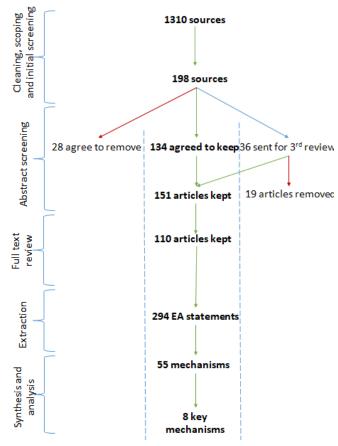
TW completed a scoping review and formed a *preliminary program theory* (supplemental A) to gain an initial understanding of SDM. The preliminary program theory was a complex program incorporating environmental and societal factors, involvement of patients, health care providers, and patient personal support, as seen in the literature. This diagram began at the point of accessing health care (or the patient's choosing to not access health care) and continued through the SDM process, demonstrating primary and secondary outcomes of SDM implementation.

6.3: Search Results and Selection and Appraisal of Documents

Our search resulted in 1,310 references through both the original and expanded search strategies. Several rounds of screening were conducted, with 198 documents undergoing full text review and 110 total articles remaining after screening (Figure 11) (full list of articles available in appendix B). The retained articles represented global findings but were highly concentrated in North America and Europe: Australia (6), Belgium (1), Canada (81) Europe – general (4), France (4), Germany (8), multi-country (10), Netherlands (9), Spain (2), Sweden (5), Switzerland (7), United Kingdom (34), United States (102), and Wales (21). The literature search was conducted by TW and VD. Literature selection and appraisal was completed by TW and TC.

Figure 11: Screening and Mechanism Formation Process.

Article screening and development of key mechanism sets by total count



6.4: Data Extraction

Data were extracted in the form of explanatory account (EA) statements. EA statements were extracted from any relevant portion of a source and were conducted by two researchers (TW and TC). A total of 294 EA statements were formed as a result of this process (appendix C). No pre-existing middle-range theories were found in CMOC format, and very few documents had a complete middle-range theory that contained all portions of a CMOC. Mechanisms were often not identified in the literature and had to be inferred or determined through multiple papers that created overlapping CMOCs.

Four categories of EA statements emerged: health care professionals (n = 180 EAs), patients (n = 374 EAs), both health care providers and patients (n = 81 EAs), and system factors (n = 10 EAs). Within these categories, EA statements were sorted according to thematic groups

(i.e., demi-regularities identified within each EA category), resulting in 61 thematic groupings between the four categories.

EA statements were sorted into all thematic groupings found relevant on a non-mutually exclusive basis. Doing so exaggerated thematic groupings and category totals when compared to the extracted EA statements. Appendix D provides a full list and counts of EA thematic groupings.

6.5: Identification of Substantive Theory

Several substantive theories were identified in the SDM literature (appendix E). However, our research team did not believe that the majority of these adequately explained the underpinnings of extracted CMOCs, as they did not elaborate on how SDM *works*, for *whom*, in *what circumstances*, or *why*. The exception was the Theory of Planned Behaviour, by Icek Ajzen (145, 146), which was identified in two papers (57, 148).

Two other theories were identified through additional searching in medical decision-making literature: the Feeling of Rightness (FOR) (152) and Normative Expected Utility Theory (158). However, each theory was found to explain only segments of the program theory. In combination, we believe that these three substantive theories depict how CMOCs are underpinned, causing mechanisms and outcomes to vary in expression.

6.6: Analysis and Synthesis

Our research team analyzed all extracted EA statements by thematic groupings to identify CMOCs with the intent of forming a synthesis of key mechanisms. Key mechanisms were those believed to hold the most causal powers based on clinical and content expertise. This process was piloted during a week-long intensive session attended by the entire team. Each author examined all patient thematic groups and formed CMOCs as a collective. This process was repeated by TW and TC for the remaining three categories.

A total of 55 mechanisms were formed from this analysis and synthesis process (appendix F). These mechanisms were kept in their original categories: health care provider (33), patient (17), health care provider—patient interaction (3), and system (2). At this point in our analysis, we formed our *expanded IP-SDM mechanism map* (appendix G) outlining the 55 mechanisms and depicting how they interact with the IP-SDM process. This was done by placing

mechanisms above or below the previously published IP-SDM steps (62, 67), corresponding to whether the literature described them as promoting or hindering SDM. Each mechanism was placed in line with where it was first believed to arise as a factor in decision-making, based on our analysis of the literature. The IP-SDM process was slightly adapted, based on the literature, to more explicitly explain the feasibility and preferred choice steps.

We isolated nine key mechanism sets (Table 4) that we believed were the most critical in explaining *how* SDM works, for *whom*, in which *circumstances*, and *why* – or *why not*. Mechanism sets contain a single label (e.g., anxiety) but include mechanisms that act in either inhibitory or facilitating ways. Identification of key mechanisms was completed, as incorporation of all 55 mechanisms was likely to reduce the overall accuracy and detail of the final program theory. Key mechanism sets were isolated based on the team members' clinical and research experience. These were originally identified by TW and TC and were then verified by the research team as a collective.

Table 4: Initial Key Mechanisms.

The initial nine key mechanism sets identified by our team, sorted alphabetically.

Health care provider recognition of need for decision
Health care provider and patient preference/willingness for engagement
Health care provider perception of patient competency/capacity
Health care provider perception of time available and required for SDM
Health care system support (including decision aids)
Patient anxiety
Patient capacity to access external support and information
Patient belief in his or her ability (self-efficacy) to participate in SDM
Patient trust in individual health care provider as a person and as a professional

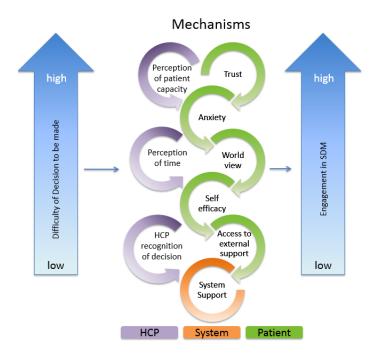
We revised our *expanded IP-SDM mechanism map* into a *focused IP-SDM mechanism map* including only the nine key mechanism sets. This used the same formatting as the *expanded IP-SDM mechanism map*. Within both mechanism maps, we acknowledge that mechanisms can act both in inhibitory and promoting ways. Rather than duplicating all mechanisms, each was placed where the literature indicated it would be most influential in either an inhibitory or facilitating manner. *Expanded and Focused IP-SDM mechanism maps* are necessary to form a comprehensive understanding of the program theory.

To better demonstrate the level of complexity within our program theory, we developed our *Initial Program Theory*, focusing on CMOCs without the overlap of IP-SDM (Figure 12). This model begins with the complexity of the diagnosis, which influences how mechanism gradients will present. For example, receipt of a highly complex diagnosis may trigger a higher level of anxiety in a patient. Accordingly, each of the key mechanism sets in the *Initial Program Theory* has its own gradient that may shift in expression. Together these result in the level of

SDM engagement on the part of both the patient and the HCPs. We hypothesize that engagement in SDM is then the mechanism for a patient-centered and informed decision.

Figure 12: Initial Program Theory.

Initial program theory shown to stakeholders for confirmation, revision, and/or refuting.



6.7: Expert Consultation and Stakeholder Session

To ensure the best possible program theory product, we consulted with experts and stakeholders on three separate occasions.

6.8.1: Expert Consultation

Expert consultation was held with two separate groups: a methodology expert (Dr. Gill Westhorp) and a group of SDM experts (led by Dr. France Légaré). Dr. Westhorp was consulted on several occasions throughout the duration of this project. As realist synthesis protocols are still emerging in the field, Dr. Westhorp was able to guide us through any conflicting accounts of methodology procedures. She also enabled us to maintain the philosophical grounding in realism throughout this process and assisted our team in the consolidation of CMOCs. Dr. Westhorp consulted on the validation of key mechanism sets.

To ensure that our program theory was in accordance with basic SDM principles, we presented our *Initial Program Theory* (Figure 4) to Dr. France Légaré, her team, and an SDM

implementation team from Denmark. Minor changes were implemented as a result of this meeting. One recommendation was to revise the final outcome from "mutually agreed upon decision" to "patient-centered and informed decision" to match current terminology in the field. This recommendation was applied to our final *Revised Program Theory* (discussed hereafter).

6.8.2: Stakeholder Session

Stakeholders were supportive of most findings; however, some key points of refinement were suggested. One addition was a context to reflect the potential impact of pre-existing relationships between patients and HCPs. This context was described as one that could both facilitate and hinder the process of SDM. For example, a physician who knows a patient well may already know the patient's preferred level of engagement or may incorrectly assume which treatment will be preferred and thus not involve the patient. The second key point of refinement was stakeholders' belief that the majority of key mechanism sets could apply to both patients and HCPs, in contrast to the separation we had initially illustrated.

6.8: Revised Program Theory

Incorporating all data sources, our team formed the *Revised Program Theory* (Figure 13). In our final refinement stage, a small adjustment was made. Health care system support changed from a key mechanism set to a context after a final review of data indicated that health care system support acted as a context to the remaining eight key mechanism sets.

Our *Revised Program Theory* contains three contexts, eight key mechanism sets, and an outcome. Mechanism sets were used to distinguish multiple mechanisms revolving around the same mechanism category. This was formed by TW following the analysis completed by TW and TC. The *Revised Program Theory* begins with the pre-existing relationship and difficulty of decision, which combine with one another to create a cumulative effect on the key mechanism sets. A third context, system support, is shown at the bottom of the diagram. Key mechanism sets $({}_kM_{1-8})$ are shown in the centre honeycomb. The honeycomb pattern is designed with white space between hexagons to represent the existence of mechanisms beyond those identified in the diagram, as we recognize that each situation may differ and that additional contexts can influence which mechanisms are key in those circumstances. Each factor (context, mechanism, and outcome) is presented with gradients that represent the ability for each to hold a different power level, ranging from low to high. Key mechanism sets are shown with two separate

gradients: purple represents the strength of the mechanism from the HCP perspective, whereas green represents patient mechanism strength. These key mechanism sets interact with the three contexts to determine the level of engagement in SDM during the consultation – the final presented gradient. We further developed this program theory to overlap with the IP-SDM steps, reflected in the *revised focused IP-SDM mechanism map* (Figure 14).

Figure 13: Revised Program Theory.

Final program theory with three contexts, eight mechanism sets, and a single outcome following stakeholder consultation.

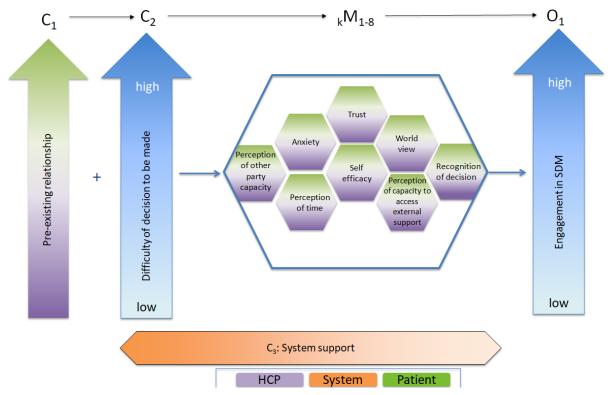
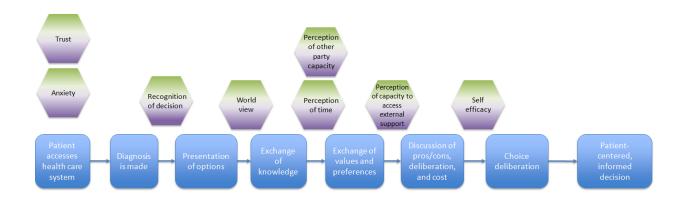


Figure 14: Revised Focused IP-SDM Mechanisms Map.

Key mechanism sets interconnected to IP-SDM steps. All identified mechanism sets may act in inhibiting or facilitating roles, depending on contexts. Mechanisms are represented at the point at which they are thought to first influence IP-SDM.



Each context, mechanism, and outcome was derived from our analysis of the literature. From this analysis process we formed definitions of each term used in our program theory (Table 5). In addition to this, CMOCs were created for each mechanism set (table 6). Together, these two tables illustrate the nuances within each category, leading to further understanding of *who* SDM works for, as well as in *which situations* and *why* or *why not*.

Table 5: Definition of Concepts in the Revised Program Theory.

This table presents the contexts, mechanisms, and outcomes that are incorporated into the Revised Program Theory, defining each concept. These definitions represent what was found in our synthesis; future research may highlight the need for modification.

	Factor	Definition
Key Mechanisms	Anxiety	The level of worry or nervousness felt before or during the consultation. This can be specifically related to the decision process/diagnosis or other outside influences.
Key Mechanisms	Perception of capacity to access external support	The perception of the individual* in relation to his or her ability to obtain support outside the consultation. This can include, but is not limited to, support groups, family and friends, colleagues, Internet resources, and manuscripts.
Key Mechanisms	Perception of other party capacity	One individual's perception of another's ability to successfully meet the expectations of his or her role within the consultation – for example, a patient's perception of an HCP's knowledge about and experience with a disease.
Key Mechanisms	Perception of time	The perception of how long it takes to implement SDM and the amount of time available for the consultation. HCPs may perceive inadequate time as being allotted to implementation of SDM. This can include potential time pressures on the patient and also incorporates the perception of time available to make a decision (e.g., perceived urgency of treatment).

	Factor	Definition
		An individual's belief that he or she is able to participate in the SDM process – for example, whether
Key Mechanisms Key Mechanisms	Self-efficacy Trust	the HCP believes that he or she can successfully exchange knowledge and expertise with the patient and whether the patient believes that he or she can adhere to potential treatment options. This may also be influenced by whether a health care system has provided appropriate supports for patients and HCPs with which to successfully implement SDM. The level of trust and confidence that an individual feels in another person. For patients, this includes trust in the HCP as a professional; for HCPs, it may include
Key Mechanisms	World view	trust that a patient will adhere to a treatment or be forthcoming. The set of beliefs, customs, values, morals, and/or understandings that an individual holds about the medical process, which may align with, or clash against, biomedical definitions of health care. This
		may incorporate aspects such as religion and culture.
Key Mechanisms	Recognition of decision	Whether an HCP or patient consciously acknowledges that a decision-choice exists.
Context	Difficulty of decision to be made	An individual's perception of the complexity of the decision needing to be made. This can be significantly affected by values and preferences, as well as experience.

	Factor	Definition
Context	Pre-existing relationship	The existence, duration, and quality of a professional relationship between patient and HCP before consultation. This may also include assumptions that may be made based on the nature of the pre-existing relationship.
Context	System support	The presence of policy, training, financial, decision tools, and managerial support for the implementation and use of SDM within consultation. This can extend to the extended time allotment for consultation and providing decision tools, among other supports.
Outcome	Engagement in SDM	The degree to which individuals, together and individually, are able to cohesively engage within the SDM process given the interaction of key mechanisms.

^{*} *Individual* is operationally defined as including the health care professional and/or the patient.

*Table 6: Descriptions of Key Mechanisms in the Revised Program Theory.*This table presents the CMOCs for each mechanism set identified within the program theory.

Mechanism Category	Detailed CMOCs		
Anxiety	cilitation of SDM: 1. A patient who faces a moderately difficult decision regarding treatment may experience a moderate increase in anxiety, fostering a drive to engage within SDM. Moderate difficulty of decision (C) + Moderate anxiety (M) → Patient engages in SDM (O) 2. An HCP who has received system support to gain skills in SDM may have reduced anxiety about using it in consultation, increasing his or her engagement in SDM. System support for SDM (C) + Reduced anxiety (M) → HCP engagement in SDM (O) **ndering of SDM:** 1. A physician who perceives high patient anxiety may unilaterally decide that engaging in SDM is inappropriate. Patient displaying high anxiety characteristics (C) + HCP perception of patient anxiety (M) → Low engagement in SDM by the HCP (O) 2. A patient who has a difficult decision regarding treatment may experience a debilitating increase in anxiety, resulting in low patient engagement in SDM. High difficulty of decision (C) + High patient anxiety (M) → Low patient engagement in SDM (O)		

Mechanism Category	Detailed CMOCs		
Perception of capacity to access external support	 Facilitation of SDM: An HCP who perceives that the system offers supports to aid in the decisional process is more likely to engage in SDM. Perception of system support (C) + Perception of capacity to access external support (M) → High engagement in SDM (O) A patient who believes that he or she has supports beyond the HCP is likely to experience reduced anxiety and increased self-efficacy, resulting in high SDM engagement. Perception of capacity to access external support (C) + Reduced anxiety (M) + Increased self-efficacy (M) → High engagement in SDM (O) Hindering of SDM: An HCP who is dealing with a complex diagnosis and who does not perceive that he or she is able to access external supports, such as journal articles, is likely to experience low self-efficacy in SDM and have reduced SDM engagement. Complex diagnosis (C) + Perception of capacity to access external support (M) + Low self-efficacy → Low SDM engagement (O) 		
Perception of other party's capacity	 Facilitation of SDM: 1. HCPs who have received appropriate training through their system are able to adjust their SDM approach based on their perception of patient capacity, increasing HCP engagement and improving the patient's ability to engage in SDM. System support (C) + Accurate perception of patient capacity (M) → High patient and HCP engagement in SDM (O) 		

Mechanism Category	Detailed CMOCs		
	Hindering of SDM:		
Perception of	If a patient is displaying high levels of anxiety, the HCP may		
other party's	perceive the patient as not having the capacity to participate in		
capacity	decision-making, resulting in low HCP engagement in SDM.		
(cont'd)	HCP perception of patient anxiety (C) + HCP perception of patient		
	capacity (M) \rightarrow Low HCP engagement in HCP (O)		
	Facilitation of SDM:		
	1. If an HCP perceives that he or she has system support to give patients		
	as much time as they require for decision-making, then the HCP and		
	patient will have a higher level of engagement in SDM.		
	System support (C) + Perception of time (M) \rightarrow High engagement		
	for HCP and patient in SDM process (O)		
	Hindering of SDM:		
	1. If a system is set for a fee-for-service schedule – which does not		
	incorporate consultation time appropriately into the schedule – and		
	the HCP perceives that SDM increases appointment times, the HCP		
Perception of	may elect to reduce his or her time spent with the patient, negatively		
time	impacting the HCP's level of engagement.		
time	Negative system support for SDM (C) + Perception of inadequate		
	time to conduct SDM (M) → Low HCP engagement in SDM (O)		
	2. An HCP who perceives that a decision must be made immediately		
	may not engage the patient through a belief that too little time is		
	available in which to incorporate the patient's opinions. As an		
	example, if an individual comes in with a life-threatening emergency,		
	the HCP is more likely to act without patient consultation.		
	High complexity of diagnosis (C) + Perception of limited time to		
	make a decision (M) \rightarrow Low engagement of SDM by the HCP,		
	limiting patient engagement (O)		
	make a decision (M) \rightarrow Low engagement of SDM by the HCP,		

Mechanism	Datailed CMOCs		
Category	Detailed CMOCs		
	Hindering of SDM:		
Perception of time (cont'd)	 3. An HCP who believes that he or she does not have flexibility within his or her schedule (e.g., case load, system support to appropriately consult) may elect to not involve, or to inadequately involve, the patient in the decision process. Low system support (C) + Perception of inadequate time available (M) → Low SDM engagement (O) 		
Self-efficacy	 (M) → Low SDM engagement (O) Facilitation of SDM: A patient who is able to express his or her preferences and values through the implementation of SDM experiences higher confidence in his or her ability to participate in SDM, resulting in higher levels of SDM engagement. System support for SDM use (C) + Increased patient self-efficacy (M) → High engagement in SDM (O) Hindering of SDM: An individual (HCP or patient) who does not believe that he or she is capable of participating in SDM will avoid attempting engagement. Unidentified context + Low self-efficacy (M) → Low engagement in 		

Table 6 continued:

Mechanism Category	Detailed CMOCs		
	Facilitation of SDM: 1. A patient who trusts the HCP (or an HCP who trusts the patient) will engage in SDM. Pre-existing relationship (C) + Trust (M) → High SDM engagement (O)		
Trust	 2. An HCP who perceives that the patient trusts him or her will engage in SDM. Unidentified context + Perceived trust (M) → High engagement in SDM (O) 		
	 Hindering of SDM: 1. A patient who does not trust the HCP (or an HCP who does not trust the patient) will not engage in SDM. Pre-existing relationship (C) + Lack of trust (M) → Low engagement in SDM (O) 		
World view	 Facilitation of SDM: 1. If an HCP is willing to incorporate the patient's world view of the biomedical model into the treatment options, the patient will be more likely to engage in SDM. For example, patients may not wish to explore certain treatment options (such as blood transfusions) based on their world view. HCP acceptance of world view* (C) + World view (M) → High SDM engagement (O) 		

Mechanism	Detailed CMOCs		
Category			
World view cont'd	 Hindering of SDM: 1. If an HCP is not willing to incorporate the patient's world view of the biomedical model into the treatment options, the patient will be unlikely to engage in SDM. HCP unaccepting of world view* (C) + World view (M) → Low SDM engagement (O) 		
Recognition of decision	 Facilitation of SDM: 1. If a diagnosis is complex and requires much information exchange, HCPs will be more likely to recognize that the patient must be involved in the decision, and SDM engagement will increase. Complex diagnosis (C) + Recognition of decision (M) → SDM engagement (O) Hindering of SDM: 1. If an HCP recognizes that a decision must be made, then SDM engagement will occur. Unidentified context (C) + Recognition of decision requirement (M) → SDM engagement (O) 		

^{*} Italics represent hypothesized contexts.

Using the substantive theories identified (ToPB, FOR, and the Normative Expected Utility Theory), we examined how each underpinned SDM within our program theory. These three substantive theories combine to provide insight into how different people react in certain situations and why. We have examined the effects of these substantive theories at the program theory level (Table 7).

Table 7: Substantive Theories Underpinning the Revised Program Theory
This table presents the substantive theories that are incorporated into the Revised Program
Theory and that are believed to underpin the SDM process.

Formal theory	Area of program theory which the theory underpins	Impact of theoretical underpinning on SDM
Theory of Planned Behaviour (TOPB)	Anxiety, trust, world view, self-efficacy, perception of capacity to access external support, pre-existing relationship, recognition of decision, engagement in SDM	The TOPB combines attitude towards behaviour, subjective norms of the individual, and the individual's perceived behaviour control to form the individual's intention to engage in a certain behaviour. In SDM, someone can enter a consultation process with a predetermined idea of how he or she foresees the process going, and this can bias the success of the engagement process. For example, one may have norms engrained in one's world view that create a behavioural intent to disengage from Western medicine, thus blocking the engagement process.
Feeling of Rightness (FOR) Normative Expected	Trust, world view, self-efficacy, perception of other party's capacity, pre-existing relationship	Patients and health care providers will make an initial assessment based on their previous knowledge and similar experiences from which they will conclude a feeling of rightness based on the fluency of recall, familiarity, and metacognitive beliefs. This will cause an individual to either accept his or her initial judgement or re-evaluate. If the outcome probabilities of a given treatment are known, then individuals will have an easier time
Utility Theory	Difficulty of decision	engaging with the decision-making process than if the effect were uncertain.

6.9: Chapter Summary

This chapter summarized the results of the realist synthesis. The *Revised Program Theory* formed based on this synthesis includes three contexts, eight mechanism sets, and an outcome, and it was developed by iterative searching, CMOC analysis, expert consultation, and stakeholder input. This chapter discussed the substantive theories identified and their relation to the program theory. The final chapter of this thesis will discuss the effect of these results in research and practical implications.

CHAPTER SEVEN DISCUSSION OF RESULTS

7.1: Discussion of Results

To my knowledge, this research comprises the first realist synthesis of SDM literature and resulting program theory that identifies facilitating and hindering mechanisms for implementation. The aim of this thesis was to explore "In which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved patient-centered decision-making?" This research thesis identified three contexts, eight key mechanism sets, and a final outcome. Identified key mechanism sets interact with one another and with preceding contexts to explain when SDM may work – or not work – as well as for whom, in what circumstances, and why. These key mechanism sets were connected to IP-SDM, allowing an understanding to be reached of when these factors may become important during the decisional process.

Our research answered our three sub-questions:

1. What mechanisms can facilitate or hinder patient and health care provider engagement in the SDM process?

We identified eight key mechanism sets, each encompassing at least two mechanisms (i.e., at minimum, each mechanism set could promote or hinder SDM). Key mechanism sets include anxiety, trust, world view, perception of time, self-efficacy, access to external support, recognition of decision, and the perception of the other party's capacity. Through identification of these key mechanism sets, we are able to understand *how* and for *whom* SDM may work or not work when implemented. For example, patients who experience high anxiety which reduces their ability to deliberate options clearly may not be able to engage in SDM. However, further work in this area is required to unpack whom these individuals may be and in which situations these mechanism sets inhibit SDM.

2. What contexts can affect the expression of the identified mechanisms?

We identified three contexts that help understand in *which situations* key mechanism sets act. These three contexts include pre-existing relationship, difficulty of decision, and system support. How these contexts present themselves influences how key mechanism sets act. Continuing the example discussed in research question one, a patient who has high anxiety but who has a positive pre-existing relationship with his or her HCP may be more likely to engage in SDM, as the pre-existing relationship may increase patient trust, thereby lowering anxiety. Through nuanced interactions between these contexts and mechanisms, this program theory helps explain *why* SDM may work or not work. These contexts do not, however, reflect all potential contexts that may affect the program theory; rather, they are key contexts that will exist throughout other contexts that may be identified in future research.

3. What are the outcomes that form between identified contexts and mechanisms?

A single outcome, engagement in SDM, was identified through the interaction of contexts and mechanisms. The gradient expressions and interactions of both contexts and mechanisms depict *how* varying levels of SDM engagement can occur for both HCPs and patients. As discussed in chapter two, SDM can create both clinical and patient-level outcomes. Our *Revised Program Theory* outcome is focused on engagement, the better to allow for patient-centered decision-making rather than clinical outcomes. We know that patient-centered care improves outcomes such as satisfaction (188), which can then be hypothesized to reduce the decisional conflicts that patients face during their treatment process. Engagement in SDM is thus presented as the final outcome, being an indicator of the potential quality of patient-centered decision-making.

While SDM has been established in previous literature as a decisional style focusing on patient values and preferences, until this point literature had not tied potential barriers and facilitators into the nuanced steps of SDM. During this synthesis it became apparent that SDM involved a seemingly infinite number of CMOCs, as well as that mechanisms were inherently entangled. However, our identification of eight key mechanism sets and formation of the *Revised Program Theory* will allow knowledge users to better understand the underpinnings of SDM.

With increased interest in implementing SDM in health care systems, this research is timely in its ability to help unpack SDM.

Our *Revised Program Theory* was made with relevant knowledge users having relevant knowledge: HCPs, policy makers, and patients. We have designed this program theory to help HCPs identify key areas for which they should maintain awareness and training to provide patient-centered care tailored to each individual. We hope that this program theory will help break down the complexity of patient care and act as a guiding model for implementation of SDM. Similarly, policymakers may be able to identify where system changes, such as increased consultation times or additional training, may be necessary. Finally, the patient will ideally understand his or her right to have a voice.

7.1.1: Key Mechanism Sets in Relation to SDM

As shown in chapter six, figure 14 each mechanism set interacts with IP-SDM steps. Each mechanism set has a connecting process that will determine whether a specific step within IP-SDM is met (Table 8). This table extends current knowledge by creating a tangible understanding of how IP-SDM may or may not be successful in implementation through the connection to the Revised Program Theory. Examining each connecting process allows knowledge users to efficiently understand how mechanism sets can affect the way in which the decision-making process occurs and, more important, what barriers must be overcome to successfully implement SDM. The findings conveyed by this table identify key areas of impact that may be used to form interventions with which to reduce the influence of barriers. It can also help ascertain areas in which certain interventions may have a larger impact, as certain mechanism sets – such as trust and anxiety – influence the success of SDM implementation at very early points in the decision-making process. If supports are offered in areas with early impact, this may create a better environment for successful implementation. For example, if support is offered that seeks to increase patient trust in the health care system from the onset, this may increase patients' HCP-specific trust. Such a result would offer an improved ability to engage in the SDM process and could result in a higher likelihood of patients' and HCPs' reaching an informed, patient-centered decision.

*Table 8: Connecting Processes between Mechanism Sets and IP-SDM Steps*This table outlines the connecting process between each mechanism set and corresponding step to IP-SDM.

Mechanism set	IP-SDM step	Connecting process
Trust	"Patient accesses	A patient who has high trust in the health care
	health care system"	system and low anxiety is more likely to feel
Anxiety	"Patient accesses health care system"	comfortable seeking health care. The reverse expression of these mechanisms would predict the likelihood of a patient's avoiding accessing health care. The literature indicates that both trust and anxiety
		affect each step of IP-SDM.
Recognition of	Subsequent to	HCPs' and patients' overt recognition that a decision
decision	"Diagnosis is	is required regarding treatment (or lack of
	made"	treatment).
World view	Subsequent to	Potential options are affected by what both the
	"Presentation of	patient and the HCP(s) feel comfortable
	options"	implementing based on their individual world views.
Perception of	Subsequent to	If either the HCP(s) or the patient perceive that there
time	"Exchange of	is inadequate time to properly exchange knowledge,
	knowledge"	then this stage is unlikely to occur.
Perception of	Subsequent to	Both parties must perceive that the other party is
other party	"Exchange of	able to understand the information that must be
capacity	knowledge"	exchanged for this step to occur in an adequate
		fashion.

Mechanism set	IP-SDM step	Connecting process
Perception of capacity to access external support	Subsequent to "Exchange of values and preferences"	From the patient perspective, a personal cost may be whether the patient's family members support his or her decision or whether they are able to attend appointments. From an HCP perspective, this may include having the ability to draw on colleagues or articles for additional support regarding potential options and resulting consequences.
Self-efficacy	Subsequent to "Discussion of pros/cons, deliberation, and cost"	If any individual (HCP or patient) does not believe that he or she is able to participate in SDM or adhere to the treatment, his or her self-efficacy will prohibit the progression of this discussion.

7.1.2: Formation of Testable Hypotheses

A key benefit to using realist research is the formation of testable hypotheses. These testable hypotheses have the potential to be evaluated in future projects. Each CMOC listed in chapter six has the potential to be tested in order to confirm, refine, or refute the hypothesis formed based on the analysis. Although the *Revised Program Theory* has incorporated synthesized CMOCs into a single program theory, researchers are still able to test individual aspects or the entire program.

7.1.3: Support of Substantive Theories

The identification of three substantive theories (ToPB, FOR, and Normative Expected Utility Theory) strengthens understanding of *how* CMOCs affect SDM. Mechanisms allow us to understand the causality between context and outcome, whereas substantive theories lend further reasoning for how a mechanism may present differently for different people. Specifically, the application of substantive theories helps explain how mechanism sets may express as different gradients. It also illuminates *why* a single mechanism component that is part of a mechanism set may inhibit one individual while facilitating another's engagement in SDM.

There have been few attempts to apply substantive theories to SDM, as explained in chapter two. The research presented herein explicitly attaches substantive theories to the *Revised Program Theory*, allowing knowledge users to understand the theoretical underpinnings of *how* SDM works, as well as for *whom*, *when*, in *what circumstances*, and *why*. Furthermore, we believe that the *Revised Program Theory* acts as a first step to forming a substantive theory of SDM on its own. This will require further exploration in future works seeking to fully understand and act at the substantive level of theory.

7.1.4: Comparison of Findings to Current Literature

Our findings align with previous studies focusing on facilitators and barriers of SDM. A previous systematic review identified eight themes expressing potential factors that patients self-reported could inhibit their involvement in SDM (189). These themes were concentrated on system organization and consultation specific processes, with a key focus on the power imbalance between health care professionals and patients. A power imbalance may translate into patient anxiety and likely varies depending on the nature of the pre-existing relationship. Described conclusions are congruent with our finding that anxiety and pre-existing relationships are key mechanisms in the SDM process. These mechanisms are likely reflected in whether the physician consciously recognizes the need for a decision and the subsequent involvement of the patient.

Gravel et al., in their systematic review, also examined factors that promote and hinder SDM from a clinical perspective (114). They identified physician self-efficacy and perception of time to implement SDM as inhibitors of the process and also listed HCP world view as a motivator, noting the importance of providers' belief that SDM leads to improved patient outcomes.

Although both papers identify barriers and facilitators to SDM, neither examined the full spectrum of potential effects at the patient, HCP, and system levels. They also failed to indicate how these barriers and facilitators interacted with the SDM process. Without this step, it is difficult to know *when* these barriers and facilitators play a role, let alone in what *situations* and *how*.

7.2: Limitations

Although we believe that this program theory explains the connection between mechanisms and IP-SDM, we cannot rule out the possibility of alternate results. Realist methodology acknowledges that there will always be other interpretations of data and that no final knowledge is achievable, as individuals interpret the real world differently (16). We have strived to compile the most extensive and least biased sets of mechanisms by using multiple sources of information: literature, clinical expertise, and stakeholder consultation. It is possible that interpretation bias existed when key mechanisms were initially identified by researchers from the 55 mechanisms found within literature. Further, the nature of EA statements as "if x, then y" can be viewed as a positivist approach. This is an area that we intend to overcome in future research by refining our data extraction processes. Additionally, it is impossible to identify the infinite number of mechanisms and contexts that can play into SDM engagement. We hope that the additional step of including stakeholders to confirm, refine, and refute the findings helped validate the program theory in a manner encapsulating the most important factors for SDM.

Another limitation of this work is the inability to identify specific variables of who SDM works for. While we did collect information regarding general categories and demographics of individuals for whom SDM often works, the current literature was not extensive enough to provide an understanding of how these are intertwined within CMOCs. This area can be tested by using formed hypotheses with large sample sizes to determine whom SDM does and does not work for. We are further limited in our understanding of this area by the lack of substantive theory on the systematic level. All identified substantive theories identified act on an individual level, removing the dynamic interpersonal nature of SDM. We intend to address this limitation in future work by further developing this *Revised Program Theory* into a substantive theory for decision-making.

Our research was also limited by language. Although SDM research is being undertaken worldwide, language barriers prevented the review of non–English-language sources, creating the potential for cultural bias. We highly encourage researchers to test our program theory in their local health systems with a view to confirming, refining, and refuting our findings in an effort to reduce cultural biases. To lessen the effect of the language barrier and gain a wider

perspective, literature was included from all countries. We did note that our sources predominantly represent countries that often rank high in health and financial security. We therefore caution use of this program in countries and health systems that experience greater health and economic disparities.

7.3: Future Implications

The information presented in this thesis can act as a foundation for policy makers. It is possible to adapt the *Revised Program Theory* to an array of contexts, refining the key mechanisms to each unique health region or population group. This will allow the appropriate resources to be put in place from a system level to help promote informed patient-centered decisions. Although resources are necessary to change policy, it is likely that the resulting outcomes may reduce strain on a health system, as patients are likely to have increased satisfaction and reduced decisional conflict – potentially limiting revisits and second opinions.

HCPs may apply this program theory in a multitude of forms, from training to daily consultations. Training programs may capitalize on this program theory as a tool for understanding which factors may lower engagement. As this program theory becomes increasingly specialized for each context, it can further help HCPs predict the necessary consultation times. The creation of tools that can help patients indicate which mechanisms are most important to them may also be possible.

Chapters one and two introduced the previously popular paternalistic decision-making style. The identification of facilitators and barriers to SDM, along with *how* these interact with SDM steps, helps fill previous gaps in the literature and may also help eliminate potential remnants of paternalistic decision-making as the program theory makes implementation more feasible for health care systems to mandate. HCPs may also be better equipped to listen to patient values and preferences as they relate to treatment options. Through reduction of paternalistic decision-making, patients are less likely to be pressured into a decision that does not conflict with their value system. This correspondingly increases the likelihood of patients' engaging in SDM and the formation of an informed, patient-centered decision.

7.4: Future Research

We believe that this program theory acts as the first step towards unpacking the complexities of SDM. Future research can confirm and refine this program theory by testing the

applicability of the program theory in different contexts. Our team has begun exploring decision-making in the context of Saskatchewan Indigenous populations – specifically, by examining how the historical trauma experienced by this group may affect trust and world view for decision-making in the context of Western medical health care systems. We anticipate testing the program theory within this context as well as with prostate cancer and mental health patients. We hope that other research teams will be able to use this program theory and test it within their local contexts.

We have formed testable hypotheses through each CMOC presented in this thesis. Each hypothesis may represent a potential research project that could be undertaken to further understand the nuances of SDM. Future projects will further refine the program theory and enhance implementation of SDM, allowing for a wider breadth of applicability. Further exploration of each CMOC will allow researchers to expand our knowledge of *what works*, as well as for *whom*, in *which situations*, and *why*. An example of a specific project derived from a CMOC could be as follows: "When faced with a medical decision of moderate difficulty, for whom does the mechanism of anxiety facilitate improved engagement within SDM"? This could include exploring smaller aspects of this question: "How do individuals (both HCPs and patients) assess difficulty of decision", for example, or "How do patients react when faced with decisional conflict resulting in increasing anxiety?" Such questions could be produced for each individual CMOC presented in chapter six.

Future research may explore SDM tool development at both the educational and the implementation levels. The *Revised Program Theory* can be applied to training programs to help explain the complexity and nuances within medical decision-making. However, this body of research did not attempt to determine how the interconnected key mechanisms influence one another. Further research into this area will help educators form tools with which to train HCPs in effective SDM implementation. Implementation tools may also be developed to help HCPs succeed in their use of SDM. The literature presented in chapter two discussed the influence of preference-matching on patient satisfaction outcomes. The development of tools to determine patient preferences for SDM as a precursor to the *Revised Program Theory* may increase HCPs' ability to successfully engage in SDM.

7.5: Chapter Summary

By adapting Molnar's steps for realist syntheses and following RAMESES guidelines, we have conducted a realist synthesis and evaluation of SDM. To our knowledge, this is the first realist synthesis of SDM and thus the first investigation into the mechanisms of SDM and how they inhibit and facilitate positive SDM implementation through patient and health care provider engagement. The use of realist synthesis as the methodology for this project presented the best opportunity for us to explore SDM at a systems theory level. The knowledge gained from this research allows us to better understand "In which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved patient-centered decision?" We formed a program theory depicting key mechanisms that can be personalized by HCPs to tailor their consultation process to each individual patient. Through the identification of facilitators and barriers to SDM engagement, patients and HCPs will be able to navigate this process to engage in informed, patient-centered decision-making.

CHAPTER EIGHT

REFERENCES

- 1. Charles C, Gafni A, Whelan T. Shared Decision-Making in the Medical Encounter: What Does it Mean? (Or it Takes at Least Two to Tango). Social Science Medicine. 1997 Mar 1;44(5):681-92.
- 2. Azoulay E, Chaize M, Kentish-Barnes N. Involvement of ICU families in decisions: fine-tuning the partnership. Annals of Intensive Care. 2014 Dec;4(1): p. 37.
- 3. Bryant D, Bednarski E, Gafni A. Incorporating patient preferences into orthopaedic practice: Should the orthopaedic encounter change? Injury International Journal of the Care of the Injured. 2006 Apr 1;37(4):328-34.
- 4. Stacey D, Samant R, Bennett C. Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation. CA: A cancer journal for clinicians. 2008 Sep 1;58(5):293-304.
- 5. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. American journal of preventative medicine. 1999 Nov;17(4):285-94.
- 6. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Social Sciene & Medicine. 1999 Sep 1;49(5):651-61.
- 7. Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. Patient Education and Counseling. 2006 Jun 1;61(3):319-41.
- 8. Gattellari M, Butow PN, Tattersall MHN. Sharing decisions in cancer care. Social Science & Medicine. 2001 Jun 1;52(12):1865-78.
- 9. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient education and counseling. 1998 Mar 1;33(3):267-79.
- 10. Say R, Robson S, Thomson R. Helping pregnant women make better decisions: a systematic review of the benefits of patient decision aids in obstetrics. Reproductive medicine, obstetrics and gynaecology. 2011 Jun 1;1(2):e000261.
- 11. Shay LA, Lafata JE. Where Is the Evidence? A systematic review of shared decision making and patient outcomes. Medical Decision making. 2015 Jan;35(1):114-31.
- 12. Guimond P, Bunn H, O'Connor AM, Jacobsen MJ, Tait VK, Drake ER, Graham ID, Stacey D, Elmslie T. Validation of a tool to assess health practitioners' decision support and communication skills. Patient education and counseling. 2003 Jul 1;50(3):235-45.
- 13. O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. A survey of the decision-making needs of Canadians faced with complex health decisions. Health Expectations. 2003 Jun 1;6(2):97-109.

- 14. Pawson R, Manzano-Santaella A. A realist diagnostic workshop. Evaluation. 2012 Apr;18(2):176-91.
- 15. Wong G, Westhorp G, Pawson R, Greenhalgh T. Realist Synthesis: RAMESES training materials. London: University of London. 2013.
- 16. Pawson R, Tilley N. Realistic Evaluation. Thousand Oaks, California: Sage; 1997 Jun 23.
- 17. Pawson R. The Science of Evaluation: A Realist Manifesto. Sage; 2013 Feb 1.
- 18. Groot G, Waldron T, Carr T, McMullen L, Bandura L-A, Neufeld S-M, Duncan, V. Development of a program theory for shared decision-making: a realist review protocol. Systematic Reviews. 2017 Dec;6(114).
- 19. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush P, Henderson J Sirett E, Wong G, Cargo M, Herbert CP, Seifer SD. Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. The Milbank Quarterly. 2012 Jun 1;90(2):311-46.
- 20. Kane SS, Gerretsen B, Scherpbier R, Dal Poz M, Dieleman M. A realist synthesis of randomised control trials involving use of community health workers for delivering child health interventions in low and middle income countries. BMC Health Services Research. 2010 Dec; 10(1):286.
- 21. Clark AM, Whelan HK, Barbour R, MacIntyre PD. A realist study of the mechanisms of cardiac rehabilitation. Journal of Advanced Nursing. 2005 Nov 1;52(4):362-71.
- 22. Clark AM, MacIntyre PD, Cruickshank J. A critical realist approach to understanding and evaluating heart health programmes. Health. 2007 Oct;11(4):513-39.
- 23. Fletcher AJ. Applying critical realism in qualitative research: methodology meets method. International Journal of Social Research Methodology. 2017 Mar 4;20(2):181-94.
- 24. Maxwell JA. A realist approach for qualitative research. Sage; 2012.
- 25. Sæther B. Retroduction: an alternative research strategy? Business Strategy and the Environment. 1998 Sep 1;7(4):245-9.
- 26. Elit L, Charles C, Gold I, Gafni A, Farrell S, Tedford S, Dal Bello D, Whelan T. Women's perceptions about treatment decision making for ovarian cancer. Gynecologic Oncology. 2003 Feb 1;88(2):89-95.
- 27. Charles C, Gafni A, Whelan T. Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. Health Expectations. 2004 Dec 1;7(4):338-48.
- 28. Elwyn G. Idealistic, impractical, impossible? Shared decision making in the real world. British Journal of General Practice. 2006 Jun 01;56(527):403-4.
- 29. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwrads A. Shared Decision Making: A Model for Clinical Practice. Journal of General Internal Medicine. 2012 Oct 1;27(10):1361-7.
- 30. Lloyd A, Joseph-Williams N, Edwards A, Rix A, Elwyn G. Patchy 'coherence': using normalization process theory to evaluate a multi-faceted shared decision making implementation program (MAGIC). Implement Science. 2013 Dec;8(1):102.
- 31. Legare F, Moumjid-Ferdjaoui N, Drolet R, Stacey D, Harter M, Bastian H, Beaulieu MD, Borduas F, Charles C, Coulter A, Desroches S. Core competencies for shared decision

- making training programs: insights from an international, interdisciplinary working group. Journal of Contining Education in the Health Professions. 2013 Sept 1;33(4):267-73.
- 32. Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and Evaluating Shared Decision Making in Oncology Practice. CA: A Cancer Journal for Clinicians. 2014 Nov 1;64(6):377-88.
- 33. Durand M-A, Barr PJ, Walsh T, Elwyn G. Incentivizing shared decision making in the USA where are we now? Healthcare. 2015 Jun 1;3(2);97-101.
- 34. Elwyn G, Edwards A, Hood K, Robling M, Atwell C, Russell I, Wensing M, Grol RP. Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. Family Practice. 2004 Aug;21(4):337-46.
- 35. Tlach L, Wusten C, Daubmann A, Liebherz S, Harter M, Dirmaier J. Information and decision-making needs among people with mental disorders: a systematic review of the literature. Health Expectations. 2015 Dec1;18(6):1856-72.
- 36. Frost DW, Cook DJ, Heyland DK, Fowler RA. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review. Critical Care Medicine. 2011 May 1;39(5):1174-89.
- 37. Levinson W, Kao A, Kuby A, Thisted RA. Not All Patients Want to Participate in Decision Making. Journal of General Internal Medicine. 2005 Jun 1;20(6):531-5.
- 38. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and Decision-Making Preferences of Hospitalized Adult Cancer Patients. Social Science Medicine. 1988 Jan 1;27(11):1139-45.
- 39. Jordan P, Quadrelli S, Heres M, Belli L, Ruhl N, Colt H. Examining patients' preferences for participation in clinical decision-making: the experience in a Latin American chronic obstructive pulmonary disease and cancer outpatient population. Internal Medicine Journal. 2014 Mar 1; 44(3):281-7.
- 40. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Education and Counseling. 2006 Mar 1;60(3):301-12.
- 41. Stacey D, Legare F, Pouliot S, Kryworuchko J, Dunn S. Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. Patient Education and Counseling. 2010 Aug 1;80(2):164-72.
- 42. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expectations. 2006 Mar 1;9(1):25-36.
- 43. D'Amour D, Ferrada-Videla M, San Martin Rodriguez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks Journal of Interprofessional Care. 2005 May 1;19(sup1):116-31.
- 44. Coulter A. Paternalism or partnership? Patients have grown up—and there's no going back BMJ:British Medical Journal. 1999 Sep 18;319(7212):719.
- 45. King JS, Eckman MH, Moulton BW. The Potential of Shared Decision Making to Reduce Health Disparities. Journal of Law, Medicine & Ethics. 2011 Feb;39(1_suppl):30-3.

- 46. Légaré F, Elwyn G, Fishbein M, Frémont P, Frosch D, Gagnon M-P, Kenny DA, Labrecque M, Stacy D, St-Jacques S, van der Weijden T. Translating shared decision-making into health care clinical practices: Proof of concepts. Implementation Science. 2008;3(2).
- 47. Moore JE, Titler MG, Kane Low L, Dalton VK, Sampselle CM. Transforming Patient-Centered Care: Development of the Evidence Informed Decision Making through Engagement Model. Womens Health Issues. 2015 May 1;25(3):276-82.
- 48. Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Ziniel S, Fowler J, Floyd Jr FJ, Levin CA, Fagerlin A. Deficits and Variations in Patients' Experience with Making 9 Common Medical Decisions: The DECISIONS Survey Medical Decision Making. 2010 Sep;30(5_suppl):85-95.
- 49. Shepherd HL, Barratt A, Trevena LJ, McGeechan K, Carey K, Epstein RM, Butow PN, Del Mar CB, Entwistle V, Tattersall MH. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling. 2011 Sep 1;84(3):379-85.
- 50. Fenton WS. Shared decision making: a model for the physician-patient relationship in the 21st century? Acta Psychiatrica Scandinavica. 2003 Jun 1: 107(6):401-2.
- 51. Coulter A. Patient information and shared decision-making in cancer care. British Journal of Cancer. 2003;89.
- 52. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. British Journal of General Practice. 1999 Jun 1;49(443):477-82.
- 53. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. British Journal of General Practice. 2000 Nov 1;50(460):892-9.
- 54. Ford S, Schofield T, Hope T. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Social Science & Medicine. 2003 Feb 1;56(3):589-602.
- 55. Seale C, Chaplin R, Lelliott P, Quirk A. Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences. Social Science & Medicine. 2006 Jun 1;62(11):2861-73.
- 56. Quaschning K, Korner M, Wirtz M. Analyzing the effects of shared decision-making, empathy and team interaction on patient satisfaction and treatment acceptance in medical rehabilitation using a structural equation modeling approach. Patient Education and Counseling. 2013 May 1;91(2):167-75.
- 57. Maffei RM, Dunn K, Zhang J, Hsu CE, Holmes JH. Understanding behavioral intent to participate in shared decision-making in medically uncertain situations. Methods Information in Medicine. 2012;51(4):301-8.
- 58. Desroches S, Gagnon M-P, Tapp S, Légaré F. Implementing shared decision-making in nutrition clinical practice: A theory-based approach and feasibility study. Implementation Science. 2008 Dec;3(1):48.

- 59. Blank T, Graves K, Sepucha K, Llewellyn-Thomas H. Understanding Treatment Decision Making: Contexts, Commonalities, Complexities, and Challenges. Annals of Behavioral Medicine. 2006 Dec 1;32(3):211-7.
- 60. Makoul G, Arntson P, Schofield T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. Social Science & Medicine. 1995 Nov 1;41(9):1241-54.
- 61. Nannenga MR, Montori VM, Weymiller AJ, Smith SA, Christianson TJ, Bryant SC, Gafni A, Charles C, Mullan RJ, Jones LA, Bolona ER. A treatment decision aid may increase patient trust in the diabetes specialist. The Statin Choice randomized trial. Health Expectations. 2009 Mar 1;12(1):38-44.
- 62. Legare F, Stacey D. IP-SDM Concepts defined. 2010. Available: https://decisionaid.ohri.ca/ip-sdm.html.
- 63. Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, Vollmer VM. Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma. American Journal of Respiratory and Critical Care Medicine. 2010 Mar 15;181(6):566-77.
- 64. Stacey D, Samant R, Bennett C. Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation. CA: A Cancer Journal for Clinicians. 2008 Sep 1;58(5):293-304.
- 65. Ford S, Schofield T, Hope T. Are patients' decision-making preferences being met? Health Expectations. 2003 Mar 1;6(1):72-80.
- 66. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. British Journal of Cancer. 2001;84(1):48.
- 67. Legare F, Stacey D. IP-SDM Model. 2010. Available: https://decisionaid.ohri.ca/ip-sdm.html.
- 68. Gattellari M, Butow P, Tattersall, M. Sharing decisions in cancer care. 2001 Jun 2001;52(12):1865–78.
- 69. Fowler Jr. FJ, Gallagher PM, Bynum JPW, Barry MJ, Lucas FL, Skinner JS. Decision-Making Process Reported by Medicare Patients Who Had Coronary Artery Stenting or Surgery for Prostate Cancer. Journal of General Internal Medicine. 2012 Aug 1;27(8):911-6.
- Rothert M, Padonu G, Holmes-Rovner M, Kroll J, Talarczyk G, Rovner D, Schmitt N, Breer L. Menopausal women as decision makers in health care. Experimental Gerontolology. 1994 May 1;29(3-4):463-8.
- 71. Heyland DK, Frank C, Groll D, Pichora D, Dodek P, Rocker G, Gafni A. Understanding Cardiopulmonary Resuscitation Decision Making: Perspectives of Seriously III Hospitalized Patients and Family Members. Chest. 2006 Aug 1;130(2):419-28.
- 72. Uldry E, Schafer M, Saadi A, Rousson V, Demartines N. Patients' preferences on information and involvement in decision making for gastrointestinal surgery. World Journal of Surgery. 2013 Sep 1;37(9):2162-71.
- 73. White DB, Braddock CH, Bereknyei S, Curtis RJ. Toward Shared Decision Making at the End of Life in Intensive Care Units: opportunities for improvement. Archives of Internal Medicine. 2007 Mar 12;167(5):461-7.

- 74. Kehl KL, Landrum MB, Arora NK, Ganz PA, van Ryn M, Mack JW, Keating NL. Association of Actual and Preferred Decision Roles with Patient-Reported Quality of Care: Share Decision Making in Cancer Care. JAMA Oncology. 2015 Apr 1;1(1):50-8.
- 75. Weston WW. Informed and shared decision-making: the crux of patient-centred care. 2001 Aug 21;165(4):438-9.
- 76. Goscha R, Rapp C. Exploring the experiences of client involvement in medication decisions using a shared decision making model: results of a qualitative study. Community Mental Health J. 2015 Apr 1;51(3):267-74.
- 77. Davis K, Haisfield L, Dorfman C, Krist A, Taylor KL. Physicians' Attitudes About Shared Decision Making for Prostate Cancer Screening Family Medicine. 2011 Apr 1;43(4):260.
- 78. Joosten EAG, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CPF, de Jong CAJ. Systematic Review on the Effects of Shared Decision-Making on Patient Satisfaction, Treatment Adherence and Health Status. Psychotherapy and Psychosomatics. 2008;77(4):291-26.
- 79. Flynn D, Knoedler MA, Hess EP, Murad MH, Erwin PJ, Montori VM, Thomson RG. Engaging patients in health care decisions in the emergency department through shared decision-making: a systematic review. Acad Emerg Med. 2012 Aug 1;19(8):959-67.
- 80. Edwards A, Elwyn G. Involving patients in decision making and communicating risk: a longitudinal evaluation of doctors' attitudes and confidence during a randomized trial. Journal of Evaluation in Clinical Practice. 2004 Aug 1;10(3):431-7.
- 81. Loh A, Simon D, Wills CE, Kriston L, Niebling W, Harter M. The effects of a shared decision-making intervention in primary care of depression: A cluster-randomized controlled trial. Patient Education and Counseling. 2007 Aug 1;67(3):324-32.
- 82. Schubart JR, Dominici LS, Farnan M, Kelly TA, Manahan ER, Rahman ER, Smith JS, Kass RB. Shared Decision Making in Breast Cancer: National Practice Patterns of Surgeons. Annals of Surgical Oncology. 2013 Oct 1;20(1):3323-9.
- 83. Legare F, O'Connor AC, Graham I, Saucier D, Cote L, Cauchon M, Paré L. Supporting patients facing difficult health care decisions: use of the Ottawa Decision Support Framework. Cananadian Family Physician. 2006 Apr 1;52:476-7.
- 84. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review a new method of systematic review designed for complex policy interventions. Journal of Health Services Research and Policy. 2005 Jul;10(1_suppl):21-34.
- 85. Taylor C, Alastair J, Glynne-Jones R, Griffith C, Trevatt P, Richards M, Ramirez AJ. Multidisciplinary team working in cancer: what is the evidence? British Medical Journal. 2010 Mar 23:340.
- 86. Turner S, Maher E, Young T, Young J, Vaughan Hudson G. What are the information priorities for cancer patients involved in treatment decisions? An experienced surrogate study in Hodgkin's disease. British Journal of Cancer. 1996 Jan;73(2):222.
- 87. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities Health Expectations. 2000 Sep 1;3(3):182-91.

- 88. Stacey D, Pomey MP, O'Connor AM, Graham ID. Adoption and sustainability of decision support for patients facing health decisions: an implementation case study in nursing. Implement Science. 2006 Dec;1(1):17.
- 89. Legare F, Ratte S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. Patient education and counseling. 2008 Dec 1;73(3):526-35.
- 90. Legare F, Stacey D, Pouliot S, Gauvin F-P, Desroches S, Kryworuchko J, Dunn S, Elwyn G, Frosch D, Gagnon MP, Harrison MB. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. Journal of Interprofessional Care. 2011 Jan 1;25(1):18-25.
- 91. Stacey D, Legare F, Pouliot S, Kryworuchko J, Dunn S. Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. Patient Education and Counseling. 2009 Aug 1;80(2):164-72.
- 92. Légaré F, Stacey D, Gagnon S, Dunn S, Pluye P, Frosch D, Kryworuchko J, Elwyn G, Gagnon MP, Graham ID. Validating a conceptual model for an interprofessional approach to shared decision making: a mixed methods study. Journal of Evaluation in Clinical Practice. 2011 Aug 1;17(4):554-64.
- 93. Manyonga H, Howarth G, Dinwoodie M, Nisselle P, Whitehouse S. From informed consent to shared decision-making. South African Medical Journal. 2014 Aug;104(8):561-2.
- 94. Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter BMJ. 2012 Nov;345:23.
- 95. Wennberg JE, O'Connor AM, Collins ED, Weinstein JN. Extending the P4P Agenda, Part 1: How Medicare Can Improve Patient Decision Making and Reduce Unnecessary Care. Health Affairs. 2007 Nov;26(6):1564-74.
- 96. O'Connor. Ottawa Decision Support Framework to Address Decisional Conflict. Retrieved June. 2006;15:2009.
- 97. Lalonde L, O'Connor AM, Drake E, Duguay P, Lowensteyn I, Grover SA. Development and preliminary testing of a patient decision aid to assist pharmaceutical care in the prevention of cardiovascular disease. Pharmacotherapy. 2004 Jul;24(7):909-22.
- 98. Legare F, Stacey D, Graham ID, Elwyn G, Pluye P, Gagnon M-P, Frosch D, Harrison MB, Kryworuchko J, Pouiot S. Advancing theories, models and measurement for an interprofessional approach to shared decision making in primary care: a study protocol. BMC Health Service Research. 2008 Dec;8(1):2.
- 99. Stacey D, Briere N, Robitaille H, Fraser K, Desroches S, Legare F. A systematic process for creating and appraising clinical vignettes to illustrate interprofessional shared decision making. Journal of Interprofessional care Care. 2014 Sep;28(5):453-9.
- 100. Suurmond J, Seeleman C. Shared decision-making in an intercultural context. Barriers in the interaction between physicians and immigrant patients. Patient Education and Counseling. 2006 Feb;60(2):253-9.
- 101. Dogba MJ, Menear M, Stacey D, Briere N, Legare F. The Evolution of an Interprofessional Shared Decision Making Research Program: Reflective Case Study of an Emerging Paradigm. Journal of Interprofessional Care. 2016 Jul 19;16(3).

- 102. Chamot E, Charvet A, Perneger TV. Women's Preferences for Doctor's Involvement in Decisions about Mammography Screening. Medical Decision Making. 2004 Aug;24(4):379-82.
- 103. Deber RB. Physicians in health care management: 8. The patient-physician partnership: decision making, problem solving and the desire to participate. CMAJ: Canadian Medical Association Journal. 1994 Aug 15;151(4):423.
- 104. George TP. How nurses can encourage shared decision making. Nursing. 2013 Aug 1;43(8):65-6.
- 105. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. Bmj. 2000 Oct 7;321(7265):867-71.
- 106. Wright JG, Hawker GA, Bombardier C, Croxford R, Dittus RS, Freund DA, Coyte PC. Physician enthusiasm as an explanation for area variation in the utilization of knee replacement surgery. Medical Care. 1999 Sep;37(9):946-56.
- 107. Jones IR, Berney L, Kelly M, Doyal L, Griffiths C, Feder G, Hillier S, Rowlands G, Curtis S. Is patient involvement possible when decisions involve scarce resources? A qualitative study of decision-making in primary care. Social Science & Medicine. 2004 Jul 1;59(1):93-102.
- 108. Irvine R, Kerridge I, McPhee J, Freeman S. Interprofessionalism and ethics: consensus or clash of cultures? Journal of Interprofessional Care. 2002 Jan 1;16(3):199-210.
- 109. King JS, Moulton BW. Rethinking informed consent: the case for shared medical decision-making. Americal Journal of Law & Medicine. 2006 Dec;32(4):429-501.
- 110. McGuire AL, McCullough LB, Weller SC, Whitney SN. Missed expectations? Physicians' views of patients' participation in medical decision-making. Medical Care. 2005 May;43(5):466-70.
- 111. Say R, Robson S, Thomson R. Helping pregnant women make better decisions: a systematic review of the benefits of patient decision aids in obstetrics BMJ Open. 2011 Jan 1;1(2):e000261.
- 112. Makoul, G, Arntson, P, & Schofield, T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. Social Science & Medicine. 1995;41(9):1241-1254.
- 113. Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. Health Affairs. 2012 May 1;31(5):1030-8.
- 114. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. Implement Science. 2006 Dec; 1:16.
- 115. Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Legare F. Decision Coaching to Prepare Patients for Making Health Decisions: A Systematic Review of Decision Coaching in Trials of Patient Decision Aids. International Journal of Evidence-Based Healthcare. 2011 Sep 1;9(3):327.
- 116. Whelan T, Levine M, Willan A, Gafni A, Sanders K, Mirsky D, Chambers S, O'brien MA, Reid S, Dubois S. Effect of a Decision Aid on Knowledge and Treatment Decision

- Making for Breast Cancer Surgery. Journal of American Medical Association. 2004;292(4):7.
- 117. Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, Julian J, Dent S, Abu-Zahra H, Chouinard E, Tozer R. Helping Patients Make Informed Choices: A Randomized Trial of a Decision Aid for Adjuvant Chemotherapy nLymph Node-Negative Breast Cancer. Journal of National Cancer Institute. 2003 Apr 16;95(8):581-7.
- 118. Woolf SH, Chan ECY, Harris R, Sheridan SL, Braddock III CH, Kaplan RM, Krist A, O'Connor AM, Tunis. Promoting Informed Choice: Transforming Health Care To Dispense Knowledge for Decision Making. Annals of Internal Medicine. 2005 Aug 16:143(4):293-300.
- 119. Waljee JF, Rogers MAM, Alderman AK. Decision Aids and Breast Cancer: Do They Influence Choice for Surgery and Knowledge of Treatment Options? Journal of Clinical Oncology. 2007 Mar 20;25(9):1067-73.
- 120. Stiggelbout AM, Van der Weijden T, De Wit MPT, Frosch D, Legare F, Montori VM, Trevena L, Elwyn G. Shared decision making: really putting patients at the centre of healthcare. BMJ. 2012 Jan 27;344:e256.
- 121. Dowie J, Kaltoft MK, Nielsen JB, Salkeld G. Introduction to Multi-Criteria Decision Analysis (MCDA) as a way of bringing SDM and EBP together. Research Unit for General Practice, University of South Denmark; 2015.
- 122. Lipstein EA, Dodds CM, Britto MT. Real life clinic visits do not match the ideals of shared decision making. The Journal of Pediatrics. 2014 Jul 1;165(1):178-83.
- 123. Ruland C, Bakken S. Developing, implementing, and evaluating decision support systems for shared decision making in patient care: a conceptual model and case illustration. 2002 October 1;35(5–6):313–21.
- 124. Tiedje K, Shippee ND, Johnson AM, Flynn PM, Finnie DM, Liesinger JT, May CR, Olson ME, Ridgeway JL, Shah ND, Yawn BP. 'They leave at least believing they had a part in the discussion': Understanding decision aid use and patient—clinician decision—making through qualitative research. Patient Education and Counseling. 2013 Oct 1;93(1):86-94.
- 125. Kim YM, Kols A, Martin A, Silva D, Rinehart W, Prammawat S, Johnson S, Church K. Promoting informed choice: evaluating a decision-making tool for family planning clients and providers in Mexico. International Family Planning Perspectives. 2005 Dec 1;31(4):162-71.
- 126. Barry MJ, Wescott PH, Reifler EJ, Chang Y, Moulton BW. Reactions of Potential Jurors to a Hypothetical Malpractice Suit Alleging Failure to Perform a Prostate-Specific Antigen Test. Journal of Law, Medicine & Ethics. 2008 Jun;36(2):392-402.
- 127. Elwyn G, Edwards A, Gwyn R, Grol R. Towards a Feasible Model for Shared Decision Making: Focus Group Study with General Practice Registrars. BMJ. 1999 Sep 18;319(7212):753-6.
- 128. Dahlqvist-Jonsson P, Schon UK, Rosenburg D, Sandlund M, Svedberg P. Service users' experiences on participation in decision making in mental health services. Journal of Psychiatric and Mental Health Nursing. 2015 Nov 1;22(9):688-97.

- 129. Lifford KJ, Witt J, Burton M, Collins K, Caldon L, Edwards A, Reed M, Wyld L, Brain K. Understanding older women's decision making and coping in the context of breast cancer treatment. BMC: Medical Informatics & Decision Making. 2015 Dec;15(1):45.
- 130. Valdez-Martinez E, Noyes J, Bedolla M. When to stop? Decision-making when children's cancer treatment is no longer curative: a mixed-method systematic review. BMC Pediatrics. 2014 Dec;14(1):124.
- 131. Gillick MR. Re-engineering shared decision-making. Journal of Medical Ethics. 2015;41(9).
- 132. Larochelle M, Rodriguez K, Arnold R, Barnato A. Hospital staff attributions of the causes of physician variation in end-of-life treatment intensity. Palliative Medicine. 2009 Jul;23(5):460-70.
- 133. Dobrow MJ, Goel V, Lemieux-Charles L, Black NA. The impact of context on evidence utilization: A framework for expert groups developing health policy recommendations. Social Science and Medicine. 2006 Oct 1;63(7):1811-24...
- 134. Hamann J, Kohl S, McCabe R, Buhner M, Mendel R, Albus M, Bernd J. What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists. Social Psychiatry and Psychiatric Epidemiology. 2016 Apr 1;51(4):617-25.
- 135. Karnieli-Miller O, Eisikovits Z. Physician as partner or salesman? Shared decision-making in real-time encounters. Social Science & Medicine. 2009 Jul 1;69(1):1-8.
- 136. Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware Jr. JE. Characteristics of Physicians with Participatory Decision-Making Styles. Annals of Internal Medicine. 1996 Mar 1;124(5):497-504.
- 137. D'Antonio PO, Walsh Brennan AM, Curley MA. Judgment, inquiry, engagement, voice: reenvisioning an undergraduate nursing curriculum using a shared decision-making model. Journal of Professional Nursing. 2013 Nov 1;29(6):407-13.
- 138. Heyland DK, Tranmer J, O'Callaghan CJ, Gafn A. The Seriously Ill Hospitalized Patient: Preferred Role in End-of-Life Decision Making?. Journal of Critical Care. 2003 Mar 1;18(1):3-10.
- 139. Schulman-Green DJ, Naik AD, Bradley EH, McCorkle R, Bogardus ST. Goal setting as a shared decision making strategy among clinicians and their older patients. Patient Education and Counseling. 2006 Oct 1;63(1-2):145-51.
- 140. Fowler Jr. FJ, McNaughton Collins M, Albertsen PC, Zietman A, Elliot DB, Barry MJ. Comparison of Recommendations by Urologists and Radiation Oncologists for Treatment of Clinically Localized Prostate Cancer. American Medical Association. 2000 Jun 28;283(24):3217-22.
- 141. Pearce A, Newcomb C, Husain S. Recommendations by Canadian urologists and radiation oncologists for the treatment of clinically localized prostate cancer Canadian Urological Association. 2008 Jun;2(3):7.
- 142. Stevenson FA. General practictioners' views on shared decision making: a qualitative analysis. Patient Education and Counseling. 2003 Jul 1;50(3):291-3.

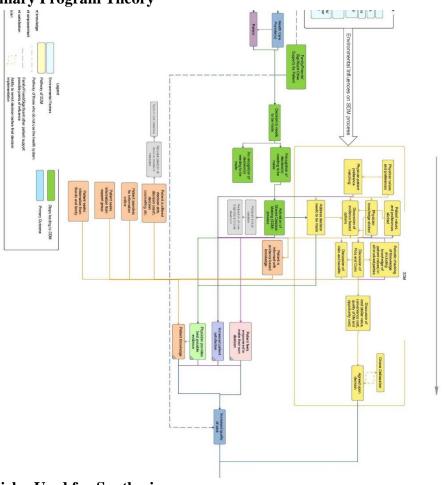
- 143. Naik AD, Schulman-Green D, McCorkle R, FAAN, Bradley EH, Bogardus J, Sidney T. Will Older Persons and Their Clinicians Use a Shared Decision-making Instrument? Journal of General Internal Medicine. 2005 Jul 1;20(7):640-3.
- 144. Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R. GPs' views on involvement of older patients: an European qualitative study. Patient Education and Counseling. 2004 May;53(2):183-8.
- 145. Ajzen I. From intentions to actions: A theory of planned bahavior. Action Control: Springer Berlin Heidelberg; 1985. p. 11-39.
- 146. Ajzen I. The Theory of Planned Behavior. Organizational Behavior and human decision processes. 1991;50:179-211.
- 147. Montano DE, Kasprzyk D. Health Behavior and Health Education: Theory, Research, and Practice. John Wiley & Sons. 2008 Aug 28. 557 p.
- 148. Allaire A-S, Labrecque M, Giguere A, Gagnon M-P, Legare F. What Motivates Family Physicians to Participate in Training Programs in Shared Decision Making? Journal of Continuing Education in the Health Professions. 2012 Mar 1;32(2):98-107.
- 149. Thompson V. Dual-process theories: A metacognitive perspective. In: Evans J, Frankish K, editors. In two minds: dual processes and beyond: Oxford University Press; 2009. p. 171-95.
- 150. Fletcher L, Carruthers P. Metacognition and reasoning. Phil. Trans. R. Soc. B. 2012 May 19;367(1594):1366-78.
- 151. Kahneman D. A perspective on judgment and choice: Mapping bounded rationality. American Psychologist. 2003;58(9):697-720.
- 152. Thompson VA, Prowse Turner JA, Pennycook G. Intuition, reason, and metacognition. Cognitive Psycholology. 2011 Nov;63(3):107-40.
- 153. Jacoby L, Whitehouse K. An illusion of memory: False recognition influenced by unconscious perception. Journal of Experimental Psychology. 1989 Jun;118(2):126-35.
- 154. Evans JSBT, Curtis-Holmes J. Rapid responding increases belief bias: Evidence for the dual-process theory of reasoning. Thinking & Reasoning. 2005 Sep 1;11(4):382-9.
- 155. Roberts MJ, Newton EJ. Inspection times, the change task, and the rapid-response selection task. The Quarterly Jounnal of Experimental Psychology: Section A. 2001 Nov 1;54(4):1031-48.
- 156. Evans J. How many dual-process theories do we need? One, two, or many? In: (Eds.) EKF, editor. In two minds: Dual processes and beyond. 2009. p. 33-54.
- 157. Stanovich K. Who Is Rational?: Studies of Individual Differences in Reasoning. Psychology Press; 1999. 312 p.
- 158. Chapman G, Elstein A. Decision Making in Health Care: theory, psycholgy, and applications. Cambridge, United Kingdom: Cambridge University Press; 2003.
- 159. Cohen BJ. Is Expected Utility Theory Normative for Medical Decision Making?, Medical Decision Making. 1996 Feb; 16(1):1-6.
- 160. Tversky A. A Critique of Expected Utility Theory: Descriptive and Normative Considerations. Erkenntnis. 1975;9(2):163-73.
- 161. Nishioka K. Francis Bacon's Life and the Formation of His Realism. Okayama. 1998;34:29-39.

- 162. Bierstedt R. A Critique of Empiricism in Sociology. American Sociological Review. 1949 Oct 1;14(5):584-92.
- 163. Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. BMC Medicine. 2013 Dec;11(1):21.
- 164. Wong G, Greenhalgh T, Westhorp G, Pawson R. Development of methodological guidance, publication standards and training materials for realist and Meta-narrative reviews: the RAMESES (Realist and Meta-narrative Evidence Synthesis Evolving Standards) project. National Institute for Health Research. 2014;2(30).
- 165. Pawson R. A Realist Family Tree. 2017 International Conference for Realist Research, Evaluation and Synthesis; Brisbane, Australia 2017.
- 166. Bhaskar R. Reclaiming reality: A critical introduction to contemporary philosophy. Taylor & Francis; 2010 Oct 25.
- 167. Archer M, Decoteau C, Gorski P, Little D, Porpora D, Rutzou T, et al. What is critical realism? Perspectives: A Newsletter of the ASA Theory Section. 2016. Epub Fall.
- 168. Boyd RN. On the Current Status of the Issue of Scientific Realism. Erkenninis. 1983 May 1;19(1-3):45-90.
- 169. Scotland J. Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. English Language Teaching. 2012 Jul 25;5(9):9.
- 170. Westhorp G. Key assumptions in realist philosophy. Get Real 2018: Introduction to Realist Methodologies; Saskatoon, Saskatchewan 2018.
- 171. Joseph J. Philosophy in International Relations: A Scientific Realist Approach. Millennium: Journal of International Studies. 2007;35(2):345-59.
- 172. Kurki M. Critical Realism and Causal Analysis in International Relations. Millennium: Journal of International Studies. 2007;35(2):361-78.
- 173. Pawson R. Evidence-Based Policy: A Realist Perspective. Sage Publications Ltd; 2006.
- 174. Pearson M, Brand SL, Quinn C, Shaw J, Maguire M, Michie S, Briscoe S, Lennox C, Stirzaker A, Kirkpatrick T, Byng R. Using realist review to inform intervention development: methodological illustration and conceptual platform for collaborative care in offender mental health. Implementation Science. 2015 Dec;10(1):134.
- 175. Jagosh J, Bush P, Salsberg J, Greenhalgh T, Wong G, Cargo M, Green LW, Herbert CP, Pluye P. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. BMC Public Health. 2015 Dec;15(1):725.
- 176. Jagosh J, Pluye P, Wong G, Cargo M, Salsberg J, Bush PL, Herbert CP, Green LW, Greenhalgh T, Macaulay AC. Critical reflections on realist review: insights from customizing the methodology to the needs of participatory research assessment. Research Synthesis Methods. 2014 Jun;5(2):131-41.
- 177. Merton R. Social Theory and Social Structure. Simon and Schuster; 1968.
- 178. Wong G, Westhorp G, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh T. RAMESES II reporting standards for realist evaluations. BMC Medicine. 2016 Dec;14(1):96.

- 179. Molnar A, O'Campo P, Ng E, Mitchell C, Muntaner C, Renahy E, John AS, Shankardass K. Protocol: Realist synthesis of the impact of unemployment policies on poverty and health. Evaluation and Program Planning. 2015 Feb 1;48:1-9.
- 180. Waldron T, Groot G. Shared Decision Making and Decision Aids. 2015. Unpublished.
- 181. Suri H. Purposeful Sampling in Qualitative Research Synthesis. Qualitative Research Journal. 2011 Aug 3;11(2):63-75.
- 182. Jackson S, Kolla G. A New Realistic Evaluation Analysis Method: linked coding of context, mechanism, and outcome relationships. American Journal of Evaluation. 2012 Sep;33(3):339-49.
- 183. Wilson M. Institutionalism, critical realism, and the critique of mainstream economics. Journal of Institutional Economics. 2005;1(2):217-31.
- 184. Lawson T. Economics and Reality. New York, NY: Routledge: Taylor and Francis Group; 1997.
- 185. Harris J, Croot L, Thompson J, Springett J. How stakeholder participation can contribute to systematic reviews of complex interventions. Journal of Epidemiology and Community Health. 2015 Oct 16:jech-2015.
- 186. Meyer SB, Lunnay B. The Application of Abductive and Retroductive Inference for the Design and Analysis of Theory-Driven Sociological Research. 2013 Feb; 18(1):1-1.
- 187. Ward C, Gimbel S. Retroductive Analogy: How to and How Not to Make Claims of Good Reasons to Believe in Evolutionary and Anti-Evolutionary Hypotheses. Argumentation. 2010 Mar 1;24(1):71-84.
- 188. Venetis MK, Robinson JD, LaPlant Turkiewicz K, Allen M. An evidence base for patient-centered cancer care: A meta-analysis of studies of observed communication between cancer specialists and their patients. Patient Education and Counseling. 2009 Dec 1;77(3):349-83.
- 189. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making Patient Education and Counseling. Patient Education and Counseling. 2014 Mar 1;94(3):291-309.

CHAPTER NINE APPENDICES

9.1: A: Preliminary Program Theory



9.2: B: All Articles Used for Synthesis

Allaire A-S, Labrecque M, Giguere A, Gagnon M-P, Legare F. What Motivates Family Physicians to Participate in Training Programs in Shared Decision Making? Journal of Continuing Education in the Health Professions. 2012 Mar 1;32(2):98-107.

Adam JA, Khaw FM, Thomson RG, Gregg PJ, Llewellyn-Thomas HA. Patient decision aids in joint replacement surgery: a literature review and an opinion survey of consultant orthopaedic surgeons. The Annals of The Royal College of Surgeons of England. 2008 Apr;90(3):198-207.

Adsul P, Wray R, Spradling K, Darwish O, Weaver N, Siddiqui S. Systematic review of

decision aids for newly diagnosed patients with prostate cancer making treatment decisions. The Journal of urology. 2015 Nov 1;194(5):1247-52.

Alden DL. Decision aid influences on factors associated with patient empowerment prior to cancer treatment decision making. Medical Decision Making. 2014 Oct;34(7):884-98.

Azoulay E, Chaize M, Kentish-Barnes N. Involvement of ICU families in decisions: fine-tuning the partnership. Annals of Intensive Care. 2014 Dec;4(1): p. 37.

Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and Decision-Making Preferences of Hospitalized Adult Cancer Patients. Social Science Medicine. 1988 Jan 1;27(11):1139-45.

Blank T, Graves K, Sepucha K, Llewellyn-Thomas H. Understanding Treatment Decision Making: Contexts, Commonalities, Complexities, and Challenges. Annals of Behavioral Medicine. 2006 Dec 1;32(3):211-7.

Briss P, Rimer B, Reilley B, Coates RC, Lee NC, Mullen P, Corso P, Hutchinson AB, Hiatt R, Kerner J, George P. Promoting informed decisions about cancer screening in communities and healthcare systems. American journal of preventive medicine. 2004 Jan 1;26(1):67-80.

Bryant D, Bednarski E, Gafni A. Incorporating patient preferences into orthopaedic practice: Should the orthopaedic encounter change? Injury International Journal of the Care of the Injured. 2006 Apr 1;37(4):328-34.

Chamot E, Charvet A, Perneger TV. Women's Preferences for Doctor's Involvement in Decisions about Mammography Screening. Medical Decision Making. 2004 Aug;24(4):379-82.

Charles C, Gafni A, Whelan T. Shared Decision-Making in the Medical Encounter: What Does it Mean? (Or it Takes at Least Two to Tango). Social Science Medicine. 1997 Mar 1;44(5):681-92.

Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Social Sciene & Medicine. 1999 Sep 1;49(5):651-61.

Charles C, Gafni A, Whelan T. Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. Health Expectations. 2004 Dec 1;7(4):338-48.

Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. Patient education and counseling. 2012 Jan 1;86(1):9-18.

Coulter A. Patient information and shared decision-making in cancer care. British Journal of Cancer. 2003;89.

D'Amour D, Ferrada-Videla M, San Martin Rodriguez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks. Journal of interprofessional care. 2005 May 1;19(sup1):116-31.

Dahlqvist-Jonsson P, Schon UK, Rosenburg D, Sandlund M, Svedberg P. Service users' experiences on participation in decision making in mental health services. Journal of Psychiatric and Mental Health Nursing. 2015 Nov 1;22(9):688-97.

D'Amour D, Ferrada-Videla M, San Martin Rodriguez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks Journal of Interprofessional Care. 2005 May 1;19(sup1):116-31.

Davis K, Haisfield L, Dorfman C, Krist A, Taylor KL. Physicians' Attitudes About Shared Decision Making for Prostate Cancer Screening Family Medicine. 2011 Apr 1;43(4):260.

- Davis RE, Dolan G, Thomas S, Atwell C, Mead D, Nehammer S, Moseley L, Edwards A, Elwyn G. Exploring doctor and patient views about risk communication and shared decision-making in the consultation. Health Expectations. 2003 Sep 1;6(3):198-207.
- Deyo RA, Cherkin DC, Weinstein J, Howe J, Ciol M, Mulley AG. Involving patients in clinical decisions: impact of an interactive video program on use of back surgery. Medical care. 2000 Sep 1;38(9):959-69.
- Edwards A, Elwyn G. Involving patients in decision making and communicating risk: a longitudinal evaluation of doctors' attitudes and confidence during a randomized trial. Journal of Evaluation in Clinical Practice. 2004 Aug 1;10(3):431-7.
- Edwards M, Davies M, Edwards A. What are the external influences on information exchange and shared decision-making in healthcare consultations: a meta-synthesis of the literature. Patient education and counseling. 2009 Apr 1;75(1):37-52.
- Elit L, Charles C, Gold I, Gafni A, Farrell S, Tedford S, Dal Bello D, Whelan T. Women's perceptions about treatment decision making for ovarian cancer. Gynecologic Oncology. 2003 Feb 1;88(2):89-95.
- Elwyn G. Idealistic, impractical, impossible? Shared decision making in the real world. British Journal of General Practice. 2006 Jun 01;56(527):403-4.
- Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. British Journal of General Practice. 1999 Jun 1;49(443):477-82.
- Elwyn G, Edwards A, Gwyn R, Grol R. Towards a Feasible Model for Shared Decision Making: Focus Group Study with General Practice Registrars. BMJ. 1999 Sep 18;319(7212):753-6.
- Elwyn G, Edwards A, Hood K, Robling M, Atwell C, Russell I, Wensing M, Grol RP. Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. Family Practice. 2004 Aug;21(4):337-46.
- Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. British Journal of General Practice. 2000 Nov 1;50(460):892-9.
- Ford S, Schofield T, Hope T. Are patients' decision-making preferences being met? Health Expectations. 2003 Mar 1;6(1):72-80.
- Fowler Jr. FJ, Gallagher PM, Bynum JPW, Barry MJ, Lucas FL, Skinner JS. Decision-Making Process Reported by Medicare Patients Who Had Coronary Artery Stenting or Surgery for Prostate Cancer. Journal of General Internal Medicine. 2012 Aug 1;27(8):911-6.
- Fowler Jr. FJ, McNaughton Collins M, Albertsen PC, Zietman A, Elliot DB, Barry MJ. Comparison of Recommendations by Urologists and Radiation Oncologists for Treatment of Clinically Localized Prostate Cancer. American Medical Association. 2000 Jun 28;283(24):3217-22.
- Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. American journal of preventative medicine. 1999 Nov;17(4):285-94.
- Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. Health Affairs. 2012 May 1;31(5):1030-8.
- Gattellari M, Butow P, Tattersall, M. Sharing decisions in cancer care. 2001 Jun 2001;52(12):1865–78.

Godolphin W, Towle A, McKendry R. Challenges in family practice related to informed and shared decision-making: a survey of preceptors of medical students. Canadian Medical Association Journal. 2001 Aug 21;165(4):434-5.

Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. Implement Science. 2006 Dec; 1:16.

Hamann J, Kohl S, McCabe R, Buhner M, Mendel R, Albus M, Bernd J. What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists. Social Psychiatry and Psychiatric Epidemiology. 2016 Apr 1;51(4):617-25.

Heyland DK, Frank C, Groll D, Pichora D, Dodek P, Rocker G, Gafni A. Understanding Cardiopulmonary Resuscitation Decision Making: Perspectives of Seriously Ill Hospitalized Patients and Family Members. Chest. 2006 Aug 1;130(2):419-28.

Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities Health Expectations. 2000 Sep 1;3(3):182-91.

Isebaert S, Van Audenhove C, Haustermans K, Junius S, Joniau S, De Ridder K, Van Poppel H. Evaluating a decision aid for patients with localized prostate cancer in clinical practice. Urologia internationalis. 2008;81(4):383-8.

Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. British Journal of Cancer. 2001;84(1):48.

Jordan P, Quadrelli S, Heres M, Belli L, Ruhl N, Colt H. Examining patients' preferences for participation in clinical decision-making: the experience in a Latin American chronic obstructive pulmonary disease and cancer outpatient population. Internal Medicine Journal. 2014 Mar 1; 44(3):281-7.

Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and Evaluating Shared Decision Making in Oncology Practice. CA: A Cancer Journal for Clinicians. 2014 Nov 1;64(6):377-88.

Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware Jr. JE. Characteristics of Physicians with Participatory Decision-Making Styles. Annals of Internal Medicine. 1996 Mar 1;124(5):497-504.

Kehl KL, Landrum MB, Arora NK, Ganz PA, van Ryn M, Mack JW, Keating NL. Association of Actual and Preferred Decision Roles with Patient-Reported Quality of Care: Share Decision Making in Cancer Care. JAMA Oncology. 2015 Apr 1;1(1):50-8.

Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. Patient Education and Counseling. 2006 Jun 1;61(3):319-41.

King JS, Eckman MH, Moulton BW. The Potential of Shared Decision Making to Reduce Health Disparities. Journal of Law, Medicine & Ethics. 2011 Feb;39(1_suppl):30-3.

Legare F, Moumjid-Ferdjaoui N, Drolet R, Stacey D, Harter M, Bastian H, Beaulieu MD, Borduas F, Charles C, Coulter A, Desroches S. Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group. Journal of Contining Education in the Health Professions. 2013 Sept 1;33(4):267-73.

Légaré F, Stacey D, Gagnon S, Dunn S, Pluye P, Frosch D, Kryworuchko J, Elwyn G, Gagnon MP, Graham ID. Validating a conceptual model for an inter-professional approach to shared decision making: a mixed methods study. Journal of Evaluation in Clinical Practice. 2011 Aug

1;17(4):554-64.

Legare F, Stacey D, Graham ID, Elwyn G, Pluye P, Gagnon M-P, Frosch D, Harrison MB, Kryworuchko J, Pouiot S. Advancing theories, models and measurement for an interprofessional approach to shared decision making in primary care: a study protocol. BMC Health Service Research. 2008 Dec;8(1):2.

Legare F, Stacey D, Pouliot S, Gauvin F-P, Desroches S, Kryworuchko J, Dunn S, Elwyn G, Frosch D, Gagnon MP, Harrison MB. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. Journal of Interprofessional Care. 2011 Jan 1;25(1):18-25.

Légaré F, Turcotte S, Stacey D, Ratté S, Kryworuchko J, Graham ID. Patients' perceptions of sharing in decisions. The Patient-Patient-Centered Outcomes Research. 2012 Mar 1;5(1):1-9.

Levinson W, Kao A, Kuby A, Thisted RA. Not All Patients Want to Participate in Decision Making. Journal of General Internal Medicine. 2005 Jun 1;20(6):531-5.

Lifford KJ, Witt J, Burton M, Collins K, Caldon L, Edwards A, Reed M, Wyld L, Brain K. Understanding older women's decision making and coping in the context of breast cancer treatment. BMC: Medical Informatics & Decision Making. 2015 Dec;15(1):45.

Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for prostate cancer treatment: a systematic review of the literature. CA: a cancer journal for clinicians. 2009 Nov 1;59(6):379-90.

Lloyd A, Joseph-Williams N, Edwards A, Rix A, Elwyn G. Patchy 'coherence': using normalization process theory to evaluate a multi-faceted shared decision making implementation program (MAGIC). Implement Science. 2013 Dec;8(1):102.

Loh A, Simon D, Wills CE, Kriston L, Niebling W, Harter M. The effects of a shared decision-making intervention in primary care of depression: A cluster-randomized controlled trial. Patient Education and Counseling. 2007 Aug 1;67(3):324-32.

Maffei RM, Dunn K, Zhang J, Hsu CE, Holmes JH. Understanding behavioral intent to participate in shared decision-making in medically uncertain situations. Methods Information in Medicine. 2012;51(4):301-8.

Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Education and Counseling. 2006 Mar 1;60(3):301-12.

Makoul G, Arntson P, Schofield T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. Social Science & Medicine. 1995 Nov 1;41(9):1241-54.

Manyonga H, Howarth G, Dinwoodie M, Nisselle P, Whitehouse S. From informed consent to shared decision-making. South African Medical Journal. 2014 Aug;104(8):561-2.

McGuire AL, McCullough LB, Weller SC, Whitney SN. Missed expectations? Physicians' views of patients' participation in medical decision-making. Medical Care. 2005 May;43(5):466-70.

McKeown RE, Reininger BM, Martin M, Hoppmann RA. Shared decision making: views of first-year residents and clinic patients. Academic Medicine. 2002 May 1;77(5):438-45.

McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. Bmj. 2000 Oct 7;321(7265):867-71.

McMullan M. Patients using the Internet to obtain health information: how this affects the patient—health professional relationship. Patient education and counseling. 2006 Oct 1;63(1):24-8.

Ménard C, Merckaert I, Razavi D, Libert Y. Decision-making in oncology: a selected literature review and some recommendations for the future. Current opinion in oncology. 2012 Jul 1;24(4):381-90.

Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expectations. 2006 Mar 1;9(1):25-36.

Moore JE, Titler MG, Kane Low L, Dalton VK, Sampselle CM. Transforming Patient-Centered Care: Development of the Evidence Informed Decision Making through Engagement Model. Womens Health Issues. 2015 May 1;25(3):276-82.

Morant N, Kaminskiy E, Ramon S. Shared decision making for psychiatric medication management: beyond the micro-social. Health Expectations. 2016 Oct 1;19(5):1002-14.

Morgan MW, Deber RB, Llewellyn-Thomas HA, Gladstone P, Cusimano RJ, O'rourke K, Tomlinson G, Detsky AS. Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease. Journal of General Internal Medicine. 2000 Oct 1;15(10):685-93.

Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter BMJ. 2012 Nov;345:23.

Naik AD, Schulman-Green D, McCorkle R, FAAN, Bradley EH, Bogardus J, Sidney T. Will Older Persons and Their Clinicians Use a Shared Decision-making Instrument? Journal of General Internal Medicine. 2005 Jul 1;20(7):640-3.

Nannenga MR, Montori VM, Weymiller AJ, Smith SA, Christianson TJ, Bryant SC, Gafni A, Charles C, Mullan RJ, Jones LA, Bolona ER. A treatment decision aid may increase patient trust in the diabetes specialist. The Statin Choice randomized trial. Health Expectations. 2009 Mar 1;12(1):38-44.

O'Brien MA, Whelan TJ, Charles C, Ellis PM, Gafni A, Lovrics P, Hasler A, Dimitry S. Women's perceptions of their treatment decision-making about breast cancer treatment. Patient education and counseling. 2008 Dec 1;73(3):431-6.

O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. A survey of the decision-making needs of Canadians faced with complex health decisions. Health Expectations. 2003 Jun 1;6(2):97-109.

O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient education and counseling. 1998 Mar 1;33(3):267-79.

O'Connor. Ottawa Decision Support Framework to Address Decisional Conflict. Retrieved June. 2006;15:2009.

Pass M, Belkora J, Moore D, Volz S, Sepucha K. Patient and observer ratings of physician shared decision making behaviors in breast cancer consultations. Patient education and counseling. 2012 Jul 1;88(1):93-9.

Petrova D, Garcia-Retamero R, Cokely ET. Understanding the harms and benefits of cancer screening: A model of factors that shape informed decision making. Medical Decision Making. 2015 Oct;35(7):847-58.

Pollard S, Bansback N, Bryan S. Physician attitudes toward shared decision making: A systematic review. Patient education and counseling. 2015 Sep 1;98(9):1046-57.

Quaschning K, Korner M, Wirtz M. Analyzing the effects of shared decision-making, empathy and team interaction on patient satisfaction and treatment acceptance in medical rehabilitation

using a structural equation modeling approach. Patient Education and Counseling. 2013 May 1;91(2):167-75.

Reyna VF, Nelson WL, Han PK, Pignone MP. Decision making and cancer. American Psychologist. 2015 Feb;70(2):105.

Russell A, Abidi SR, Abidi SS. Shared decision making: using theories and technology to engage the patient in their health journey. InMIE 2014 Sep 30 (pp. 303-307).

Sacchi L, Rubrichi S, Rognoni C, Panzarasa S, Parimbelli E, Mazzanti A, Napolitano C, Priori SG, Quaglini S. From decision to shared-decision: Introducing patients' preferences into clinical decision analysis. Artificial intelligence in medicine. 2015 Sep 1;65(1):19-28.

Say R, Robson S, Thomson R. Helping pregnant women make better decisions: a systematic review of the benefits of patient decision aids in obstetrics. Reproductive medicine, obstetrics and gynaecology. 2011 Jun 1;1(2):e000261.

Seale C, Chaplin R, Lelliott P, Quirk A. Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences. Social Science & Medicine. 2006 Jun 1;62(11):2861-73.

Silvia KA, Sepucha KR. Decision aids in routine practice: lessons from the breast cancer initiative. Health Expectations. 2006 Sep 1;9(3):255-64.

Silvia KA, Ozanne EM, Sepucha KR. Implementing breast cancer decision aids in community sites: barriers and resources. Health Expectations. 2008 Mar 1;11(1):46-53.

Slover J, Shue J, Koenig K. Shared decision-making in orthopaedic surgery. Clinical Orthopaedics and Related Research®. 2012 Apr 1;470(4):1046-53.

O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2003;2.

Stacey D, Briere N, Robitaille H, Fraser K, Desroches S, Legare F. A systematic process for creating and appraising clinical vignettes to illustrate interprofessional shared decision making. Journal of Interprofessional care Care. 2014 Sep;28(5):453-9.

Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Legare F. Decision Coaching to Prepare Patients for Making Health Decisions: A Systematic Review of Decision Coaching in Trials of Patient Decision Aids. International Jounnal of Evidence-Based Healthcare. 2011 Sep 1;9(3):327.

Stacey D, Pomey MP, O'Connor AM, Graham ID. Adoption and sustainability of decision support for patients facing health decisions: an implementation case study in nursing. Implement Science. 2006 Dec;1(1):17.

Stevenson FA. General practictioners' views on shared decision making: a qualitative analysis. Patient Education and Counseling. 2003 Jul 1;50(3):291-3.

Stiggelbout AM, Van der Weijden T, De Wit MPT, Frosch D, Legare F, Montori VM, Trevena L, Elwyn G. Shared decision making: really putting patients at the centre of healthcare. BMJ. 2012 Jan 27;344:e256.

Suurmond J, Seeleman C. Shared decision-making in an intercultural context. Barriers in the interaction between physicians and immigrant patients. Patient Education and Counseling. 2006 Feb;60(2):253-9.

Tiedje K, Shippee ND, Johnson AM, Flynn PM, Finnie DM, Liesinger JT, May CR, Olson ME, Ridgeway JL, Shah ND, Yawn BP. 'They leave at least believing they had a part in the discussion': Understanding decision aid use and patient—clinician decision-making through qualitative research. Patient Education and Counseling. 2013 Oct 1;93(1):86-94.

Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. BMJ: British Medical Journal. 1999 Sep 18;319(7212):766.

Turner S, Maher E, Young T, Young J, Vaughan Hudson G. What are the information priorities for cancer patients involved in treatment decisions? An experienced surrogate study in Hodgkin's disease. British Journal of Cancer. 1996 Jan;73(2):222.

Uldry E, Schafer M, Saadi A, Rousson V, Demartines N. Patients' preferences on information and involvement in decision making for gastrointestinal surgery. World Journal of Surgery. 2013 Sep 1;37(9):2162-71.

Waljee JF, Rogers MAM, Alderman AK. Decision Aids and Breast Cancer: Do They Influence Choice for Surgery and Knowledge of Treatment Options? Journal of Clinical Oncology. 2007 Mar 20;25(9):1067-73.

Weston WW. Informed and shared decision-making: the crux of patient-centred care. 2001 Aug 21;165(4):438-9.

Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R. GPs' views on involvement of older patients: an European qualitative study. Patient Education and Counseling. 2004 May;53(2):183-8.

Whelan T, Levine M, Willan A, Gafni A, Sanders K, Mirsky D, Chambers S, O'brien MA, Reid S, Dubois S. Effect of a Decision Aid on Knowledge and Treatment Decision Making for Breast Cancer Surgery. Journal of American Medical Association. 2004;292(4):7.

Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, Julian J, Dent S, Abu-Zahra H, Chouinard E, Tozer R. Helping Patients Make Informed Choices: A Randomized Trial of a Decision Aid for Adjuvant Chemotherapy nLymph Node-Negative Breast Cancer. Journal of National Cancer Institute. 2003 Apr 16;95(8):581-7.

Whitney SN. A new model of medical decisions: exploring the limits of shared decision making. Medical Decision Making. 2003 Jul;23(4):275-80.

Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, Vollmer VM. Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma. American Journal of Respiratory and Critical Care Medicine. 2010 Mar 15;181(6):566-77.

Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Ziniel S, Fowler J, Floyd Jr FJ, Levin CA, Fagerlin A. Deficits and Variations in Patients' Experience with Making 9 Common Medical Decisions: The DECISIONS Survey Medical Decision Making. 2010 Sep;30(5_suppl):85-95.

Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model: sharing decision-making in chronic care. Qualitative health research. 2008 May;18(5):670-85.

9.3: C: All EA statements

Generated explanatory accounts

If physicians find continuing professional development interesting, enjoyable and professionally stimulating, then they are more likely to engage in such training.

If training programs are in alignment with prior trainee needs and daily practices, then the training program is more likely to change the trainees behaviour.

If training programs are interactive, physicians are more likely to want to attend.

If training programs are perceived to be taxing (i.e. a lot of work), physicians are less likely to participate in training.

If patients have difficulties understanding information from health professionals, then SDM is more difficult to achieve.

If patients suffer emotional distress from their diagnosis and/or treatment options, then SDM is harder to optimally implement.

If health care providers adjust their delivery of treatment options to the needs and experience level of each patient, then the patient is more likely to comprehend their options and therefore more actively participate in decision-making (if the patient choses to be active in decision-making).

If nurses and practitioner's partner together, attending regular debriefing meetings and both actively involved in the decision-making, SDM in the ICU is likely to improve.

If patient prefer to receive all information regarding their diagnosis, then patients are more likely to prefer a Shared Decision-making style of decision-making.

If physicians implement SDM, patients perceive that physicians spend longer with them.

If SDM is implemented, patients perceive that physicians discuss results and future of

disease treatment.

If patients perceive an urgency in the decision-making process, there is less vigilance able to be incorporated into the decision-making process.

If patients have a lower amount of education, they are less likely to want to participate in decision-making.

If patients are older, they are less likely to participate in the decision-making process.

If patients are of a westernized decent (that is a Caucasian nationality), then they are more likely to want full disclosure on their disease.

If patients are more actively involved in the decision-making process, then the decision made will more likely reflect the patient's needs, preferences and values.

If patients are actively involved in the decision-making process, then patient outcomes (satisfaction with health care process and decision, patient adherence to chosen courses of outcomes, patient health) will increase.

If patients perceive the power differential between patient and physician (in terms of culture variance, education variance, income or gender differences), then the patient is likely to feel greater anxiety in the exchange.

If women undergoing mammography screening want the doctor-alone to make the decision, then the women patients are less apprehensive about the screening.

If women undergoing mammography screening prefer the doctor-alone to make the decision, then they are more likely to be older and immigrants.

If women undergoing mammography screening want the decision to be shared equally between themselves and the heath care provider, then they are less likely to have negative memories associated with their mammogram.

If women undergoing mammography screening want to share the decision-making equally with their health care provider, then they are more likely to overestimate the

efficacy of this screening.

If patients are severely ill, then multiple health care providers may be involved in the treatment decision.

If patient situations vary, then their preference for involvement in decision-making may also change.

If SDM is to be implemented, then the physician (at minimum) must provide treatment options and the patient (at minimum) must disclose their preferences and values.

If SDM is implemented, then a two way information exchange should occur whereby the physician (at minimum) must inform the patient of treatment options, pros risks and benefits of these options, and the patient must (at minimum) provide information on their values, preferences and lifestyles.

If a woman has early stage breast cancer, then she likely emphasizes the importance of a trusting relationship with their physician.

If SDM is to be successfully implemented, then information exchange, deliberation, and a decision must occur.

If SDM is implemented allowing for the patient to be involved in the deliberation of treatment decision, then the deliberation process may become more cumbersome and time consuming.

If education, income, culture and/or gender differences exist, then the patient may not feel comfortable enough to express their values and preferences inhibiting SDM.

If only one party (e.g. the patient OR the physician) want to participate in SDM, then SDM will not be successfully implemented.

If SDM is implemented, then neither the physician nor the patient have autonomy in decision-making.

If given the option between SDM and paternalism, the majority of oncologists and surgeons are more comfortable with SDM than paternalism.

If oncologists report feeling very comfortable implementing SDM, then these feelings do not necessarily translate into actual SDM implementation.

If a physician is comfortable with SDM, they still may face barriers to implementation such as time, contradiction between medical professionals, insufficient information, and/or cultural differences.

If patients have emotional support (present or elsewhere), then the physician is more likely to feel SDM is possible.

If the patient is perceived to be ready to participate in the decision-making, then the physician is more likely to feel that SDM can be successfully implemented.

If the physician perceived that the patient understands their disease, then the physician is more likely to feel that SDM can be successfully implemented.

If the physician perceives that the patient trusts them, then the physician is more likely to believe that SDM can be successfully implemented.

If patients are asked if they prefer SDM in a positive manner (e.g. after discussion the decision should be the patients), then the patient will indicate they prefer SDM.

If patients are asked if they prefer delegation of decision power in a positive manner, then they are more likely to agree with delegation.

If patients are not given sufficient information about illness and treatment options, then the patient is more likely to be dissatisfied.

If a goal of SDM in breast cancer patients is satisfaction, then patient should be provided three piece of information: 1) information about likelihood of cure, information about disease spread, information about treatment options.

If patients are well-informed about prognosis and treatment options, then patients are

more likely to adhere to their treatment.

If patients are apprehensive about taking responsibility for disease outcome, then they are more likely to delegate decisional power to the physician alone.

If patients are younger, then they are more likely to want to implement SDM with their HCP.

If interprofessionality is to be implemented in the health domain, then HCP need to develop practice methods to accommodate different views and conceptualizations.

If an HCP is to be a competent collaborative practitioner, then their micro (teaching) /meso (institutional) / and macro (systemic) environment must be in alignment with this goal.

If interprofessional care is to be successfully implemented, then patient factors on the micro (interactional), meso (organizational) and macro (systemic) factors must be fluid and open to this type of care.

If HCP are trained in a collaborative nature, then collaborative practice settings will develop over time.

If students are taught by an instructor biased against interprofessionality, then the student is less likely to adapt interprofessionality in the future.

If interprofessionality is adopted, the patient must be at the centre as their outcome is the main goal for all.

If interprofessionality is implemented, providers will have higher job satisfaction and a better mental health.

If interprofessionality is implemented, organization costs should reduce as efficiency should increase.

If mental health patients feel they are not taken seriously in the decision-making process, then they may be complacent with the decision as they feel they have no

power.

If mental health patients are not given full information about their treatment options, then they may feel like they are being controlled.

If mental health professionals wrongly assume patients cognitive ability to participate in decision-making, then the patient may feel they are being omitted from treatment discussions.

If the patient does not feel like the physician sees them as a person (but rather sees them as a "diagnosis"), then the patient may feel disrespected as a person.

If the patient is allowed to express their values and guide meetings with health professionals, then the patient may feel more self confidence in their abilities.

If physicians are given the choice between SDM, patient-deciding, or paternalism, then most physicians prefer using SDM.

If time is limited, SDM impacted may be less likely to occur.

If there are competing health priorities, then SDM is less likely to occur.

If HCP are concerned about appointment reimbursement, then SDM is less likely to be implemented.

- Systematic and patient factors increase in concern from interns/residents to academic clinicians and community clinicians.
- Physician factors are more likely to play a role with interns/residents.

If physicians have received risk communication, then treatment decisions within a consultation is more likely to occur.

If physicians receive risk communication training, then they are more likely to discuss treatment priorities with the patient.

If an interprofessional collaboration occurs, then sharing attributes should occur (e.g.

shared responsibilities, shared decision-making, shared health care philosophy, shared values, shared data and shared planning/intervention).

If an interprofessional collaboration is to occur, then an authentic and constructive partnership must be formed.

If an interprofessional collaboration is to exist, then HCP must be interdependent with a common goal of addressing the patient's need.

If professionals form an interprofessional collaboration, then synergy will emerge.

If professionals use interprofessional collaborations, then the power in the treatment must be split between individuals and based upon knowledge and experience rather than title.

If an interprofessional collaboration is to be successful, the patient must view the collaborators as a visible team.

If finalization, interiorization, formalization and governance occurs, then interprofessional collaboration will proceed.

If social exchange theory is incorporated into a collaboration model, then the process should include assessment and goal setting, determination of collaborative fit, identification of resources and reflection, refinement and implementation, and evaluation and feedback.

If interprofessional collaboration occurs, then we expect to have increase quality of care, innovation of professional practices and increase satisfaction.

If physicians support patient involvement in the decision-making process, then their support is unlikely to significantly change immediately following risk communication and SDM training.

If physicians support patient involvement in the decision-making process, then their support is likely to significantly increase a month following risk communication and

SDM training.

If the physician is a female, they are more likely to emphasize the importance of patient participation.

If the physician is a female, they are more likely to feel competent in SDM after the second training intervention.

If patients are competent in seeking and understanding information, then they are more likely to seek information outside the medical consultation.

If patients have poor information exchange experiences in past consultations, than the patient is more likely to seek medical information outside the medical consultation.

If the patient and physician have different cultural ideas of illness and disease, then the information exchange may be inhibited.

If a patient withholds past experiences in order to feel socially competent, then they may inhibit becoming fully engaged in the decision-making.

If patients feel that they will receive backlash from informing themselves through the internet, then the patient is unlikely to fully engage in the exchange.

If physicians have poor knowledge on cultural health beliefs and cultural values, then the physician may not elicit the appropriate information from the patient.

If women receive a lot of information prior to breast cancer treatment, then they are still able to feel overwhelmed in postoperative periods.

If women undergoing a surgical operation for breast cancer treatment and are giving morphine or analysics, then they made have difficulties retaining information while under the effects of the medication.

If women feel frightened or pressured into a certain treatment decision, then their preference for decision-making might not translate into their role in the decision-making process.

If women want to be involved in the decision-making process, they are likely to want to seek information from family and other medical sources aside from just their primary physician.

If a women is receiving treatment for their ovarian cancer, then they weigh the physician's recommendations strongly.

If individuals have not undergone an SDM interaction, then it is not appropriate to ask if they would like it.

If patients and/or physicians believe that SDM will improve outcomes, then it may cause a placebo effect on the outcomes.

If a physician is not totally knowledgeable about a treatment, then they will be unable to present all information including pros and cons on that option.

If time was not a factor, then the physician may be more likely to engage the patient in SDM.

If a physician believes that the patient is anxious, then they may decide it is inappropriate to engage in SDM.

If the physician believes that the patient would have difficulty understanding the information, then they are less likely to engage in SDM.

If patients hold the knowledge regarding their preferences and physicians hold the knowledge about treatment, then there is an information imbalance.

If shared decision-making is to occur with patients, then the following characteristics need to occur: at least two participants, both parties involved in the process, information is shared, and treatment decision is made.

If SDM is not implemented and poor communication exists, then there may be an increased chance of non-adherence.

If information exchange is done clearly, questions are elicited from patients,

willingness to share decisions, and agreeance with patients and doctors is made, then it is more likely that positive outcomes will occur.

If the patient has a lower education status at the time of the decision-making, then they are more likely to choose a directing decision-making style rather than shared.

If the patient has a severe illness at the time of the decision-making, then they are more likely to choose a directing decision-making style rather than shared.

If SDM is used as a mechanism to exchange more information, then patients are more likely to engage than if the purpose is decision-making involvement.

If any of the following barriers occur, then SDM will be inhibited: time, threatens power relationship between doctor and patient, continuity of care means that treatment decisions are often colored by prior experiences of both individuals, lack of training/experience, lack of sharing, lack of information, lack of skills/tools, patients may perceive as physician uncertainty.

If SDM is implemented, physicians believe that patient autonomy should be respected but not enforced.

If multiple treatment options are available, then physicians feel this is an appropriate time to use SDM.

If physicians are to use SDM, they need to be competent in involving patients, exploring fears and expectations, portrayal of equipoise and options, identifying and tailoring information, checking understanding, checking process, making and discussing a decision, and following up with the patient.

If patients are receiving a new "problem" that they need treatment for, then they most likely want to receive all possible information.

If patients prefer a paternalistic decision-making approach, then they are likely to be significantly older.

If patients were undergoing prostate cancer treatment, then they often were told

multiple treatment options.

If patients were undergoing a heart stent, they often were not given alternative approaches.

If patients have a higher education level, they are more likely to report a higher participation level in the decision-making process.

If patients are Caucasian, then they are more likely to participate in the decision-making process.

If patients have a partner, then they are more likely to participate in the decision-making process.

If a patient is seeing an urologist, they are more likely to be recommended for PSA testing than if they saw a radiation oncologist.

If a patient sees an urologist, then they are more likely to be told that radical prostectomy has a better survival rate than external beam radiation than if they say a radiation oncologists.

If a patient sees a radiation oncologists, then they are more likely to be told that brachytherapy and external beam radiation have a survival benefit than if they saw an oncologist.

If a patient accesses the internet for their disease, then they are able to access a support group to disseminate information and obtain information about treatment and physicians.

If physicians disagree about treatment courses, then they likely feel that treatment outcomes vary.

If the goal of a treatment decision should result in the most desirable outcome for the patient, then active participation and engagement is required from both the physician and the patient.

If patients are aged 20 to 39 years, then they are highly (87%) likely to want to participate in SDM.

If individuals are 40 to 59 years of age, then they are less likely (62%) to participate in SDM than their younger counterparts.

If patients are over 60 then they are even less like (51%) to want to participate in SDM.

If diabetic patients are low-income, then they are unlikely to want to participate in SDM.

If patients have a severe disease, their desire to participate in decision-making decline as severity increase.

If physicians lack the communication skills, then it less likely that SDM will be implemented.

If patients want to participate in SDM, then they feel that the physicians must be willing to engage to initiate SDM.

If patients perceive that the physicians do not want engage in SDM, then the patient will likely avoid engaging in order to be the "good patient".

If patient's preferences for involvement in decision-making is matched with their experience, then patients are more likely to experience decreases anxiety following their consultation.

If patient's preferences for involvement in decision-making is matched with their experience, then patients are more likely to feel satisfied with their consultation.

If patient's preferences for involvement in decision-making is matched with their experience, then patients are more likely to feel satisfied with the amount of emotional support and the amount of information they received.

If undergraduate students are trained in communication skills, they should be able to

implement SDM better and reduce conflict with the patient.

If time is limited, then SDM may be more difficult to implement

If the physician does not feel that SDM applies to the patient, then it is less likely that SDM will be implemented.

If the physician perceives that the patient does not want to participate in SDM, then SDM is less likely to be attempted.

If the physician does not want to ask the patient their preference for participation in the decision-making process, then they are less likely to implement SDM.

If the health professional is motivated to use SDM, then they are more likely to implement SDM.

If the health care professional perceives that SDM will lead to positive impacts on the clinical process, then they are more likely to implement SDM.

If the physician perceives that SDM is useful and practical, then SDM is more likely to be implemented.

If patient preferences match an SDM model, then SDM is more likely to be implemented.

If patients are able to discuss their feelings in an honest manner, then this action will facilitate SDM implementation.

If patients trust their physician and feel respected, then SDM will be more facilitated.

If psychiatrists believe the patient does not have the decisional capacity, then SDM is unlikely to be implemented.

If patients have a mental illness, they may feel their interest in participating in the decisional process is reduced.

If patients are being treated in an acute setting, then they will react different to SDM

than those in long-term outpatient treatment.

If patients are suffering from end-stage cancer or advanced disease, then their preferences for decision-making on CPR is unpredictable.

If patients are too ill, then the families wish to make the decision with the physician regarding CPR.

If patients are being diagnoses with a disease, then they want all possible information about the disease whether it's good or bad.

If patients are younger, then they are even more demanding on receiving all information.

If patients are women, then they are even more likely to want all the information.

If patients are being diagnoses with a disease, then they want all possible information about the disease whether it's good or bad (this is not a duplicate).

If patients are being diagnosed, then they want to receive survival rates.

If patients are being diagnosed with a serious disease, then the majority want to make a decision with their physician.

If a patient is older, then they are more likely to prefer a passive role in decision-making as they will have low health literacy and numeracy.

If a patient is older, then they are more likely to bring a caregiver to their health appointment.

If patient information values and preferences are taken into consideration by the health care provider, then SDM is more likely to be implemented and a mutually agreed upon decision is likely to be made.

If patients have a caregiver during their cancer, then they are likely to receive more social support and someone to help translate their treatment options.

If patients have a caregiver during treatment decisions, then their SDM participation may be affected as the caregiver may bias the consultation with their own biases.

If health care providers sense time constraints, they may be less likely to implement SDSM.

If health care providers believe that patient characteristics will inhibit SDM, then they are less likely to try to implement SDM.

If health care providers think that the clinical situation does not warrant SDM, then they are less likely to try to implement SDM.

If physicians have a high workload, then they are less likely to use SDM.

If physicians are not trained, then they are less likely to implement SDM.

If a patient is diagnosed with a cancer that has a lot of lay-information available, then the physician is more likely to implement SDM.

If patient information values and preferences are taken into consideration, then SDM is more likely to be implemented and a mutually agreed upon decision is likely to be made.

If physicians are trying to implement SDM, then they can use the following steps: invite the patient to participate, present options, provide information on benefits and risks, assist patients in evaluating options based on their goals and concerns, facilitate deliberation and decision-making, and implement SDM.

If patients are involved in the decision-making process, then they are less likely to switch physicians.

If physicians are seeing a large quantity of patients (high workload), then they are less likely to implement SDM.

If physicians are cardiologists, general internists, family practice physicians, or endocrinologists, then they are more likely to participate in SDM.

If physicians are trained in primary care-track program or had interviewing skills during residency, then they are more likely to implement SDM.

If patient's preference for decision-making is matched or is not matched, then the patient rating of quality of care is not effected.

If patients perceive that physicians do not share the decision power, then they are likely to rate the physician lower in quality.

If patients are receiving a diagnosis, then they want to receive as much information as possible on their illness, treatment options, and expected recovery.

If patients receive their preference match for decision-making style, then they are more likely to have positive patient outcomes.

If patients are less educated, then they may feel very well educated about treatment options regardless of what is shared.

If patients are better informed and more engaged in treatment decisions, then health outcomes will be improved.

If patients do not receive their preferred decision-making match, then it is likely they will have negative patient outcomes such as satisfaction and emotional well-being along with treatment effectiveness.

If SDM is to be implemented, then physicians need to recognize a decision needs to be made and that the patient is a partnership.

If SDM is to be implemented, physicians need to adapt the information to the level of the patient.

If an interprofessional approach is taken to SDM, then the quality of decision support provided to patients in team-based primary care practices will be improved.

If an interprofessional approach is taken to SDM, then patient-centered care will truly be valued

If IP-SDM is implemented then sharing the common goal of achieving quality health decisions that are informed and based on patients' values; (b) having a sense of trust among the different professionals participating in the process by which the decision is made; (c) being governed by leaders that value SDM; and (d) having organizational structures to facilitate implementing SDM within the processes of care

If an interprofessional perspective is used in primary care settings, then SDM will be enhanced.

If an interprofessional approach to decision-making occurs, then health care system factors have had an influence.

If health care professionals are familiar with each other's expertise, roles, and responsibilities, then collaboration and enhancement of SDM is possible.

"Patient follows a structured process to make an informed, value-based decision in concert with a team of health care professionals".

If patients perceive that health professionals have adopted shared decision-making as indicated by degree of agreement with the statement: My doctor and I made the decision together (also Control Preference Scale and COMRADE), then SDM is more likely to occur.

If interventions are created at the level of both the health professional and the patient, then shared decision-making is more likely to occur.

If physicians' attitudes about SDM are positive, then their patients' and their own willingness to engage in shared decision-making is enhanced.

If patients perceive the physician-patient consultation to involve shared decision-making, then SDM is more likely to translate into routine clinical practice.

If there are variations in sex, race, age, and health status, then preferences for SDM will vary.

If patients are male, non-white, older (45+), and have poorer health status, then they

tend to prefer physician-directed decision-making.

If patients experience barriers such as lack of confidence in asking questions, difficulty in understanding information and failure to understand that there is a choice, their active participation in treatment decision-making will be jeopardized.

If older patients defer to (i.e., trust) clinical expertise and knowledge of health professionals, it may provide them with an opportunity to conserve personal resources.

If SDM is to be successfully implemented, then the following generative mechanisms of Normalization Process Theory must exist: coherence (HPs sharing same understanding of SDM principles, how SDM differs from existing approach, and willingness to adopt SDM into routine); cognitive participation (engaging team members in SDM intervention development); collective action (leaders initiate, each team member understands their roles/responsibilities, all levels have buy-in); and reflexive monitoring (examining data collected from patient decisions leads to monitoring SDM impacts and sustained implementation).

If SDM is to be normalized, then intensive work to ensure teams have a shared understanding of the purpose of involving patients in decisions is required.

If SDM is to be normalized, then there needs to be attitudinal shifts among many health professionals.

If physicians are provided with content/training for enhancing skills for involving patients in the decision-making process and with disease specific guidelines for best practice (depression), then patient participation in decision-making is higher and patient satisfaction is higher than those who do not receive the intervention.

If education and training in inter-professionalism and SDM is provided and there is mutual knowledge and understanding of disciplinary roles, then the patient will receive essential elements as they move through the decision-making process [doesn't say what these elements are].

If there is high uncertainty in medical circumstances, then SDM is practiced less often.

If patients lack past experiences with medically uncertain situations, then they experience increased anxiety in respondents' answers, and an increased desire and intent to move toward a completely hyper-vigilant information seeking and decision-making behavior.

If patients were uncertain, then they indicated that they would prefer their physicians to tell them about the uncertainty and to let them know the options and concerns, but the final decision should be made by the physician.

Key aspects of patient's intent to engage in SDM: 1) an individual's representation of medical uncertainty, 2) how the individual copes with medical uncertainty, and 3) the individual's behavioral intent to seek information and participate in shared decision-making during times of medically uncertain situations.

If physicians can help patients increase appropriate control over their health by emphasizing the importance of information exchange during medical encounters (information exchange also closes the competence gap created by knowledge disparities), then patient decision-making competencies will be fostered.

If physicians accurately perceive the information they are providing to patients, then communication with patients should improve.

If patients do not accurately perceive information provided by physicians (re: risks of prescribed medication), then they may leave the consultation with an illusion of [decision-making] competence.

If SDM is to occur (essential element), then patients and providers must first define and/or explain the problem that needs to be addressed.

If SDM is to occur (essential element), then physicians should review options, if options exist, and patients should raise options of which they may be aware.

If SDM is to occur (essential element), then physicians and patients should discuss the pros and cons of options raised, particularly because they may have different perspectives on the relative importance of benefits, risks, and costs, including convenience and opportunity cost.

If SDM is to occur (essential element), then there should be the explication of patient values and preferences – including ideas, concerns, and outcome expectations – as well as physician knowledge and recommendations in the context of the decision at hand.

If SDM is to occur, then discussing patients' ability to follow through with a plan should be considered (self-efficacy).

If patient preferences are misdiagnosed, then SDM cannot occur.

If patient autonomy is respected, then SDM is more likely.

If the practitioner listens, informs, discusses, decides, and documents, then SDM will occur.

If physicians perceive patient participation in decision-making as positive, then they also identify patient autonomy as valuable.

If physicians perceive patient participation in decision-making as positive, then they also identify patient beneficence as valuable.

If physicians perceive patient participation in decision-making as positive, then they also value their own self-interest in avoiding legal liability.

If there is a situation with only one medically reasonable choice, then physicians tend to diminish the role of the patient decision-maker.

If the clinical decision is hysterectomy and cholesteatoma, then patients want more control and residents want less.

If the clinical situation is hypertension, depression, and prostate cancer, then patients

want equal roles in decision-making; whereas residents want more control in the decision.

If patients are from lower classes and are smokers, then they tend to prefer a shared approach to decision-making.

If patients are "internet" informed, then HP may respond by 1) being defensive and asserting expertise (HP-centered relationship); 2) collaborating to obtain/analyze information (patient centered); 3) HP guides pts to reliable websites (Internet prescription).

If tools, guidelines and professional training exist, then the awareness of patient roles in SDM is increased among both patient and heath care professional.

If decision-making occurs in chronic care situations (compared to acute care decisions), then they are more likely to require a more active patient role.

If decision-making occurs in chronic care situations (compared to acute care decisions), then decisions can be revisited and reversed without important losses

If women trust their clinician, then they make their decisions based on the clinicians' opinion (what they considered the primary and most influential source of evidence).

If the clinician frames (framing effect) the information presented to the patient in such a way as to influence the decision toward the preferred clinician's outcome, then this biases both the perception of the problem and the way that it is processed by the patient.

If users are viewed by practitioners as 'experts by experience' within recoveryoriented practice, and their account of subjective experiences ae acknowledged as essential to judging the impact of medication, then their opinions will considered valid.

If users are perceived by practitioners to lack capacity or insight, then the validity of their views can questioned.

If practitioners and users fundamentally disagree about when a person is mentally ill or medication is desirable, then a shared decision may not be achievable.

If users fear coercion, then there is a barrier to their involvement in decisions.

If there are agendas in the broader organizational and social context of mental health care, then SDM is affected.

If doctors adopt a preference diagnosis, then they adopt a mindset of scientific detachment; use data to formulate a provisional diagnosis; and engage the patient in conversation and deliberation.

If patients have access to decision supports (clinical counselling, decision aids and coaching), then decision quality (informed, values-based choices) and actions (e.g., delay), health outcomes, emotions (regret, blame) and appropriate use of health services will be improved.

If patients ask GPs about their options, then the amount of quality of information GPs provide increases and physician consideration of patient preferences increases.

If patients ask GPs about the possible benefits and harms of those options, then the amount and quality of information increases and physician consideration of patient preferences increases.

If patients ask GPs about the likely benefits and harms of each option, then the amount and quality of the information improves and physician consideration of patient preferences increases.

When women view their consultations, they describe their treatment decision-making process as iterative processes - gathering information from informal and formal networks and wanting more information from their surgeon in order to engage with medical oncologist.

If doctors present benefits "a lot", patients may not hear the risks.

If information is counterintuitive and requires integration of complex harms and

benefits, then user-friendly communications can facilitate comprehension, improve high-stakes decisions and promote SDM.

If previous beliefs about effectiveness of screening or strong fears about specific cancers exist, then comprehension and informed decision-making may be compromised.

If physicians perceive patients to be competent to participate, patients have the desire to be involved in the process, and patients are informed about their condition, then physicians are more likely to support SDM.

If physicians perceive scenarios where multiple treatment options exist, where treatment options were likely to impact the patient's lifestyle/self-image, where there is severe disease, chronic disease or end of life decisions, where the options carry significant risks, or where treatment stopping is common, then physicians are more likely to support SDM.

If the setting is general practice as opposed to hospital based care (i.e., emergency care), then physicians are more likely to support SDM.

If well-evidenced clinical practice guidelines exist in favor of one treatment, then physicians tend to be less favorable towards SDM.

If physicians worked under physicians who did not favor SDM, then they are less likely to favor SDM.

If physicians receive training in SDM related communication skills, then they are more likely to support SDM.

If physicians don't discuss uncertainty with patients, it may be because they fear that they may appear incompetent.

If the treatment is accepted, then SDM is mediated by satisfaction with the decision.

If SDM is used, it predicts patient satisfaction.

If all other factors are equal, people prefer a sure or safe option over a risky one (risk aversion); sometimes so much that they choose suboptimal treatments because they are perceived to be less risky.

If patients are given options, they will prefer 'known' probabilities and they respond to ambiguity by forming pessimistic judgments of risk and avoiding decision-making (ambiguity aversion).

If advanced cancer patients are facing limited options then they may view ambiguity as a source of hope (greater outcome variability-that one can 'beat the odds').

If other numbers are presented in context of risk numbers, then those numbers will also have an influence on decision-making.

If a patient is low in numeracy, then they rely on more non-numerical information and are more susceptible to heuristics and biases, exhibiting more inconsistent values and preferences.

If a technology tool is used in combination with behavioral theory and choice architecture, then SDM will be enhanced.

If patients are seen as too ill to make 'good' decisions, then the interactions will be asymmetrical and SDM is abandoned.

If psychiatrists perceive that patients will be non-compliant to medication, then they are more conflicted about sharing the medication's side effects.

If SDM is delivered to health professionals via clinical vignettes, then SDM has the potential to be better understood by health professionals.

If GPs perceive that they don't know how to determine whether decisions are shared, then a barrier to SDM exists.

Even if GPs agree with SDM, they may not practice it due to time constraints and their perceptions of patients' interests in and capacity for SDM.

If clinician has created awareness of "equipoise" then they have made the first and most important step in SDM.

If SDM has occurred, then a form of partnership that goes beyond rapport and involves shared responsibility has been built.

If patients are fearful of being assertive, then a good doctor-patient relationships will be jeopardized and this leads to lower quality of care.

If patients are given time to contemplate decisions outside the consultation that may benefit the SDM process.

If clinical practice guidelines promoted SDM by highlighting decision points and suggesting what information to communicate about reasonable options and how to involve patients, then SDM would be more integrated into health care.

If physician and patient do not share same linguistic background, then there are barriers to SDM.

If physicians and patients do not share similar ideas about health and illness, then there is a barrier to SDM.

If physician and patient have prejudices and do not always speak to each other in an unbiased manner, then there are barriers to SDM.

If physicians and patients do not have similar role expectations, then there are barriers to SDM.

If physicians perceive lack of time, then putting SDM into practice is challenged.

If physicians lack predisposition and skill, then putting SDM into practice is challenged.

If patients have inexperience with making treatment decisions, then putting SDM into practice will be challenged.

If patients feel satisfied with the adequacy of information they are given, then they

are more likely to feel happy with their level of participation in the overall process of decision-making.

If patients are elderly and low-educated, then they have less interest in SDM and receiving information.

If patients are elderly and male, then they are less interested in involving their families in decision-making.

If the nature of the operation is minor or major, the disease is malignant or benign, then the impact on SDM, information and family involvement was unaffected.

If patients are treated as an equal partner, then SDM is more likely.

If FIFE is used (Feelings, Ideas, Function, Expectations of Pt), then SDM is facilitated.

If GPs perceive older patients as having feelings of respect for their profession, then a barrier to SDM may exist.

If GPs perceive a lack of time, then a barrier to SDM may exist.

If GPs perceive older patients lack experience being involved, then a barrier to SDM exists.

If GPs perceive possible physical and mental impairments among older patients, then a possible barrier to SDM exists.

If major choices have low certainty, then patients should be encouraged to be the primary decision makers, with physician assistance as needed.

IF minor decisions have high certainty, then physicians should be expected to make them.

If major decisions have high certainty, then they are likely to cause serious conflict when patients and physicians disagree. If patients with poorly controlled asthma share in making decisions about their treatment, then they tend to show significantly better adherence to medications.

If patients with poorly controlled asthma share in making decisions about their treatment, then they experience better asthma-related quality of life, fewer asthma-related medical visits, lower use of rescue medication, higher likelihood of well controlled asthma, and better lung function.

If decisions are about initiating medication, then they are more likely made by the providers.

If decisions are about cancer screening, then prostate screen decisions are least likely to be made by patient alone, whereas breast cancer screen are most likely to be made by patients.

If patients are seen for depression, knee/hip replacement, lower back surgery, then they are most likely to be asked their preferences.

If patients are seen for colon or breast cancer testing, they report being asked their preferences least often.

If patients are confident that their decision is "right" then they see no reason to discuss other options.

9.4: D: EA Thematic Groups by Category

	Health Care Provider Specific EAs		
Sub-heading	Theoretical	Empirical	Total
IP-SDM	27	3	30
Specialty Specific	0	27	27
Perception	9	17	26
SDM Training	10	15	25
Willingness	4	10	14

Time (Barrier)	5	6	11
Location	7	0	7
Patient-centered Care	7	0	7
SDM Delivery	1	4	5
Fee-for-service	0	5	5
Preference	0	4	4
Communication	2	2	4
Knowledge	1	2	3
Bias	2	1	3
Involvement	2	0	2
Outcomes	2	0	2
Competence	0	2	2
Implementation	0	1	1
Satisfaction	1	0	1
Gender	0	1	1
Total	80	100	180

	HCP and	l PT EAs	
Sub-heading	Theoretical	Empirical	Total
Information Exchange	24	30	54
Mutual Decision	12	10	22
Deliberation	3	0	3
Knowledge	1	0	1
Power Differential	1	0	1
Total	41	40	81

	Non-indivi	dual specific	
Sub-heading	Theoretical	Empirical	Total
Theories	3	1	4
System Influence	2	0	2
Efficacy	1	0	1
System Cost	1	0	1
Overall Outcomes	1	0	1
Implementation	1	0	1
Total	9	1	10

Patient Specific EAs			
Sub-heading	Theoretical	Empirical	Total
Preference	22	31	53
Disease Specific	13	37	50
Perception	12	18	30
Involvement	15	11	26
Gender	5	18	23
Age	7	17	24
Disease Severity	12	7	19
Comprehension / Competence	9	10	19
Ethnicity / Culture	5	8	13
Knowledge	5	8	13
Satisfaction	5	7	12
Support	6	4	10
Information Seeking	4	6	10

Education	6	3	9
Zuucuiioii			
Willingness / Engagement	7	3	10
Anxiety	3	4	7
Preference Matching	3	4	7
Outcomes	5	1	6
Trust	3	3	6
Adherence	3	2	5
SES	3	1	4
Autonomy	2	2	4
Multiple Health Concerns and Uncertainty	0	4	4
Communication	1	1	2
Efficacy	1	1	2
Quality of Care	1	1	2
Participation	1	0	1
Readiness	0	1	1
Environment	1	0	1
Family involvement	0	1	1
Total	160	214	374

9.5: E: Theories Identified in SDM Literature Review.

Theories identified in SDM literature

Theory	Paper identified in:	Theory type
Normalization Theory	Lloyd et al, 2012	Patient and health care professional orientated
Social Exchange Theory	D'Amour et al, 2008	Patient and health care professional orientated
Theory of Planned Behaviour	Allaire et al, 2012 Maffei et al, 2012	Patient and health care professional orientated
Theory of Interpersonal Complementarity	Kiesler and Auerbach, 2006	Patient and health care professional orientated
Cognitive-Affective Processing System Theory	Alden et al, 2014	Patient and health care professional orientated
Theory of Situation Cognition	Alden et al, 2014	Patient and health care professional orientated
Cultural Task Theory	Alden et al, 2014	Patient and health care professional orientated
Regulatory Fit Theory	Alden et al, 2014	Patient orientated
Coupled Systems Theory	D'Amour et al, 2014	Health care professional orientated

9.6: F: All Identified Mechanisms

HCP perception of patient competency/capacity Physician perception of severity of illness/urgency of treatment Physicians perception of patient as too ill to make good decisions Physician perception of older pts feelings of respect for profession Physician belief that patient is anxious Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician support of patient involvement	9.6: F: All Identified Mechanisms Health Care Provider Specific Mechanisms
Physician perception of patient as too ill to make good decisions Physician perception of older pts feelings of respect for profession Physician perception of patient trust Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Treatm Care I Tovider Specific Mechanisms
Physician perception of patient as too ill to make good decisions Physician perception of older pts feelings of respect for profession Physician belief that patient is anxious Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	HCP perception of patient competency/capacity
Physician perception of older pts feelings of respect for profession Physician belief that patient is anxious Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of severity of illness/urgency of treatment
Physician belief that patient is anxious Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physicians perception of patient as too ill to make good decisions
Physician perception of patient trust Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of older pts feelings of respect for profession
Physician perception of patient preference for involvement/engagement Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician belief that patient is anxious
Physician perception of patient support (external) HCP perception of treatment options HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of patient trust
HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of patient preference for involvement/engagement
HCP perceive treatment impacts pts lifestyle/self-image Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of patient support (external)
Physician perception of likelihood of compliance + treatment Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	HCP perception of treatment options
Physician perception of quantity and quality of information available Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	HCP perceive treatment impacts pts lifestyle/self-image
Physician perception of workload Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of likelihood of compliance + treatment
Physician perception of time available <-> time required for SDM Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of quantity and quality of information available
Physician perception of level of effort involved in training programs HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of workload
HCP comfort with implementing SDM Physician concern about reimbursement	Physician perception of time available <-> time required for SDM
Physician concern about reimbursement	Physician perception of level of effort involved in training programs
	HCP comfort with implementing SDM
Physician support of patient involvement	Physician concern about reimbursement
	Physician support of patient involvement
Physician belief that patient autonomy should be respected but not enforced	Physician belief that patient autonomy should be respected but not enforced

Physician considers FIFE - feelings, ideas, function, expectations of PATIENT
Physician perception in the effectiveness of SDM
HCP has perception of value of patient centered care
HCP perceives patient as equal
HCP considers Patient values/preferences
HCP recognize a decision needs to be made
HCP perceive they don't know how to determine SDM
Physician emphasis of importance of information exchange
HCP preference for engagement
Physician perception of appropriateness of SDM for situation
Physician competence <-> ability to "hear" patient preference
Physician dissonance: prior beliefs interfere with ability to accept and understand info
Fear of prosecution / loss of credentials
Decreased HCP anxiety

Patient Specific Mechanisms
Patient perception of lack of power/ not being taken seriously
Patient sense of being respected
Patient trust in individual HCP-person + professional
Patient perception of physician disclosure

Patient fear of backlash / upset physician Patient perception of own knowledge Alignment between eventual decision and patient values/aspirations Patient efficacy for SDM Patient capacity to understand and process information (diagnosis, options, etc.) Patient dissonance: prior beliefs interfere with ability to accept and understand info (Cultural beliefs / world view) Patient anxiety Fit between patient desire for participation <-> experience in "this shared decision" experience Patient preference for engagement Patient desire for information Patient desire to please – good patient – compliance Patient expectations of physician Increased treatment efficiency

Health Care Provider – Patient Interaction Specific Mechanisms

Physician – patient communication – physician ability and willingness to bring the patient capacity gap

HCP and PT Enhanced awareness and education of SDM

Perception of partnership (authentic and constructive)

System Specific Mechanisms
Influence of training environment on HCP
System support

9.7: G: Expanded IP-SDM Mechanism Map

