Towards a Comprehensive Framework for Shared Decision-making: Defining the Process and Examining the Decision-making Preferences of Millennial Women

A Dissertation
SUBMITTED TO FACULTY OF THE UNIVERSITY OF MINNESOTA BY

Priyanka J. Desai

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

Donna McAlpine, PhD; Mary Butler, PhD, MBA

April 2020

ACKNOWLEDGEMENTS

This research would not have been possible without the women who participated in the qualitative interviews. I am incredibly grateful for their time and willingness to share their health care experiences with me. I am also grateful to the women who volunteered to test my interview guide as I developed this research. Their input and feedback helped shape this work.

This dissertation would not have been possible without my committee (Dr. Donna McAlpine, Dr. Mary Butler, Dr. Timothy Beebe, Dr. Cynthia Peden-McAlpine, and Dr. Danielle Lavallee). My advisors Donna McAlpine and Mary Butler provided endless support throughout this process. Their belief in the merit of my research was a constant source of reassurance. I am grateful to Donna for the guidance she provided to help develop my research and improve the analysis. I am beyond grateful to Mary for her years of mentorship at the Minnesota Evidence-based Practice Center. My work with the Evidence-based Practice Center gave me the skills and confidence to pursue a complex review as part of my dissertation. I also thank Mary for acting as a second reviewer for the systematic review that is part of this dissertation.

The feedback from my committee members Timothy Beebe, Danielle Lavallee, and Cynthia Peden-McAlpine helped shape this research for the better. I am grateful for their time and support in pursuing this work. In addition to providing their expertise, Timothy and Danielle shared relevant publications and resources, which I greatly appreciated. I am also grateful to Danielle for her

support and mentorship over the past decade. Cynthia provided essential guidance and feedback in the process of developing of my qualitative research.

I am indebted to Kari Mentzer and for acting as a second reviewer for my qualitative analysis. Her contribution ensured the methodological rigor and quality of this dissertation. I am also grateful to my peers Lianna Weissblum and Sarah Kolvenbach for their endless encouragement. Finally, I would like to thank my mother Rohini Desai for her constant support throughout all my academic pursuits (I am sorry I did not do better on my MCAT), my sister Namita Desai for always being available for a work break, and my father Jayant Desai who taught me to use a big hammer.

DEDICATION

This dissertation is dedicated to my mother, Rohini Desai.

ABSTRACT

This research aimed to conduct a systematic literature review to synthesize and evaluate models of shared decision-making (SDM) and identify common: goals and objectives of SDM, components of SDM and how these are operationalized, and responsibilities assigned to patients and clinicians for participating in SDM. This research also aimed to conduct qualitative interviews with millennial women residing in Minnesota to examine the role of clinical severity and time in the formation of health care decision-making preferences of millennial women. The interviews used card sort exercise to examine decision-making preferences for three scenarios: painful periods, polycystic ovary syndrome (PCOS), and recurring ovarian cysts.

The review findings outline the minimum necessary process steps to conduct SDM. I found that six SDM process components were common across models. These six components were: acknowledging that there is a decision to be made and there are options; patient preferences, values, or goals; information delivery/exchange, deliberation; making a decision; and post-decision evaluation and follow-up. Based on the available evidence, both the patient and the clinician have the responsibility of implementing two components: patient values, preferences, and goals and information delivery/exchange. Evidence was minimal to insufficient to for SDM goals and objectives and SDM model efficacy.

The interview findings suggest that millennial women prefer a more active approach to health care decision-making for some clinician situations. During the interviews, participants preferred a more active form of decision-making for

painful periods, but preferred SDM for PCOS and recurring ovarian cysts. For more uncertain and severe situations, participants expressed a willingness to give more power to clinicians due to their training and expertise, but were rarely willing to cede all decision-making power. This is a large shift from the traditional medical model and will most likely require investments in training and support for clinicians. While participants acknowledged the value of sufficient time with clinicians, there was not consensus regarding the role of time in decision-making preferences.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

1.1 Background

Shared decision-making (SDM) is a process where patients and clinicians collaborate to make heath care decisions.[1] This practice can be used to improve communication between the patient and clinician, holding the promise of better health care decisions and patient outcomes.[2] Efforts to implement SDM in clinical practice have increased over the past decade, as have federal and state policy efforts to implement SDM as part of patient-centered care.[3] Patient-reported outcomes platforms include measurements for SDM and the National Quality Forum has released guidance on SDM in health care, with the intention of making SDM a standard of care.[4,5]

These implementation efforts are concerning given that there is no common definition or framework for SDM.[6] The use of SDM as a metric for quality indicate that clinicians will soon be evaluated on their ability to provide SDM. This creates a considerable challenge for health care organizations as they are expected to deliver SDM with no common understanding of what it is, what it should accomplish, and how it should be implemented.[7] This inconsistency makes SDM challenging to implement in health care delivery. Community clinics and small hospital systems may find it difficult to implement a process that is still developing and lacks proof of concept in some areas.[2]

In addition, approaches to SDM do not account for the decision-making preferences of patients. As a result, not all patients may want to participate in

SDM and under some circumstances the patients may prefer to defer to their clinician.[7,8] Whether or not an individual wants to actively participate in health care decision-making can be based on demographic characteristics (e.g., gender, race/ethnicity, education) as well as factors specific to the clinical encounter such as clinical severity and time available with clinicians.[8-10] "Nothing about me without me" has long been the motto of advocates for patient-centered care and SDM, yet guidance on when to implement SDM infrequently considers the patient perspective.[11] Prominent SDM models have largely relied the input of providers and researchers.[12-15]

1.2 Purpose of the Study

This study focuses on the "what" and "when" of SDM. If the health care system is to implement and evaluate SDM, it must understand the defining characteristics of the process (the "what" of SDM). Uncertainty about what is SDM, the components of SDM, and how it should be implemented are significant barriers to practice.[16] In addition, the term SDM is inconsistently used in literature.[17] Researchers can conflate the testing and validation of decision aids with the use of a comprehensive SDM framework during clinical encounters.[12]

Frameworks for SDM must also account for when patients think it is necessary and appropriate (the "when" of SDM). This research will examine preferences for health care decision-making from the perspective of millennial women. Millennials are now the largest generation in the United States, have a high prevalence of chronic conditions compared to previous generations when they were the same age, and are considered industry disruptors.[18-22] Yet, the health care decision-making preferences of this generation are largely unstudied. Studying the preferences of millennial women is especially important given the gender bias women face when they seek care.[23] Millennial women have also become an important and active demographic in discussions about health care reform, especially issues related to health care access, which may influence their decision-making preferences.[24] Examining the decision-making preferences of this population will have implications for the health care system for implementing SDM and providing care that is responsive to the needs of a large segment of current and future patients.

1.3 Research Objectives

To address the gaps in the current evidence-base, this study examines three specific aims:

Aim 1. Synthesize and evaluate models of SDM in the literature to identify common: a) goals and objectives of SDM, b) components of SDM and how these are operationalized, and c) responsibilities assigned to patients or clinicians for participating in SDM.

Aim 2. Examine the role of clinical severity in the formation health care decision-making preferences, including the motivation for such preferences.

Aim 3. Examine the role of available time with clinician in the formation health care decision-making preferences, including the motivation for such preferences.

1.4 Significance

Aim 1 provides a necessary appraisal of current approaches and frameworks for SDM. The lack of consistency in defining SDM and confusion about what it involves makes it difficult to execute and to measure its impact.[7] Over the past decade, the field has a seen an increase in SDM publications.[25] The quality of these publications vary, adding additional confusion and inconsistency.[25] There is no common definition of SDM.[26] A 2006 systematic review identified 31 different concepts used to describe the process, while a 2019 systematic review identified 24 components.[6,26] Adding to this confusion is the development of SDM measures that are not tied to a common definition or framework.[14,27]

The systematic review evaluates and synthesizes the SDM literature to provide clarity to the conceptualization and practice of SDM. This review expands the scope of previous work in three ways. First, in addition to the peer-reviewed literature, I searched the gray literature for definitions and operational guides for SDM. Second, I searched for randomized controlled trials (RCTs), observational studies, and qualitative studies with the goal of evaluating the evidence in support of the theoretical literature. Third, I addressed concerns about literature quality by excluding editorials or thought pieces, using validated tools and rubrics to assess the quality of included publications, and assessing the confidence in evidence.

Aims 2 and 3 examine when SDM is necessary and appropriate from the perspective of millennial women residing in Minnesota. Under Aim 2, I identified how millennial women's decision-making preferences change with clinical severity. As severity increases, the decisions patients face may become more complex and uncertain. Patients may have different preferences for making health care decisions for mild conditions like bronchitis than severe diseases like cancer.[8,28-30] Previous studies have mostly examined patient preferences for health care decisions under a specific clinical context (e.g., studies of patients making decisions about early-stage cancer treatment).[8] Studies examining if preferences change as severity changes are primarily survey-based.[29-31] This provides little insight into why or how these preferences are formed.

Aim 3 examines the role of time with health care providers in forming preferences for health care decision-making. Lack of time is frequently cited as a barrier to SDM by both clinicians and patients.[16,32,33] Patients who cite time as a barrier worry that there is inadequate time during their consultations for SDM or that their clinicians are too busy for SDM.[32] The potential for patient decision-making preferences to vary by clinical severity and time creates uncertainty about when patients want to participate in SDM. Using a qualitative methodology, I was able to examine not only if there are changes in decision-making preferences based on these two factors, but also the underlying reasoning behind these preferences.

This research lays the groundwork for a unified model of SDM by evaluating the current evidence-base and identifying commonalities across the available literature. As part of my synthesis, I propose a process model for SDM based on the common components I identified in the literature. A collective approach for SDM based on well-defined and tested frameworks is essential to supporting broad implementation and evaluation efforts. Without a common understanding, SDM implementation will remain. The process model is a critical step in moving the field towards a collective approach to SDM.

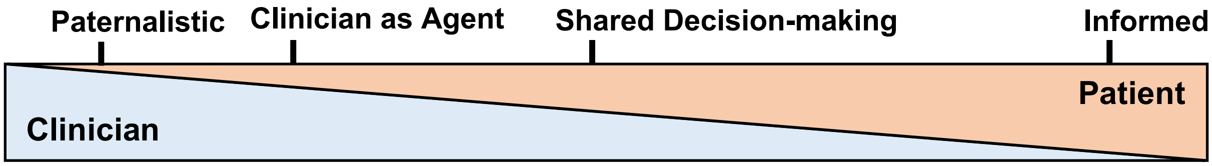
This study also provides greatly needed context for when and how a key segment of the population, millennial women, want to participate in health care decision-making when considering the roles of clinical severity and time. The qualitative interviews provide information on the underlying factors that drive preferences for health care decision-making. This will support health services researchers, clinicians, and health care organizations in delivering care to millennial women that is responsive to their needs. The interview findings also provide information how patients view SDM and when they think it should be implemented in clinical practice.

CHAPTER 2: LITERATURE REVIEW

2.1 The Patient-Clinician Relationship

Henderson (1935) defines the dynamic between patient and clinician as a social system, emphasizing the importance of communication between clinician and patient.[34] The literature has defined several approaches within this social system: paternalistic, clinician as an agent, shared decision-making (SDM), and informed.[1] Figure 1 illustrates the relative decision-making power of the patient and clinician in each of these models.

Figure 1. Decision-making Power of Patient and Clinician Relationship Models



The paternalistic model places power in the hands of the clinician who, as an expert in medicine and medical care, is the decision-maker for the passive patient. In this model, the clinician acts as a warden of the patient by selecting and implementing what they feel is best.[35] A key assumption of this model is that there is enough objective information for the clinician to determine what is best with little input from the patient.[35] The “clinician as an agent” still places decision-making in the hands of the clinician; however, effort is made to elicit the preferences of the patient.[1,36] This model assumes that the clinician has sufficient knowledge of the patient’s needs and preferences to act as a “perfect agent” for the patient.[36] The clinician makes decisions for the patient while taking on the patient’s point of view.[36] This model is of interaction between patient and clinician is unrealistic for real-world practice as clinicians are unable to perfectly take on the role of the patient.[13] However, clinicians may feel that they are practically able to understand the needs of the patient to act as a perfect agent.

Both SDM and the informed model increase the patient’s power. SDM requires two-way flow of medical and personal information between patient and clinician.[12] The patient and clinician jointly deliberate and share decision-making power.[12,37] Informed decision-making takes this process a step further, with the patient as the sole decision-maker.[12,36] The role of the clinician is to provide all necessary medical information to the patient, but play no role in making decisions.[12,36]

The medical model has historically been paternalistic, with the role of patients limited to passive participation.[12] The traditional sick role limits the responsibilities of patients to seeking assistance from a competent medical professional.[38] In the sick role, patients do not have a responsibility to actively participate in medical decision making, suggesting that the patient surrenders agency to the clinician once they have sought medical treatment.[38]

Paternalism in medical care is becoming less acceptable as health care stakeholders embrace patient-centered care, which is “…respectful of and responsive to individual patient preferences, needs, and values, and [ensures] that patient values guide all clinical decisions.”[39] Patient-centered care moved to the forefront of the US health care system with the passing of the Patient

Protection and Affordable Care Act in 2010.[40] This change has sparked renewed interest in SDM, an important method to delivering patient-centered care.[11]

Several policymakers and health care organizations have explored ways to implement SDM. In 2007, Washington State created a SDM pilot program and partnered with health care organizations to examine and facilitate implementation of the process through the use of decision aids.[41] Section 3506 of the Patient Protection and Affordable Care Act sought to establish a program to facilitate SDM, which focused on developing standards for decisions aids.[40] Initiatives like the Mayo Clinic Shared Decision-Making National Resource Center and the Dartmouth-Hitchcock Center for Shared Decision-Making have created resources to help implement SDM in clinical practice.[42]

There have also been efforts to measure SDM implementation. The National Committee for Quality Assurance and the Agency for Healthcare Research an Quality have developed a composite measure of SDM for the Consumer Assessment of Healthcare Providers and Systems survey and Healthcare Effectiveness Data and Information Set.[43] Organizations are using electronic health records to deliver decision aids to patients.[44] In addition, some patient-reported outcomes measures include metrics for SDM. For example, the International Consortium for Health Outcomes and Measurement standard set for primary care for older adults includes questions about clinician communication and participation in decision-making.[4]

Research and implementation efforts focused on the development of SDM resources and measures fail to address important theoretical and practical barriers to implementing SDM.[7,45] The field has yet to clearly define the goals and objectives of SDM and develop a common framework for the process. It is unclear if we have good-quality empirical evidence that support theoretical models of SDM. We need to determine if decision-making between patient and clinician should be adaptive based on clinical severity. Finally, we have not fully examined the role of practical constraints like limited time during consultations in guiding patient preferences for health care decision-making.

2.2 Shared Decision-making in the Literature

SDM is not a novel concept. Early models of the patient-clinician relationship include iterations where the patient works in partnership with their clinician with variety of terminology.[10] Szasz and Hollander (1956) used the term “mutual participation” for a model of the patient-clinician relationship where the two actors work in partnership.[10] Emanuel and Emanuel (1992) outline “interpretive” and “deliberative” models of the patient-clinician relationship, both of which have overlap with SDM.[35] The first significant use of SDM was in 1982 in a report from President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.[37,46] The report contextualized SDM as a process “based upon the mutual respect and participation of patients and health professionals” that was essential to establishing informed consent.[46] In more recent years, SDM has become linked to the delivery of patient-centered care and the broader concept of patient engagement.[11] Since the publication of the report, researchers have attempted to further define SDM, but the literature remains incomplete. The objective of Aim 1 is to provide clarity to our understanding of SDM.

2.2.1 Previous Efforts to Define Shared Decision-making

Multiple publications outline steps or components for SDM. Major works include Charles et al.'s (1997) four key characteristics,[1,12] Towle and Goldophin's (1999) patient and clinician competencies,[47] and Elwyn et al.'s (2012) choice talk, option talk, and decision talk model.[37] There have been previous attempts to synthesize the available definitions and models in the literature, the most prominent being the systematic review from Makoul et al. (2006).[6] The review found 76 articles with non-redundant definitions of SDM with 31 separate concepts use to explain or define SDM.[6] Finding no integrated definition, Makoul et al. synthesized a list of essential and ideal SDM elements as well as a list of general qualities. Essential elements included defining the problem and patient values/preferences; ideal elements included unbiased information and mutual agreement; and general qualities included deliberation/negotiation and mutual respect.[6] Building off of Makoul et al., a recent systematic review from Bomhof-Roordink et al. (2019) identified 53 elements in 40 publications, which were subsequently clustered into 24 components of SDM.[26]

There were several limitations to previous review methodologies.[6,26] The authors did not consider the quality the available literature. Approximately 14% of publications included by Makoul et al. review were editorials or commentaries.[6] The authors aimed to create a definition that was conceptually sound and applicable to clinical practice, but they did not examine whether there was any evidence to support or test the models they identified.[6] The authors formed their list elements by focusing on those that were central to the most frequently cited definitions of SDM, assuming prominence would be a reasonable proxy for quality.[6] The authors also added two elements to the list at their discretion—discuss patient ability/self-efficacy and arrange follow-up—without a clear explanation of the decision-making process behind the selections.[6] The proposed review aims to address these flaws by evaluating the quality of the included literature and examining empirical research to see if there is evidence to support the theoretical constructs of SDM.

In addition, neither Makoul et al. nor Bomhof-Roordink et al. address two important issues in conceptualizing the process of SDM: how researchers define the goals and objectives of SDM and responsibilities of both patients and clinicians within the process.[6,26] The goals and objectives of SDM are broadly and inconsistently defined. This raises the question of what is the central hypothesis behind practicing SDM. Is the incentive patient satisfaction, developing patient agency, or reducing clinical practice variation? Are there multiple intermediate benefits that contribute to the long-term goal of improved patient outcomes? Or is SDM simply a mechanism to reduce decisional conflict and reach agreement? Authors frequently scope SDM as a process to improve aspects or outcomes of the decision-making process (e.g., patient satisfaction, decisional conflict, patient knowledge, patient self-efficacy).[1,37,48,49] However, there are also discussions of broader objectives for SDM such as improving patient outcomes, reducing variation and health care utilization, and translating evidence-based research into clinical practice.[48,50,49]

The extent to which the literature supports these claims is unclear; partially due to researchers mischaracterizing studies that test SDM tools as studies that comprehensively evaluate the SDM process. Studies of SDM tools do not always provide information on the overall or model framework of SDM used in the study to guide implementation of the tool and the interaction between patient and clinician. While decision aids can help facilitate the SDM process, use of an information delivery or discussion tool does not always guarantee that SDM will occur (it is dependent on how the tool is used).[51] Consequently, studies of decision support tools that do not provide a clear process for SDM practice in their methods cannot automatically be categorized as studies of the SDM process.

A previous systematic review of randomized controlled trials (RCTs) comparing SDM interventions with non-SDM interventions found mixed evidence regarding the superiority of SDM interventions in improving patient satisfaction.[2] However, the SDM interventions were primarily decision-aids or other tools and authors did not clearly describe implementation of a comprehensive SDM process in the methods.[2] This highlights the need to not only define and evaluate the SDM process, but also distinguish research that examines SDM as a whole from research that tests or validates tools that may support the process. A 2015 systematic review examining the impact of SDM found mixed evidence regarding the ability of SDM to improve patient outcomes.[51] While the review considered the quality of including studies, it did not consider how studies defined SDM.[51]

Another aspect missing from previous reviews is an examination of the responsibilities of the patient and clinician in performing SDM.[6,26] In discussing the list of SDM elements, the reviewers do not consider who is responsible for initiating SDM or ensuring that necessary steps occur. Towle and Goldophin (1999) assign both the patient and clinician competencies and responsibilities for SDM. [47] This includes a specific competency for patients to first self-assess their health, feelings, beliefs, and expectations prior to engaging with their clinician.[47] In contrast, Elywn et al. (2012) outlines a SDM process where the clinician is the steward of each step, with guidance on how clinicians can prompt patients to think about needs and preferences.[37] Outlining the responsibilities of both patient and clinician in SDM is an important part of understanding how to implement SDM in the health care system.

2.2.2 New Literature on Shared Decision-making

A 2014 study of publication trends in 15 high impact journals found an exponential growth rate in the number of publications on SDM between 1996 and 2011. In 2011 alone, there were 165 publications on SDM across the 15 journals.[25] There have been limited efforts to synthesize available definitions of SDM since the 2006 review from Makoul et al.[26] These efforts have not addressed the varying quality of the literature published on SDM over the last two decades. The 2014 study found that nearly 64% of SDM literature published between 1996 and 2011 were non-research publications (e.g., letters, comments, advocacy/debate or thought pieces).[25] There is a need to distinguish publications of new or improved SDM models from non-research publications.

There are sufficient differences between each SDM model and approach to SDM to require systematic examination and synthesis. Some models are largely clinician driven while others define a clear sharing of responsibilities between patient and clinician; some models are more conceptual while others focus on proces.[1,52] Since Makoul et al., there have been several new publications that attempt to define the process of SDM that should to be synthesized with previous work. For example, Montori et al. (2006) adapted the acute care model outlined by Charles et al. to a model appropriate for chronic care.[13] Elywn et al. (2012) outlined the choice, option, decision talk model. [37] Peek et al. (2016) developed a conceptual framework for SDM for African-American LGBT patients.[53] An initial Ovid Medline search for literature on SDM published since Makoul et al. literature search in 2003 yields thousands of new publications that need to be screened, evaluated, and synthesized.

While a more recent effort from Bomhof-Roodink et al. (2019) has built upon Makoul's work, it does not take into account key resources in the gray literature. [26] The Agency for Healthcare Research and Quality outlined its own five-step approach to SDM with accompanying curriculum.[54] Health care organizations like the Mayo Clinic, Massachusetts General, and Dartmouth-Hitchcock have developed SDM resources. Any models created by these organizations should be examined in a synthesis of SDM definitions.

Researchers have difficulty defining SDM and there is not a single widely-accepted definition or measure of SDM.[45,55] While the review under Aim 1 does not produce one universal definition of SDM, it identifies where there is common ground and proposes a process model of SDM based on the available evidence. This work represents an important step in moving the field towards a unified definition and conceptual model. It provides an appraisal of the literature that examines not only how we have conceptualized SDM (specifically, the goals and objectives, the process itself, and the role of patients and clinicians), but also if there is evidence to support theoretical frameworks. This is critical to current and future SDM implementation efforts because we need a common understanding based on the best available evidence to design and evaluate SDM.

2.3 Trends in Patient Preferences for Health Care Decision-making

Patients can have a range of preferences for how they want to make health care decision. A systematic review from Chewning et al. (2012) searched for studies on patient decision-making preferences from January 1980 to 2007, finding 119 analyses from 115 unique studies.[8] The reviewers only included empirical studies, but did not assess the quality of included studies. Seventy-five out of 119 analyses found that a majority of patients wanted to participate in health care decision-making.[8] Twenty-five analyses found that the majority of patients wanted to delegate decisions to clinicians and the remaining 19 analyses had mixed findings. The mixed findings were attributed to studying two different populations within one study or using scales like the Autonomy

Preference Index.[8] The Autonomy Preference Index is a validated instrument that measures information seeking and decision-making preferences, which presents multiple hypothetical scenarios to participants. The mixed results from the Autonomy Preference Index-measured studies demonstrate how health decision-making preferences can be context specific as patient preferences changed across different scenarios.[8]

The role of clinical context is also reflected in the population-level results. The review divided the analyses into four populations: cancer, other chronic conditions, invasive procedures, and general population, and examined what percentage had patients that favored active participation. The results are displayed in Table 1. In 77% of cancer analyses, a majority of patients wanted to participate in making health care decisions. A similar percentage was observed for invasive procedures. However, only 53% of analyses on the general population and 46% of analyses on other chronic decisions found that most patients wanted to participate in decision-making.

Table 1. Variation in Decision-making Preferences from Chewning et al. (2012)

Population (Number of Analyses)	Majority Preferred to Participate (Number of Analyses)	Majority Preferred to Delegate (Number of Analyses)	Mixed Findings (Number of Analyses)
Cancer (43)	77% (33)	14% (6)	9% (4)
Other Chronic Conditions (26)	46% (12)	31% (8)	23% (6)
Invasive Procedures (14)	79% (11)	14% (2)	7% (1)
General Population (36)	53% (19)	25% (9)	22% (8)

The year of the study may have influenced results. Chewning et al. noted a distinct time trend finding that studies published after 2000 trended towards more patients who wanted to participate in decision-making, while studies published pre-2000 trended towards more patients who preferred a passive role.[8] Chewning et al. suggests that this shift is attributable to differences in the populations studied overtime.[8] This shift may also reflect broader changes in our societal expectations of health care and clinicians over the past few decades. Studies focusing on “patient-centered” behavior have been published since the 1970s.[56] However, rising distrust of clinicians in the decades before 2000 may have challenged the validity of paternalism. In particular, the shift to managed care and the focus on cost containment created distrust in clinicians and the health care system.[57] A 1997 study from Lupton found that clinicians believed the status of medical professionals had diminished, removing the view of clinicians as “god-like figures”.[58] In addition, Lupton found that patients were more knowledgeable about their care and more assertive with their clinicians.[58]

Studies published since 2012 reflect the post-2000 publication time trend towards participation in decision-making observed by Chewning et al. Krumholz et al. (2013) examined the decision-making preferences of individuals hospitalized with an acute myocardial infarction. Of 6,636 patients interviewed for the study, 68% preferred an active or shared role. Among those who preferred an active or shared role, 40% preferred that the patient be more involved than the clinician in making decisions.[59] Santema et al. (2017) examined decision-making preferences among 67 patients visiting a vascular surgery outpatient clinic.[60] The study found that 58% of participants preferred a shared role for decision-making. A cross-sectional study of 810 adults visiting ophthalmologists for diabetic retinopathy from Marahrens et al. (2017) found that 74% of patients preferred shared decision-making. Approximately 18% preferred that the ophthalmologist made the decision and 8% preferred that they made the decision autonomously.[61] Berger et al. (2017) surveyed the preferences of women 12 to 18 months after they were diagnosed with breast cancer. In both the full sample of 873 patients and a subsample 329 chemotherapy patients, approximately 50% of respondents preferred SDM for treatment decisions.[62] In both the full sample and subsample, approximately 19% of patients preferred that clinicians made the decision about treatment and approximately 31% preferred to make the decision themselves.[62]

This literature indicates that a majority of individuals prefer being involved in making their health care decisions. However, there remains a considerable proportion that prefer to defer to their clinician and a small group that prefers to make decisions themselves. Across the literature on patient preferences for SDM, there is variation in the proportion of individuals who prefer SDM.[8] In Krumholz et al. and Maharens et al., 70% of respondents preferred SDM.[59,61] In contrast, in Berger et al. only 50% of respondents preferred SDM. These studies occurred in different settings, under different clinical contexts, and with different patient populations. If we are to fully understand patient decision-making preferences, we must consider the factors that influence their formation.

2.4 Factors that Influence Preferences for Health Care Decision-making

Eisenberg (1979) outlines four sociologic factors that influence clinical decision-making: patient characteristics, clinician characteristics, the clinician's interaction with the health care system, and the clinician's relationship to the patient.[63] Patient demographics such as age, income, education, gender, and race and ethnicity may influence decision-making preferences.[64] Younger patients as well as those with higher incomes and levels of education are more likely to prefer an active role in health care decision-making.[64,65] [66-68] Evidence regarding the role of gender is mixed. Some studies show that women are more likely to want to participate in decision-making than men; however, others have found no association between decision-making preferences and gender.[64-66,69]

There are also mixed findings about the role of race and ethnicity.[64] A large, multisite observational study of 2,197 patients with chronic disease found no association between race and ethnicity and decision-making preferences.[28] A population-based survey of 2,765 respondents found that race and ethnicity did play a role.[68] African American and Hispanic patients were less likely than White patients to prefer an active role in medical decision-making.[68]

The association between race and ethnicity and decision-making preferences may be confounded by the patient-clinician relationship. The patient-clinician relationship can be an important factor in the formation of decision-making preferences.[64,70] Fear of authoritarian clinicians or being labeled difficult may suppress interest in participating in decision-making.[71] Variables such as relationships with other medical staff and clinician characteristics (e.g., interpersonal skills) can further influence this dynamic.[32,64,72,73]

For patients who are part of a minority racial or ethnic group, the patient-clinician dynamic may discourage patients from participating in health care decision-making. Clinicians are more likely to have negative perceptions of Black and/or Hispanic patients and are less likely to engage in patient-centered communication with non-White patients.[74,75] Analysis of the 2001 Commonwealth Fund Health Care Quality Survey (n=6,299) found that Black, Hispanic, and Asian patients were more likely than White patients to feel that they would receive better medical care if they were a different race.[76] These patients were also more likely to believe that medical staff treated them poorly due to their race or ethnicity.[76] These experiences disempower patients.[77,78] In interviews and focus groups with Black diabetes patients, Peek et al. (2009) found that participants felt they did not have the right to participate in health care decision-making.[77] Participants believed that clinicians limited their discussions with Black patients and that they did not receive the same level of information as White patients.[77] However, racial concordance between patient and clinician can improve patient perception of care and patient-clinician communication.[79,80]

The characteristics of the patient and clinician as well as the dynamic between patient and clinician are important factors that may affect patient decision-making preferences.[64] The objective of Aims 2 and 3 are to examine how two additional factors influence decision-making preferences: clinical severity and time.

2.4.1 Severity of Disease/Condition

The systematic review from Chewning et al. shows that decision-making preferences can vary across patient populations with different levels of disease severity.[8] However, the review does not provide a clear direction or trend for how severity influences preferences. In the formation of this research, I reviewed 11 studies that attempted to address this question through the presentation of different clinical scenarios to study participants. Table 2 summarizes the findings from these studies. All 11 studies are survey-based; Cheraghi-Sohi et al. (2008) is a discrete choice experiment.[30,31,67,70,81-87] All of the studies examine specific patient populations (e.g., primary care patients, cancer patients), except Smith et al. (2016) which is a nationally representative survey.[67]

Four studies used the Autonomy Preference Index.[30,83,84,86] Three studies used the Problem-Solving Decision-Making Scale, a decision-making measurement tool that incorporates subscales of the Autonomy Preference Index and divides prompts into “problem-solving” (e.g., who should determine what the treatment options are?) and “decision-making” (e.g., who should decide what treatment options should be selected?) tasks.[70,82,87] Both the Autonomy Preference Index and Problem-Solving Decision-Making Scale use two to three clinical scenarios to elicit decision-making preferences and a five-point Likert-type scale for decision-making options (see Table 2).[30,82] Two studies had scales similar to the structure of the Autonomy Preference Index and Problem-Solving Decision-Making Scale, using three clinical scenarios and five-point Likert-type scales to measure preferences.[31,85] For the discrete choice experiment, Cheraghi-Sohi et al. included involvement in decision-making as an attribute, with respondents indicating their willingness to pay.[81] In the nationally representative survey, Smith et al. (2016) presented respondents with six different tasks in clinical care (e.g., diagnostic testing, lifestyle changes) and asked respondents if they thought SDM was appropriate for each circumstance.[67]

The findings regarding the impact of clinical severity on decision-making preferences were mixed. Four studies (N=1,236) found that patients preferred to have more involvement in decision-making for mild conditions than severe conditions.[30,70,83,86] One study (N=535) found that patients preferred to be more involved in decision-making for severe conditions.[84] Three studies (N=1,690) found no difference between decision-making preferences for mild and severe conditions.[31,81,82] Cheraghi-Sohi et al. (N=1,193) reported no difference between the SDM willingness to pay for mild and severe conditions. The willingness to pay for an ambiguous clinical condition was higher than either that of the mild or severe conditions.[81] Derber et al. (N=300) found no difference for decision-making tasks (SDM was favored across all), but there was a preference towards clinician control for problem-solving tasks.[82]

Three studies examined decision-making preferences in terms of the type or clinical area of the decision. Both Mansell et al. (2000) (N=255) and Smith et al. (N=3,400) provided information on decision-making preferences for types of decisions.[67,85] Mansell et al. found that patients preferred to be more involved in making major decisions than minor decisions.[85] Smith et al. found that a majority of patients wanted SDM across six different types of clinical decisions ranging from selecting a clinician for referral to choosing between medical and surgical treatments.[67] Dehlendorf et al. (2010) (N=257) compared decision-making preferences for general health and decisions about birth control. The study found that the majority of participants preferred autonomous decision-making for birth control decisions, but that clinician-led decision-making was favored for general health decisions. A similar percentage preferred SDM across both scenarios, but SDM was not the most preferred choice in either scenario.[87]

There are several possible explanations for why there is no clear trend in these studies. As shown in Table 2, there were differences in the populations across the studies. Some studies included patient populations who were seeking general care while others focused on those that were undergoing treatment for severe conditions like end-stage renal disease. In addition, nearly half of the studies occurred in international settings. There is a cultural component to patient clinical experiences, expectations, and preferences.[88-90] The specific structure and culture of the health care system in the United States is notably different from the systems in other countries, which may partially account for the mixed results.

There was also variation in the conditions used to elicit preferences and the amount of information provided to participants about the conditions. Some studies provided scenarios that were one to two sentences while others provided paragraph-length descriptions. Given that the studies span from 1980 to 2016, the time trend towards patient participation in decision-making observed by

Chewning et al. may also be a factor.[8] The results of subset of studies published after 2000 do appear to trend towards a broad preference for SDM compared to the older studies. Patient preferences for decision-making may have broadly changed as the health system has transitioned from a paternalistic model to a patient-centered model. Older studies may not reflect this shift.

None of the studies provided qualitative data. The lack of qualitative data makes it difficult to understand the differences in the results of these studies. Respondents can be vocal about justifying their decision-making choices or expressing uncertainty to the researcher collecting their responses.[29] These remarks provide valuable insights into why patients feel a decision-making method is appropriate in one circumstance, but not another. Qualitative data would help clarify why we observe different results across studies. Yet, current studies do not report this type of data. While survey research is useful in examining the preference changes in a large sample of patients, a qualitative study would provide context for the underlying motivations behind the preferences. This information is critical to understanding when and why SDM is or is not desired from the perspective of the patient.

Table 2. Studies on Impact of Clinical Severity on Decision-making Preferences

First Author, Year Country Study Type Tool	Population N Age Sex	Clinical Scenarios	Decision-making Options	Findings
Ende 1989[30] US Survey API	Primary care patients N=312 65% Age 51+ 62% Female	1. Upper respiratory tract illness 2. Hypertension 3. MI	1. You 2. Mostly You 3. The clinician and you equally 4. Mostly the clinician 5. The clinician alone	Significant difference in mean decision-making score across all scenarios ($p<0.003$) with 75% of patients preferring more decision-making power for mild than severe illness. Remaining 25% had opposite preference.
Ende 1990[83] US Survey API	Patient physicians and non-physician patients N=466 49.6 (1.01) 52% Female	1. Upper respiratory tract illness 2. Hypertension 3. MI	1. You 2. Mostly You 3. The clinician and you equally 4. Mostly the clinician 5. The clinician alone	Decision-making scores were below the threshold for SDM. For both groups, illness related decision-making scores decreased as severity increased ($p<0.01$), moving towards preference for clinician control.
Derber 1996[82] Canada Survey PSDM	Patients undergoing angiogram N=300 70% Age 51+ 73% Female	1. Burning sensation during urination 2. Mild chest pain for 3 days 3. Difficulty conceiving with partner (trying for a year)	1. Clinician alone 2. Mostly the clinician 3. Both equally 4. Mostly me 5. Me alone	Significant difference between scores for problem-solving (favored clinician control) and decision-making tasks (favored SDM) ($p=0.001$). Preference for clinician control was higher for some tasks for mild chest pain than urination or pregnancy.
Nease 1996[86] US Cross-sectional Survey	Outpatients with benign prostatic hyperplasia, back	1. Upper respiratory tract illness 2. Hypertension 3. MI	1. You 2. Mostly You 3. The clinician and you equally	Decrease in median decision-making score as clinical severity increased ($p<0.0001$), moving

First Author, Year Country Study Type Tool	Population N Age Sex	Clinical Scenarios	Decision-making Options	Findings
API	pain, or mild hypertension N=167 59 (24-92) 25% Female		4. Mostly the clinician 5. The clinician alone	towards preference for clinician control.
Stigglebout 1997[31] Netherlands Survey N/A	Radiotherapy patients with cancer or nonmalignant surgical outpatients and the people accompanying them. N=197 49.5 (16) 52% Female	1. Tinea of the foot 2. Asymptomatic gallstones 3. Laryngeal cancer 4. Skin Cancer	1. The clinician should make the decisions using all that is known about the different treatments 2. The clinician should make the decisions, but strongly consider my opinion 3. The clinician and I should make the decisions together on an equal basis 4. I should make the decisions, but strongly consider the clinician's opinion 5. I should make the decisions using all I know or learn about the treatments	No statistically significant association between clinical severity and decision-making preference.
Mansell 2000[85] US Cross-sectional Survey N/A	VA outpatients N=255 63.2(10.5) 95% Male	1. Colon cancer 2. Acute MI 3.Diabetes	1. Only your clinician 2. Mostly your clinician 3. You and your clinician 4. Mostly you 5. Only you	Preference to share responsibility for most colon cancer decisions. Decision-making preferences for acute MI was mixed across the decision choices, while more physician

First Author, Year Country Study Type Tool	Population N Age Sex	Clinical Scenarios	Decision-making Options	Findings
				control was preferred for decisions related to diabetes. Across all prompts, patients preferred to be more involved in major decisions (e.g., chemotherapy, bypass surgery, amputation) than minor decisions ($p<0.001$).
Kraetschemer 2004[70] Canada Cross-sectional Survey PSDM	Outpatients at either breast cancer, prostate cancer, or fracture clinics. N=606 67% Age 50+ 51% Female	1. Current health (the condition for which they were attending the clinic) 2. Mild chest pain for 3 days	1. Clinician alone 2. Mostly the clinician 3. Both equally 4. Mostly me 5. Me alone	Approximately 67% of patients preferred a shared role for their current condition (30% preferred passive, 3% preferred active). Only 49% preferred a shared role for the mild chest pain vignette (50% preferred passive, 1% preferred active).
Cheraghi-Sohi 2008[81] UK Discrete Choice Experiment N/A	Patients from family care practices N=1,193 Age 53 (18.1) 54% Female	1. Red, sore, itchy/flaky patches on hand 2. Heavy cough/cold with sharp pain on right side of chest when coughing 3. Feeling tired and irritable with difficulty sleeping	Attribute: Clinician involves you in decision-making	WTP to be involved in decision-making for the minor physical scenario (itchy hands; \$10.55, 95% CI 7.87, 13.30) was similar to WTP for the urgent physical scenario (heavy cough/cold; \$10.98, 95% CI 6.97, 15.21), but the WTP for the ambiguous scenario (tired/irritable) was higher (\$15.31, 95% CI 12.12, 18.68).

First Author, Year Country Study Type Tool	Population N Age Sex	Clinical Scenarios	Decision-making Options	Findings
Deheldorf 2010[87] US Cross-sectional Survey PSDM	Women receiving abortion care N=257 25 (6) 100% Female	1. General health ("when you are sick") 2. Birth control choice	1. Clinician alone 2. Mostly the clinician 3. Both equally 4. Mostly me 5. Me alone	For general health decisions, 48% preferred clinician-led, 33% preferred shared, and 19% preferred autonomous decision-making. For contraception decisions, 18% preferred clinician-led, 32% preferred shared, and 50% preferred autonomous decision-making.
Jayanti 2015[84] UK Survey API	ESRD patients N=535 56 (13.24) 35% Female	1. Upper respiratory tract illness 2. Hypertension 3. MI	1. You 2. Mostly You 3. The clinician and you equally 4. Mostly the clinician 5. The clinician alone	Median decision-making scores increased with severity with higher scores indicating more active participation.
Smith 2016[67] US Cross-sectional Survey N/A	Adult respondents N=3,400 62% Age 41+ 53% Female	1. Lifestyle changes (e.g., diet and exercise) 2. Preventive screening tests 3. Choosing between treatment options (e.g., medication vs. surgery) 4. Selecting a specialist for referral 5. Choosing between medications	1. Yes (affirmative for SDM) 2. No (negative for SDM)	Majority of patients wanted SDM for all scenarios: 72% for lifestyle changes, 59% for preventive screening, 60% for treatment decisions, 55% for referral, 58% for medication choice, and 53% for deciding a diagnostic test. Level of patient activation was associated with preference for SDM for all scenarios except specialist referral ($p<0.02$)

First Author, Year Country Study Type Tool	Population N Age Sex	Clinical Scenarios	Decision-making Options	Findings
		6. Deciding whether it is diagnostic test was necessary		

API=Autonomy Preference Index; CI=Confidence Interval; ESRD=End Stage Renal Disease; N/A=Not Applicable; MI=Myocardial Infarction;

PSDM=Problem-solving Decision-making Scale; SDM=Shared decision-making; WTP=Willingness-to-pay

2.4.2 Time with Clinician

Time is an important factor in patient-clinician consultations. Patients expect clinicians to provide enough time for them to convey concerns and ask questions.[91] Individuals who want more time during consultations report lower levels of satisfaction and are less likely to comply with clinician recommendations.[92] Patients may over- or underestimate the amount of time they have during clinical visits.[92,93] The median length of a primary care consultation is around 16 minutes.[94] More time may be allotted for consultations with specialists.

Previous studies on the adoption of SDM have suggested that there is not a significant difference in time between SDM consultations and non-SDM consultations.[95] Yet, the perception of time as a barrier to SDM persists in both clinicians and patients.[16,32,33] A systematic review on patient-reported barriers to SDM found that time was the most frequently reported barrier.[32] Searching nine databases, the review found 44 relevant studies that were either qualitative interviews or surveys. Twenty of the 44 studies specifically cited time as a barrier.[32] Time-associated factors included limited time allocated for clinician visits, clinicians appearing too busy or hurried, feelings of guilt for taking up more of the clinician’s time, and feeling the need to end appointments early if the waiting room was full.[32] Time was also directly viewed as a barrier to becoming more informed, which in turn discouraged patients from being more active in making decisions.[32] Patients reported that the feeling that they had adequate time allowed for relationship building and more effective communication.[32]

Research shows that individuals may make different choices when under time pressure.[96] Given that time is considered a barrier to SDM by both patients and clinicians, patients may be more interested or willing to participate in decision-making if they were given more time with their clinician. Previous work shows that patients increase information-seeking behavior when given more time with their clinician.[97] Studies have not examined if patients would change their decision-making preferences based on how much time they have with their clinicians. The objective of Aim 3 is to examine the relationship between health care decision-making preferences and time, and to probe if respondents deliberate adjusting their preferences when considering the time available during clinical visits.

2.5. Millennial Women as Healthcare Stakeholders

Aims 2 and 3 examine the decision-making preferences of millennial women in the US. With a population of 83.1 million, millennials are now the largest generation in the US.[98] Table 3 shows key demographic differences between millennials (born 1982-2000), generation X (born 1965-1980), and baby boomers (born 1946-1964).[99]

Table 3. Demographic Differences Between Three Generations

	Millennials	Generation X	Baby Boomers
Part of minority racial or ethnic group (%)	44	38	25
With at least bachelor's degree at ages 18-33 (%)	48	38	31
Never married at ages 18-33 (%)	68	56	43

Households in poverty (millions)	5.3	4.2	5.0

Millennials are more diverse than previous generations. Approximately 56% of millennials are White, 21% are Hispanic, 14% are Black, 6% are Asian, 1% are Native American, and 2% are multi-racial.[22] In contrast, 75% of individuals age 55 and older in the US are White.[22] Despite a higher percentage of millennials obtaining bachelor's degrees, more millennial households are in poverty than households headed by generation X or baby boomers.[99] This generation is often cited as the first generation that is worse off than their parents in terms of economic opportunity.[100]

Millennials conceptualize health differently than previous generations. While over 40% of baby boomers and generation X define being healthy as the absence of sickness, only 29% of millennials define being healthy this way.[22] Instead, preventative activities like eating right and exercising are key components to millennials' definition of health.[22] Despite this focus on overall wellness, many millennials have poor health outcomes. Approximately 27% of individuals age 18 to 44 have one or more chronic conditions.[101] Millennials have higher prevalence of obesity, hypertension, and diabetes than the generations that proceed them.[18,19] Millennials also report higher levels of stress than older generations.[102,103]

Millennials are often viewed as "disruptors" of major industries including the retail, housing, technology, and automotive industries. They are the first generation of digital natives and rely on the accessibility and convenience of the internet and social media to gather information, communicate, and guide decisions.[22] Due to their economic outlook, millennials also delay traditional adult milestones like purchasing a home or car, moving away from their parents, and getting married.[22] As shown in Table 3, millennials between the ages of 18 and 33 are more likely be unmarried than previous generations at the same age.[99]

The millennial workforce is changing the process of medical education and training as well as health care delivery. [104-106] Millennial clinicians expect to use technology to rapidly gather information and instantly communicate.[106] They expect that their coworkers and mentors provide them with rapid responses. This generation is more collaborative and empowered, challenging the traditional hierarchy that guides medical education.[106] Millennials are also prone to embracing innovations in health care delivery and medicine. Academic institutions and health care organizations are learning how to adapt to meet the needs and expectations of this generation.[106] Health care organizations will also need to adapt to suit the needs of the millennial patients, whose expectations about how they interact with the health care system may be different than previous generations. Like the millennial healthcare workforce, millennial patients are prone to using technology for information and communication.[107]

Millennial women, in particular, may be patient disruptors. In 2015, females age 44 and below accounted for almost 24% of clinician office visits.[21] These women are living through a period of change in the US health care system and are very engaged in current discussions about health care reform and their access to care.[24] A 2017 Skimm/YouGov survey of a nationally representative sample of 500 millennial women found that approximately 64% of respondents considered health care the most important policy issue. In addition, 69% of respondents were specifically concerned about reduced access to women's health care services.[24] These concerns are already influencing the way millennial women approach health care decision-making. The Skimm/YouGov survey found that 21% of millennial women were considering changing their birth control method since the 2016 election. [24] Post-2016 election data shows that some millennial women have adopted an informed/active model of decision-making about contraception, resulting in an uptick in the demand for long-acting birth control.[108,109]

Studying the health care decision-making preferences of millennial women is especially important given the biases they face when seeking clinical care. Clinicians are more likely to believe that female patients make excessive demands of their time than male patients.[23] Female patients are also more likely to be viewed as emotional during clinical visits.[23] Across multiple diseases and conditions, the symptoms of women are treated less seriously than those of men.[110,111]

This can to lead to serious adverse events, especially for younger women who may not be taken seriously when presenting with symptoms of a serious condition or life-threatening illness. For example, women with endometriosis experience a 7 to 12-year gap between onset of pain and diagnosis.[112] Data suggests that younger women, in particular, experience longer delays in diagnosis of endometriosis.[113] This is partially attributable to gender bias in pain treatment and the trivialization of women's pain, especially young women.[112,114] In addition, women age 50 and younger are more likely to die from a myocardial infarction then men of the same age.[115] Using in-depth interviews, a qualitative study of 30 women age 30 to 55 hospitalized for acute myocardial infarction found that a partial driver of delayed recognition was that health care providers were not responsive to their symptoms.[116]

Gender bias may impact whether women are able to participate in their preferred model of medical decision-making. An observational study of 137 non-metastatic breast cancer patients undergoing surgery or neoadjuvant therapy found that many of the patients experienced a different decision-making process than the one they preferred.[117] Approximately 40% preferred that the clinicians make their treatment decision, 29% preferred SDM, and 31% preferred to make their treatment decision themselves. Only 63% of participants had a decision-making experience that matched their preferences. Approximately 22% were less involved and 15% were more involved than they preferred. Only 31% of patients who wanted to participate in SDM engaged in their desired decision-making style.[117]

There are several reasons why studying the decision-making preferences of millennial women is important. Millennials may require care for chronic conditions at a faster rate than previous generations. If we do not start considering how the preferences of this generation differ from that of previous generations, health care providers will be poorly equipped to provide patient-centered care that is responsive to their needs. This may exacerbate poor health outcomes. A 2019 report from Blue Cross Blue Shield suggests that if current trends continue, millennial mortality could increase by over 40% compared to generation Xers when they were of similar age.[103] Given that health care spending per capita increases as the number of chronic conditions increase, a lack of responsiveness to the needs of the millennial generation will most likely increase health care expenditures.[118] Blue Cross Blue Shield projects that a greater demand for treatment and the high cost of healthcare would result in millennial treatment costs that are 33% higher than what generation X experienced at a similar age.[103]

Focusing on the decision-making preferences of millennial women may help address the issue of gender bias in clinical care. Clinicians may be reluctant to factor in the decision-making preferences of young female patients because they believe that they are being emotional or simply over-demanding of their time.[23] This could be especially true of young female patients who want to engage in SDM, given the perception that SDM is more time consuming than other decision-making models.[16] A study that not only examines the decision-making preferences of millennial women, but also the underlying motivations behind these preferences may help dispel negative perceptions of young female patients and ultimately improve the quality of care they receive.

2.5.1 Shared Decision-Making and Women's Health

Aims 2 and 3 address an important gap in the literature on patient-centered care and women's health. Much of the available literature focuses on SDM for either maternity care, fertility treatment, or breast cancer.[119-128] While

SDM for these issues are important, they are not the only reasons women seek health care. There is an unmet need for studies of decision-making preferences beyond these areas and for discussions of patient-centered care that broadly consider the needs of young women. Gynecological health concerns, in particular, are important areas to explore the desire for SDM and patient decision-making preferences. These decisions often involve important trade-offs for the patient and clear communication between patient and clinician.

Important women's health issues not often discussed with the context of SDM and patient-centered care for women include treatment of painful periods, treatment of gynecological issues like ovarian cysts, and management of hormonal disorders like polycystic ovary syndrome (PCOS). Treatment for painful periods often involves hormonal contraception.[129] Approximately 40% of women age 15 to 44 in the US are using a form of contraception that requires a prescription, a clinical procedure, or clinician supervision (i.e. birth control pill, intrauterine device, female sterilization, or Depo-Provera™).[130] Selecting contraception requires consideration of individual needs, potential side effects, and the trade-offs of each option. Almost all women will have an ovarian cyst in their lifetime. Management of recurring cysts requires women to consider medication management and the potential for surgery.[115,116] Approximately 10% of women will require surgery to remove an ovarian cyst.[131,132] Approximately 10% of women will also be diagnosed with PCOS, which requires a complex combination of medication and lifestyle changes to manage.[133] Total national health care expenditure for managing PCOS is estimated to be $1.16 to $4.36

billion dollars.[134,135] This study provides an opportunity to examine decision-making preferences for these health care concerns and expand our view of women in a patient-centered health care system.

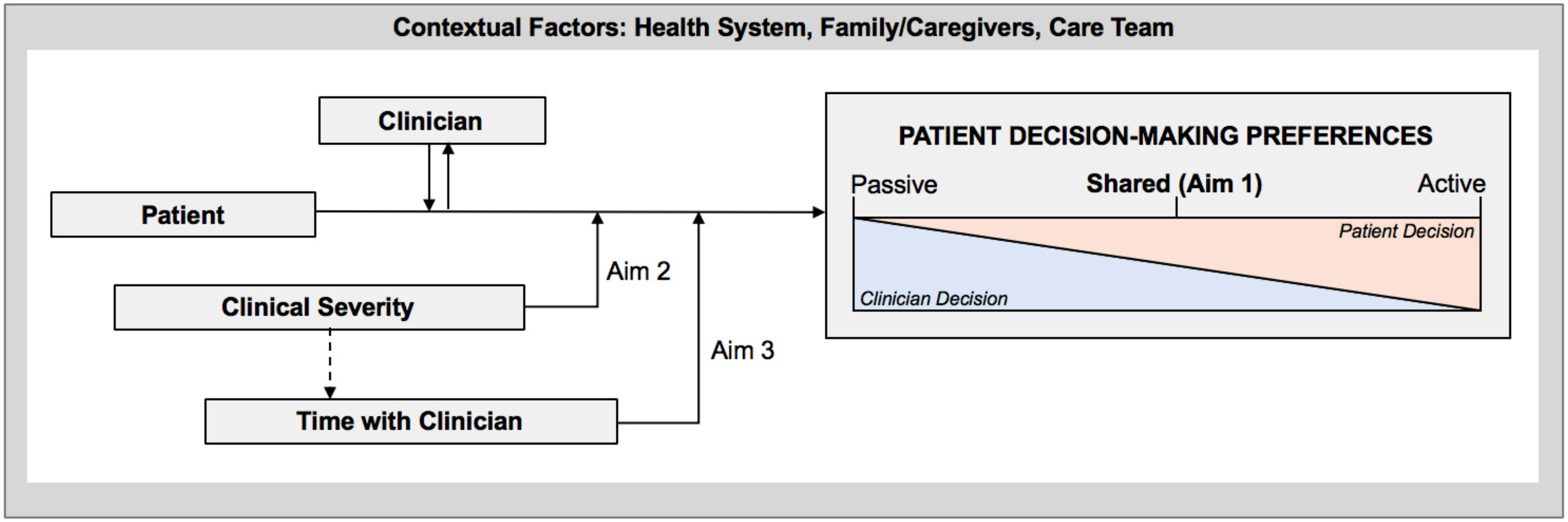
2.6 Conceptual Model

Figure 2 displays the conceptual model for this research. The model illustrates factors that can influence the patient in forming their health care decision-making preferences. The health system is included as a contextual factor that may influence this relationship. Patient characteristics can be a significant factor in determining decision-making preferences.[8,64] However, the relationship between the patient and their decision-making preferences is also influenced by the patient-clinician relationship. [63] This dynamic is represented by the lines from clinician to patient and patient to clinician. While family/caregivers and members of the care team may participate in SDM (as indicated by their inclusion as contextual factors), the model is defined at the patient-clinician dyad level.

The spectrum of patient preferences going from passive to active are shown in the “patient decision-making preferences” box. Passive decision-making represents the paternalistic model of the patient-clinician relationship while active decision-making represents the informed model. Patient preferences for decision-making may also fall between passive and shared and active and shared. Aim 1 focuses on defining the process of SDM and examining the evidence in support of current definitions.

Aims 2 and 3 focus on additional factors that may influence patient decision-making preferences: clinical severity (Aim 2) and time constraints (Aim 3). Clinical severity precedes time as a factor because severity of the condition may determine the desired amount of time with the clinician.[94] The possible interaction between severity and time is illustrated by the dotted line going from severity to time. Information about this interaction may emerge during the qualitative interviews.

Figure 2. Conceptual Model at the Patient/Clinician Dyad Level



CHAPTER 3: SYSTEMATIC LITERATURE REVIEW METHODOLOGY

The literature review under Aim 1 had three key questions (KQs) that aimed to define the practice of shared decision-making (SDM). Due to the complexities of treating children, the review focused on interactions between clinicians and adult patients. For all three KQs, the review documented any SDM models relevant to women to support Aims 2 and Aims 3.

3.1 Key Questions

KQ 1: For clinical encounters between adult patients and their clinicians(s), what are the models of SDM in the literature?

a. What are the common components of SDM across these models and how are these components operationally defined?

b. To what extent have these models been tested by empirical studies?

KQ 2: For clinical encounters between adult patients and their clinicians(s), how do models of SDM in the literature define the goals and objects of the process?

a. Is there a common premise regarding the impact of SDM across these models?

b. To what extent does the empirical research on models of SDM support the stated goals and objectives?

KQ 3: For clinical encounters between adult patients and their clinicians(s), how do models of SDM in the literature outline the responsibilities of patients and clinicians?

a. Are there common responsibilities for patients and clinicians across SDM models?

b. To what extent have empirical studies tested the responsibilities outlined in theoretical models?

3.2 Peer-Review and Gray Literature Search

I searched Ovid Medline, Embase, and PsychInfo, and Cochrane Central Register of Controlled Trials to identify reviews and studies published from 1982 to September 24, 2019. I used 1982 as a limit in order to focus on literature published since the President's Commission report on informed consent, which is the first significant use of the term "shared decision-making".[37,46] The search strategy included medical subject headings and natural language terms for the concepts of SDM and patient decision-making. The librarian at the Minnesota Evidence-based Practice Center provided a peer review of the search strategy. I also hand searched reference lists of relevant systematic reviews and included articles. I supplemented the results from the published literature with a gray literature search. This included a search of documents from Agency for Healthcare Research and Quality, the Informed Medical Decisions Foundation, the Mayo Clinic Shared Decision-Making National Resource Center, the Patient

Centered Outcomes Research Institute, and the Dartmouth Hitchcock Center for Shared Decision-Making, and select patient-reported outcomes platforms.

3.3 Inclusion/Exclusion Criteria

The inclusion/exclusion process and criteria were developed in consultation with an expert in systematic review methodology from the Minnesota Evidence-based Practice Center. I included narrative and systematic reviews, randomized and non-randomized controlled trials, observational studies, and qualitative studies (including qualitative Delphi studies) on the definition or practice of SDM without regard to country of origin. Table 4 summarizes the study inclusion criteria.

Table 4. Study Inclusion Criteria

	Criteria
Study Enrollment	Adults (any health status)
Study Design	• KQ1-3: Narrative or systematic reviews, RCT/CCTs, observational studies, qualitative studies, gray literature • KQ 1a, 2a, 3a: Narrative or systematic reviews, RCTs/CCTs, observational studies, qualitative studies, gray literature • KQ 1b, 2b, 3b: RCTs/CCTs, observational studies, qualitative studies
Data/Outcomes	• KQ1-3: Models of SDM with components, goals and objectives of, or responsibilities of patient or clinician • KQ 1b, 2b, 3b: Measures of efficacy or effectiveness of SDM models (e.g., patient outcomes) or measures of SDM outcomes (e.g., satisfaction, decisional conflict)
Timing	No minimum follow-up.
Publication Type	Published since 1982 in peer-reviewed journals and gray literature.
Publication Language	English

CCTs=Controlled Clinical Trials; KQ=Key Question; RCTs=Randomized Controlled Trials

3.3.1 Criteria for Models, Components, Definitions

For KQs 1-3a, I defined “model” as any definition of SDM that described or explained the process and provided steps or components. Definitions could focus on SDM for the clinician-patient dyad or care team-patient interaction. Publications providing a generic definition of SDM (e.g., SDM is a process of deliberation between patient and clinician) with no additional steps or explanation were excluded. Operational frameworks and guidance documents were included from the gray literature if they provided a clear SDM model.

I also excluded publications that focused on SDM implementation at the organizational level, broadly discussed health care decision-making models, or discussed or studied barriers and facilitators or preferences without synthesizing findings into a clear SDM model or definition. Publications that focused on measures and measure validation were also excluded; however, they were examined as part of the hand search to identify any SDM models that were used to develop the measures.

Components were defined as any step or item identified as a critical or necessary aspect of SDM within each model. These included process steps (e.g., elicit patient preferences) as well as items like respect and trust. Any additional detail provided to explain or describe components were accepted as definitions (e.g., eliciting patient preferences involves exploring ideas, fears, and expectations of the problem and possible treatments). This text was used for the qualitative synthesis of operational definitions.

3.3.2 Criteria for Empirical Studies

For KQs 1-3b, I required that included empirical studies clearly stated the SDM process used in the study. Included studies needed to either cite existing model(s) or outline their unique SDM process. Studies that tested decision aids without describing an underlying process for SDM were excluded. I also excluded publications focused on validating measures of decision aids. Teaching studies (teaching patients, clinicians, or students SDM) were excluded unless they clearly described the SDM model being taught and how it was implemented.

3.4 Data Abstraction and Management

All search results were downloaded into EndNote and duplicates were removed. I screened titles and abstracts based on the inclusion and exclusion criteria. Following title/abstract screening, I performed a full-text review of publications to ensure that the inclusion criteria were met. Reasons for exclusion were documented at full-text review. A second investigator independently performed title/abstract and full-text review. All disagreements about inclusion or exclusion were resolved via discussion.

Initial data abstraction included: author, year, population (if relevant), setting (if relevant), inclusion of families/caregivers or the care team, if the model was clinician-driven (i.e., SDM actions were described as provider initiated), and any contextual factors (e.g., patient factors, clinician factors) listed as influencing SDM. I also extracted additional data based on the scope of each KQ such as SDM components, definitions of components, the goals and objectives of SDM, and responsibilities of the patient and/or clinician. A grid-like structure was developed so that each new component, goal or objective, and responsibility that emerged from the literature could be documented and both quantitively (via count data) and qualitatively synthesized.

For KQ2, I included expected outcomes of SDM as proxy for goals and objectives of SDM. For KQ3, I defined responsibilities as tasks assigned to either patient or clinician as part of an SDM process. In some cases, the entire SDM process was outlined as the responsibility of the clinician. These models were categorized as “clinician driven” models.

For KQ1-3b, I extracted relevant data from empirical studies (or systematic reviews of empirical studies) to examine the extent to which SDM models have been tested. I included measures that assessed the SDM process and patient outcomes (e.g., decisional conflict, satisfaction, quality life, study specific clinical outcomes), as well as measures of health care utilization (e.g., use of follow-up care). A second investigator was consulted throughout the data abstraction process to check the accuracy of abstraction.

3.5 Assessment of Quality of Individual Studies and Reviews

I assessed the quality of all included systematic and narrative reviews, clinical trials and observational studies, non-Delphi qualitative studies, and gray literature. I did not assess the quality of Delphi studies due to a lack of clear criteria to evaluate these publications. Overall quality was assessed as high, medium, or low based on the synthesis of quality or risk of bias criteria. A second investigator was consulted throughout the assessment process to check the accuracy of quality assessments. Given the many study types eligible for inclusion, I used several tools to ensure that studies were rated using appropriate quality criteria:

- For systematic reviews, I used the Assessing the Methodological Quality of Systematic Reviews (AMSTAR) 2 checklist.[136] The AMSTAR 2 checklist includes 16 domains.[136] Items for assessment include use of a comprehensive search strategy, providing clear inclusion/exclusion criteria, conducting screening and data abstraction in duplicate, providing study characteristics, assessing risk of bias, and providing a list of excluded studies.[136]
- For narrative reviews, I used the Scale for the Assessment of Narrative Review Articles (SANARA).[137] While this scale is relatively new, I opted to use this scale due to concerns that AMSTAR 2 criteria would over penalize narrative reviews. Narrative reviews do not typically describe provide inclusion/exclusion criteria or assess risk of bias from included studies, both of which are critical under AMSTAR 2.[136] SANARA uses six assessment criteria for narrative reviews: justification of topic importance, statement of concern or aims, description of literature search, referencing, scientific reasoning, and appropriate presentation of data.[137]
- For RCTs, I used the Cochrane risk of bias tool (version 2.0) to assess risk of bias to inform an overall quality rating.[138] The Cochrane tool assesses potential for bias from five areas: randomization, deviations from

intended interventions, missing outcome data, measurement of the outcome, and selection of reported results.[138]

- For non-randomized studies, I used the Cochrane ROBINS-I tool to assess risk of bias to inform an overall quality rating.[139] ROBINS-I assesses potential for bias from six areas: confounding, selection of participants, classification of interventions, missing data, measurement of outcomes, selection of reported results.[139]
- For qualitative studies, I used Lincoln and Guba's criteria for qualitative studies.[140] Lincoln and Guba outline four domains for assessment: credibility (accurate representation of participant experiences), transferability (extent to which the findings are transferable), dependability (clear description of process), and confirmability (findings are based on data).
- For gray literature, I rated gray literature as low quality unless I could identify the methodology used to form the model and/or descriptions of the models included references that allowed us to identify source material. Gray literature sources with an identifiable methodology and/or references were rated as medium quality; with the exception of NICE clinical guidance which was rated as high quality because it is supported by rigorous evidence review.

3.6 Data Synthesis

Results were summarized into evidence tables and categorized by the unique models of SDM identified in the literature. I grouped publications when multiple references discussed the same SDM model or clinical trial. For each unique model, I examined the components of the SDM process (KQ1a), goals and objectives of SDM (KQ2), and any stated responsibilities of the patient or clinician (KQ3).

For the purpose of determining common components, goals/objectives, and responsibilities (KQs 1a, 2a, and 3a), I conservatively defined “common” as appearing in 50% or more of reporting models. For example, if 20 models reported components of SDM then components described in at least 10 of the models would be considered “common”.

Operational definitions for common components (i.e., definitions that outline the procedures of executing the component) were determined via a qualitative synthesis of SDM models that provided either definitions of the components or responsibilities for patient or clinician. For KQs 1b, 2b, and 3b, I used RCTs, observational studies, and qualitative studies to examine the extent to which SDM models have been tested by empirical research. I synthesized a process model for SDM based on the available evidence on common components.[141]

3.6 Assessment of Confidence of Evidence

I assessed the overall confidence of findings based on GRADE-CERQUAL criteria. GRADE-CERQUAL outlines four assessment components: methodological limitations, relevance, coherence, and adequacy of data.[142] Methodological limitations refers to the extent to which there are flaws in the design or execution of the studies that contribute a finding.[142] Relevance is the extent to which the available evidence is applicable to the question of interest and coherence is the extent to which the findings aligns with the trends in the available data.[142] Adequacy of data indicates the overall level of detail provided in the data (the richness of the data).[142] The overall confidence of findings were rated as high, moderate, low, or very low to indicate the degree to which the finding is a reasonable representation of the data based on the four components.[142] A second investigator was consulted throughout the assessment process to check the accuracy of ratings.

CHAPTER 4: INTERVIEW METHODOLOGY

The goal of the interviews was to examine the decision-making preferences of millennial women when considering the role of clinical severity (Aim 2) and time with clinicians during clinical encounters (Aim 3). Well-conducted qualitative interviews require questions that are clearly stated, open-ended, and sensitive to needs and perspective of the interviewee.[143] This research involves individual interviews that use a narrative and semi-structured (card sort) methodology. Use of narrative interviews to explore decision-making preferences is consistent with qualitative spirit of illness narratives used to explore the patient experience.[144] Card sort exercises have previously been used for qualitative research in health care, including exercises to examine the educational needs of patients with heart failure and cancer patients' preferences for their decision-making roles.[145-147] In these exercises, participants are given a set of cards and are asked to organize them in order of relevance, importance, or preference.[145,148] Study procedures were reviewed and approved by the University of Minnesota (UMN) Institutional Review Board.

4.1 Study Population and Sample Size

The population for this study was millennial women born from 1982 to 2000 residing in Minnesota. I used a combination of purposeful and nominated sampling for this study.[149,150] Eligible participants had to have at least one visit with a clinician (e.g., doctor, nurse, nurse practitioner) for any purpose in the 12 months prior to recruitment. Eligible women also had to speak English and be able to make their own medical decisions.

There is no ideal sample size for qualitative interviews.[151] The goal is to have rich data and reach saturation, the point at which no new themes or concepts emerge.[149,150] Interviews should be conducted until the data is adequate in relevance, completeness, and quantity.[150] A small sample size would make it difficult to reach saturation, but too large of a sample size would make it difficult to conduct a detailed thematic analysis.[151] Based on the scope of the research questions, I estimated that 15 to 30 interviews were needed to reach saturation. I evaluated the nature of the data throughout the collection process and interviews were conducted on a rolling basis until saturation was reached.

4.2 Recruitment

Participants were recruited from the Driven to Discover (D2D) Research Facility at the Minnesota State Fair and from the UMN-Twin Cities campus. All potential participants were provided information on the interview process including a description of the purpose, time commitment, and modality as well as information on data privacy. A $20 gift card was offered as a participation incentive.

The State Fair was selected for recruitment due to the potential to reach a wide range of millennial women living in Minnesota. The D2D building is a 2,400 square foot building in a permanent location at the State Fair that allows attendees to participate in research.[152] Over the course of the Fair, over 60,000 attendees visit the D2D building annually.[152] State Fair recruitment occurred on August 23 and September 3, 2018 during two shifts at the D2D research facility. Via a brief survey, prospective participants provided demographic information (age and year of birth, race/ethnicity, education, and zip code), if they had seen a clinician in the past 12 months (yes or no response options), and an email address or telephone number for scheduling interviews. At the Fair, prospective participants were offered an incentive for completing the survey (a UMN drawstring backpack). Following recruitment at the D2D facility, eligible women were contacted to schedule interviews.

In addition to recruitment at the State Fair, I placed flyers around the UMN-Twin Cities East Bank campus in multiple locations including Boynton Health Services (a clinic and pharmacy at UMN) and Coffman Memorial Union (a student union). I also contacted 31 student groups and sororities via email to let their membership know about the study. Those who completed interviews were invited to pass on the study information within their social networks.

4.3 Guide Development and Testing

The draft interview guide used an open-ended interview prompt for the first part of the interview and adapted the multi-scenario format seen in tools like the Autonomy Preference Index into a qualitative card sort exercise.[30] Three scenarios describing women's health conditions with varying clinical severity and uncertainty regarding treatment choice were selected for the card sort exercise: painful periods, diagnosis of polycystic ovary syndrome (PCOS), and recurring ovarian cysts. The conditions are linked by the use of hormonal contraception as a potential treatment/management option. The clinical scenarios were written with the aid of clinical guidelines and patient guides.[132,153-158] They were also reviewed by a practicing gynecologist.

Successful card sort exercises require choices that are both clear and meaningful to participants. Consequently, I adapted the card choices from Degner and Sloan's (1992) five statements on decision-making preferences. The card choices and corresponding decision-making styles are shown in Table 5.

Table 5. Card Sort Decision-making Choices

Decision-making Style	Card Statement
Passive	I prefer to leave all decisions regarding my treatment to my doctor.
Passive-shared	I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
Shared	I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
Active-shared	I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.
Active	I prefer to make the final decision about which treatment I will receive.

The language of the guide and the structure of the interview were piloted with seven volunteers. This process ensured that the narrative prompt was clear and not overly broad, all questions were clearly worded, and that the allotted time for the interview was reasonable. Guide testing was an iterative process. Each test was recorded and transcribed and adjustments to guide content and structure were made after each test. Based on the testing, prompts about the role of time were modified to have a broader conversation about the role of time in health care decision-making. In addition, a prompt about the role of familiarity with clinicians was added to reflect the role of the patient-clinician relationship in health care decision-making. Refinement of the guide was done in consultation with an expert in qualitative methodology. The final interview guide is available in Appendix D.

4.4. Final Interview Format

The interview format combined narrative and semi-structured interview methods. As qualitative research requires trust and respect between participant and interviewer, participants were able to ask questions throughout the interview and stop the interview at any time.[159] The first section was a brief, introductory interview about experiences with making health care decisions and general preferences for health care decision-making. The second section was a card sort exercise where participants were asked to discuss their decision-making preferences as the variable of clinical severity changed.

4.4.1 Introductory Interview

The first part of the interview began with a prompt consistent with narrative interviewing methodology. Good quality narrative interviews require that the process is participant driven.[144,159] The primary role of the interviewer is to be a supportive listener while the interviewee shares their lived experience.[160] The interviewee is telling a story, which represents their subjective perception of their experiences.[144,161] To encourage participants to tell their stories, I started with an open-ended question about previous experiences with health care decision-making, specifically related to a gynecological issue. After the participant shared their initial experiences, I used sub-prompts to further probe what they had shared and clarify specific aspects of their experiences.[143,162] Following the discussion of their previous experiences, I showed the participant the card choices for the card sort exercise to determine their baseline preferences for health care decision-making.

The purpose of the first section of the interview was to help with the execution and interpretation of the card sort exercise. Previous research shows that patients can struggle with anticipating their needs or how they will actually react to events when they are presented with hypothetical choices.[163] Participants may experience projection bias, where their current state influences their projections about future preferences.[164] Affective states (e.g., pain, anger, sadness, hunger) can influence predictions as individuals can struggle with identifying how they will feel in the future about one affective state when they are currently in another.[164]

Individuals can experience issues with forecasting when they are asked to anticipate their specific health behaviors (e.g., substance abuse patients choosing between maintenance treatment or cash) or treatment decisions (e.g., end of life care decisions).[163-165] In the card sort exercise, participants were not asked to choose between treatment options or health behaviors, but were asked to anticipate how they wanted to approach decision-making for scenarios involving different affective states. The introductory interview allowed participants to express and interpret their previous experiences in health care decision-making,[159] providing an opportunity to briefly explore experiences with decision-making in other affective states. Centering the participants on previous clinical experiences helped them to focus on their "lived experiences" and address the potential limitations of forecasting in the card sort interview. The narrative interview also provided an opportunity for me to establish a rapport with participants prior to the card sort exercise.

4.4.2 Card Sort Exercise

Prior to the start of the card choice exercise, participants were told about the three scenarios (painful periods, PCOS, and recurring ovarian cysts) and specifically asked if they had experience with any of the conditions. They were then given a description of the first clinical scenario. To avoid feelings of "test anxiety", I adapted a conversational tone with participants and reassured them prior to the exercise that there were no right or wrong answers.[166] I also used physical cards in lieu of an online tools to allow for an interactive, tactile experience. After reading the scenario, the participant was asked to sort the five card choices representing passive, passive-shared, shared, active-shared, and active decision-making from most preferred to least preferred. This process was then repeated for the second and third scenarios. I shuffled the cards prior to each scenario to ensure that they were in a random order when given to participants.

A significant challenge in card sort exercises is eliciting the reasoning of participants as they make choices.[166] To address this, participants were encouraged to think out loud as they make selections to gather data on the stream of consciousness of the decision-making process.[166] I also used prompts to probe why they laid the cards out in a particular order and what their most preferred and least preferred cards looked like in terms of interaction with the clinician. Participants were also asked what the “share responsibility” scenario looked like or meant to them. To assess the relationship between time and decision-making preference, participants were asked about how time factors into their health care decision-making preferences. Participants were also asked about the role of familiarity with health care providers. At the conclusion of the interview, I offered a brief recap of what we discussed, and asked if there was anything additional participants would like to share.

4.5 Participant Preparation and Informed Consent

To prepare participants, I sent an email prior to the interview asking them to consider their experiences with making decisions about health care, specifically related to a gynecological issue. This prepared them to engage in the open style of the first part of the interview. The email also included a study information and consent document that provided information on the purpose of the interview, time commitment, and modality as well as information regarding data privacy.

Prior to the beginning of each interview, written informed consent was obtained from each participant. Participants were able to ask questions or raise concerns anytime during the interview process. Participants were also free to pause or stop the interview at any time.

4.6. Data Collection and Confidentiality

Each interview was audio recorded using a digital recorder. Written notes were not used during the interview to ensure engagement with the participant; however, I did complete a written record of card sort choices during the exercise. The interview location was a private office at UMN-Twin Cities. Participants were able to request an alternative location as long as this location was safe and private.

All interviews were assigned a code for tracking purposes (e.g., Interview PA1). To ensure privacy of participants, names or identifying characteristics were not used during interviews. To maintain confidentiality, names were changed in the reporting of results. Interviews were transcribed and transcripts were checked against audiotapes to ensure accuracy. All audio-recordings and transcripts were stored in a secure location for the duration of the study.

4.7. Data Analysis

Preferences for decision-making for each clinical scenario were quantitatively summarized. I calculated the most preferred decision-making style (based on the card that was most frequently ranked first for each scenario) and the average ranking for each card by scenario. I used conventional content analysis to qualitatively analyze both parts of the interview. This involves reading transcripts for each interview while examining the main aspects of each story and looking for common thematic elements.[159,167] For conventional content analysis, the codes were derived from the data and defined during the analysis process.[167] For both sections, I first read all transcripts to re-familiarize myself with the content of the interviews. A draft codebook was developed after a second reading of all transcripts using open coding. This allowed me to identify broad themes to form initial categories.[167,168] Additional codes were added as new elements and themes emerge from the text during subsequent readings.[167]

To ensure accuracy, a second reviewer followed the same process of reviewing transcripts and used open coding to identify themes using the draft codebook. The second reviewer identified additional themes as needed. The second reviewer and I then discussed our findings to form consensus on major themes. After completing open coding, I grouped together related codes as appropriate and developed definitions of each code and category in consultation with the second reviewer.[167] NVivo software was used for the analysis.

I separately examined the introductory and card sort interviews. The introductory interview analysis examined previous experiences with making health care decisions and baseline preferences for health care decision-making. the card sort interview analysis examined if a trend emerges in the selection of decision-making preferences across the scenarios and the motivations/thought process behind the ordering of cards.[167].

4.8. Reflexivity and Quality Criteria

Throughout the analysis process, I used reflexivity to address personal preconceptions (such as a personal preference towards SDM) that could introduce bias.[169] Reflexivity allowed me to reflect on preconceptions and personal experiences by asking what did I notice, why did I notice it, how can I interpret what I observed, how do I know that my interpretation is correct.[159,169] This process allowed for self-reflection and reduced the possibility of introducing my personal biases or experiences in the interpretation of data.[169]

The quality and rigor of the study was assessed using Lincoln and Guba's (1985) criteria: credibility, transferability, dependability, and confirmability.[140] Table 6 outlines the meaning of each criterion and the steps I took to meet them. To address credibility, a second investigator participated in the coding and analysis process ensure consensus about the interpretation of the data. Transferability was addressed by providing detailed descriptions so that readers and other investigators may consider if the findings can transfer to other types of participants or settings.[140,159] Dependability and confirmability were addressed by a clear audit trail with a transparent and detailed description of the steps taken for recruitment, data collection, and analysis.[140,159]

Table 6. Quality Criteria for Assessing Study

Criteria	Study Methods
Credibility: The extent to which the investigator accurately represents the reality of the participant and the meaning of their experiences.	A second reviewer participated in coding and analysis.

Transferability: The extent to which the findings are transferable (context of the original narratives should be preserved)	Reporting provides detailed descriptions.
Dependability: Research should be consistent and accurate, with a clear description of the process.	Reporting provides an audit trail that includes the research protocol and detailed methodology for data collection and analysis.
Confirmability: Reader should be able to understand how the investigator came to the findings included in the study. Reader should be able to evaluate that the findings are based on the data and not pre-conceptions.	Reporting provides an audit trail that includes the research protocol and detailed methodology for data collection and analysis. A second reviewer participated in coding and analysis.

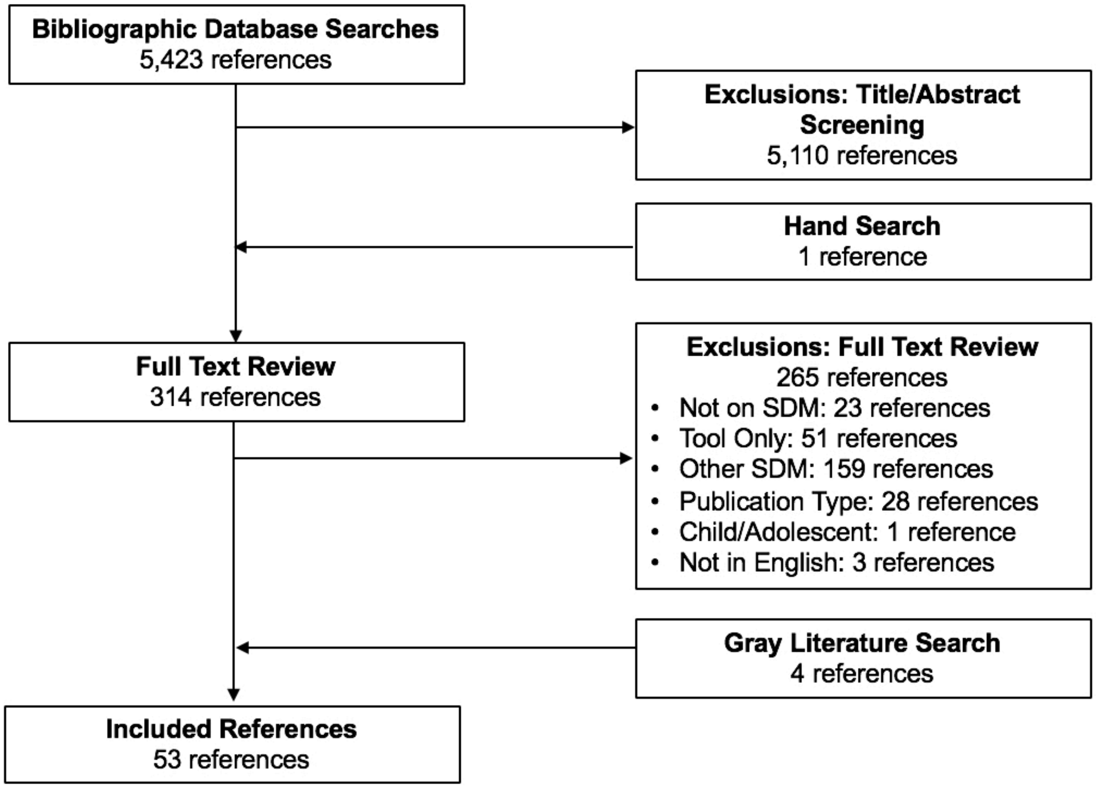
CHAPTER 5: DEFINING SHARED DECISION-MAKING

The goal of Aim 1 was to identify shared decision-making (SDM) models in both the peer reviewed and gray literature and synthesize the evidence to determine: 1) the common components of SDM, 2) operational definitions of these components, 3) the goals and objectives of SDM, 4) and the responsibilities of both patients and clinicians during the process. I also aimed to examine the extent to which models in the literature had been empirically tested, potentially linking the theoretical literature to empirical studies. The review findings are summarized below.

5.1 Search Results

The bibliographic database search identified 5,423 unique references (Figure 3). Title and abstract screening yielded 314 references for full text review. Hand searching identified one additional reference. Full text review yielded 49 references from the published literature eligible for our review. I also identified four additional references in the gray literature, resulting a total of 53 references. The most common exclusion reason was publications focused on other aspects of SDM such as measure validation studies or studies on stakeholder preferences. Appendix C provides a list of excluded publications.

Figure 3. Literature Flow Diagram



5.2 Models of Shared Decision-making

I identified 45 unique SDM models from 53 references.[1,6,12,13,15,37,47,52,170-214] Table 7 summarizes the characteristics of the identified models by publication type. The majority of models (36%) were from narrative reviews. Nearly all (96%) included models outlined components for the SDM process. The three models that did not provide components outlined SDM steps in the context of clinician or patient responsibilities.[47,187,203]

Twenty-three models considered the inclusion of family or caregivers and/or a care team in the SDM process. However, most models only briefly acknowledged that SDM could involve more than just the clinician-patient dyad.

Only one publication specifically presented an SDM model designed for a care team.[185] An additional publication examining SDM in care for dementia patients considered the perspectives of patients, caregivers, and members of the care team.[177] Seventeen models (38%) were categorized as "clinician driven", meaning that all of the steps of SDM were clinician initiated.[15,37,52,176,178,184,185,187,193,194,197,199-201,204,206-209,214] Empirical data on the efficacy of SDM was only available for ten models. All reported measures related to the SDM process. Fived reported patient outcomes and seven reported health care utilization.

Nine models were rated as high quality,[15,177,179,180,190,191,198,206,209,211] 22 were rated as medium,[1,12,13,37,47,52,170-172,174,175,178,184-186,189,192,193,195-197,204,208,210,212,213] and 12 were rated as low.[6,173,176,181-183,188,194,201-203,205,207,214] Two were not assessed for quality because they were Delphi studies, which did not have clear quality criteria for assessment.[187,199,200]

Table 7. Summary of Included Models by Publication/Study Type

	SRs	NRs	RCTs*	CCTs	Obs	Qual	Delphi	Gray	Total
Models	3	16	7	1	2	10	2	4	45
SDM Elements									
Components	3	15	7	1	2	9	1	4	42
Definitions	1	15	2	1	1	8	1	3	32
Goals or Objectives	1	5	2	0	0	0	0	1	9
Clinician Responsibilities	0	9	2	0	1	4	2	3	21
Patient Responsibilities	0	5	0	0	0	3	0	0	8
Model Characteristics									
Includes Family/Caregivers	2	11	1	0	0	5	1	3	23
Includes Care Team	1	8	5	0	1	4	1	3	23

Provider Driven	0	5	4	0	1	2	2	3	17
Outcomes Measured									
SDM	0	0	6	1	1	1	0	0	9
Patient	0	0	6	1	0	0	0	0	7
Health Care Utilization	0	0	3	1	0	1	0	0	5
Quality Assessment									
High	1	1	1	0	0	5	0	1	9
Medium	1	13	2	0	1	4	0	1	22
Low	1	2	4	1	1	1	0	2	12
Not Assessed	0	0	0	0	0	0	2	0	2

*Includes clustered RCTs
CCT=Controlled Clinical Trial; Gray=Gray Literature; NR=Narrative Review, Obs=Observational Studies; RCT=Randomized Controlled Trial; Qual=Qualitative; SR=Systematic Review

5.2.1 Clinical Context and Other Factors

Table 8 summarizes the clinical context/setting of the identified SDM models. Some studies covered multiple populations and/or settings. Fourteen (31%) models did not focus on a specific clinical population or setting when outlining SDM. The remaining models focused on a range of clinical contexts including mental health care (20%), care specific chronic conditions (13%), and outpatient/primary care (11%). While one model was in the context of maternity care, there were no models broadly focused on SDM and young women. Two publications specifically examined SDM with African American patients.

Table 8. Clinical Context by Publication/Study Type

	SRs	NRs	RCTs*	CCTs	Obs	Qual	Delphi	Gray	Total
None Specified	1	8	0	0	0	1	0	4	14
Acute Care	0	1	0	0	0	0	0	0	1
Chronic Condition Care	0	2	1	0	0	3	0	0	6
Outpatient/ Primary Care	0	1	1	0	1	2	0	0	5
Inpatients/	0	1	0	0	0	0	0	0	1

Hospitals									
Nursing Care	1	0	0	0	0	0	0	0	1
Mental Health Care	0	1	4	1	1	2	0	0	9
Maternity Care	0		0	0	0	0	1	0	1
Cancer	0	1	1	0	0	2	0	0	4
Neurologic Condition	0	1	0	0	0	1	0	0	2
African American Patients	1	0	0	0	0	1	0	0	2
LGBTQ Patients	1	0	0	0	0	0	0	0	1
Older Adults	0	0	0	0	0	1	1	0	2

*Includes clustered
CCT=Controlled Clinical Trial; Gray=Gray Literature; NR=Narrative Review, Obs=Observational Studies; Randomized Controlled Trial; Qual=Qualitative; SR=Systematic Review

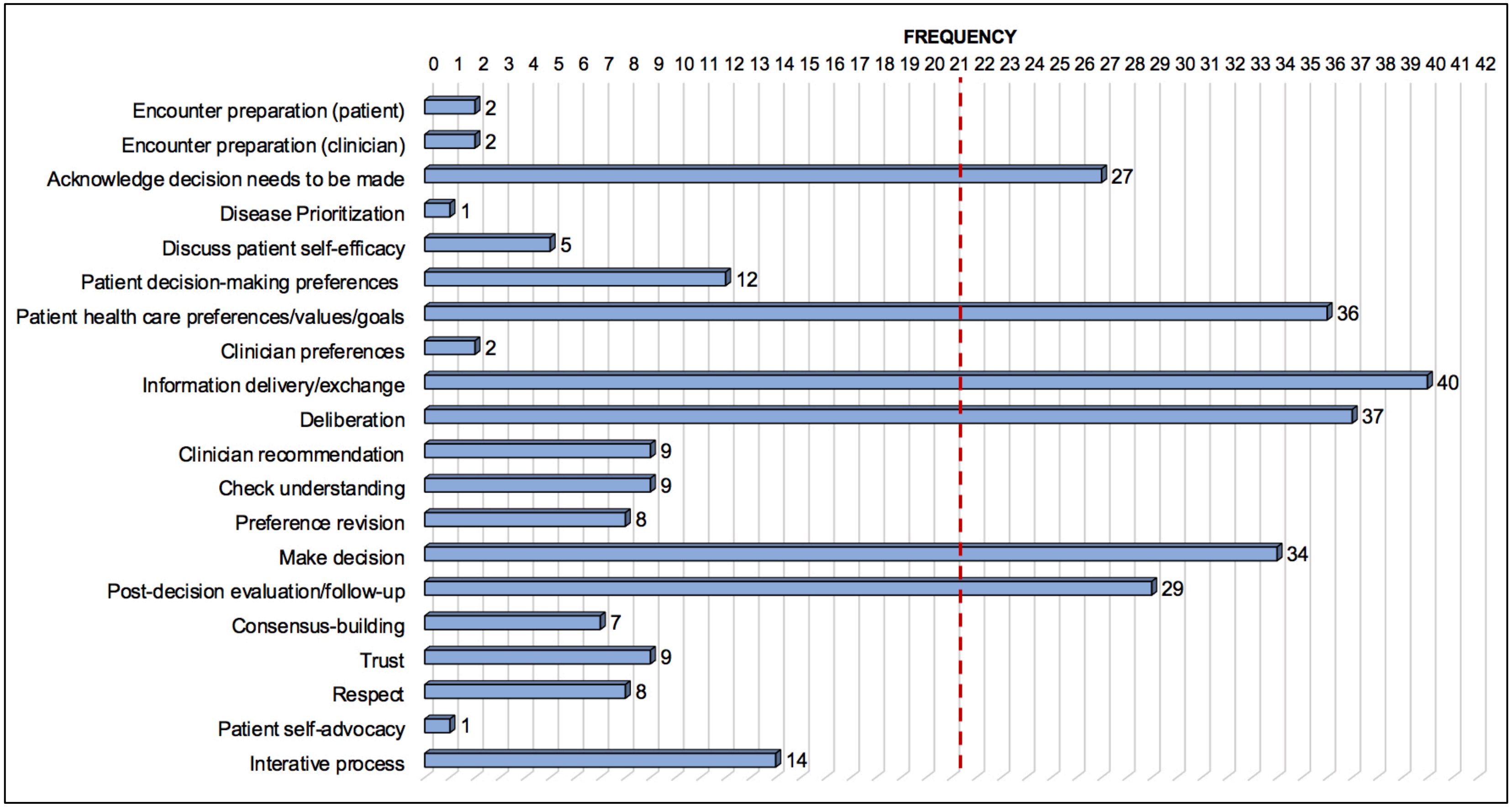
Eleven models (28%) discussed additional contextual factors that could influence the SDM process.[1,12,13,15,171,173,174,178,184,185,189,191,195,196,198-200] These included patient factors (e.g., beliefs, emotions) and clinician factors (e.g., receptiveness) as well as factors related to the clinical encounter and the health care system. Available time was mentioned by five models as a contextual factor.[1,12,13,15,198-200] Additional details on characteristics of the models including factors potentially influencing the SDM process are provided in Appendix B.

5.3 Components of Shared Decision-making Models

Forty-two models from 50 publications outlined components of the SDM process.[1,6,12,13,15,37,52,170-186,188-202,204-214] Ten models were assessed as high quality, 21 were medium, and 10 were low. One was not assessed for quality because it was a Delphi study (no clear quality criteria for assessment). I identified 20 unique components of the SDM process. Figure 4 shows each component and the frequency of the component across the 42 models. The dotted red line indicates the point at which a component is defined as “common” (included in at least 50% of the 42 models). SDM components by model are provided in Appendix B.

Six components were common: acknowledging that there is a decision to be made and there are options; patient preferences, values, or goals; information delivery/exchange, deliberation; making a decision; and post-decision evaluation and follow-up. The most frequently mentioned component was information delivery/exchange, followed by deliberation. Notably, six models did not explicitly include a specific step for discussing patient health care preferences, values, or goals, a step which is typically considered to be a hallmark of SDM. However, these models did include a step for information exchange where patients could share concerns.[172,189,190,195,196,198]

Figure 4. Frequency of Components in Shared Decision-making Models



5.4 Definitions of Common Components

Definitions for the six common components were synthesized from 32 models in 38 publications.[1,12,13,15,37,52,170-174,176-178,181-185,188,190-192,195-202,204,205,207,209-211,213] Eight models were assessed as high quality, 16 as medium, and 7 as low. One was not assessed for quality because it was a Delphi study (no clear quality criteria for assessment). Table 9 provides the operational definition of each component, and the number of models contributing to each definition. While the definitions are written in terms of a patient-clinician dyad, components may involve family members or caregivers as well as multiple members of the care team.

Table 9. Operational Definitions for Common Components

Component (Number of Models)	Operational Definition
Acknowledging that there is a decision to be made and there are options (N=22)	-Both patient and clinician recognize that they have reached a decision point; clinician may need to initiate. -Clinician states that there are multiple options available to patient and lays out all relevant options (including the option to do nothing when appropriate). -Clinician asks/invites patient to participate in decision-making process.
Patient preferences, values, or goals (N=27)	-Patient states preferences and values based on decision-point and initial discussion of options; clinicians may need to initiate and ask about preferences. -Patient and clinician discuss patient's goals for care, including patient's expectations, fears, and priorities.
Information delivery/exchange (N=31)	-Clinician shares technical information about options and risks and benefits of options with patient. -Information is delivered in the patient's preferred format and tailored based on their preferences and values (decision support tools may be used) -Patient shares additional information on preferences, values, and goals based on technical information provided. -Both clinician and patient ask questions to clarify information as needed.

Deliberation (N=30)	-Patient and clinician engage in joint discussion of options while considering the potential benefit and harms and the preferences of the patient. -Patient and clinician negotiate a mutually satisfactory decision.
Making a decision (N=25)	-Patient or clinician initiate finalization of a decision/plan. -Mutually acceptable decision/care plan is determined (including the option to do nothing when appropriate) or decision is deferred.
Post decision-evaluation and follow-up (N=22)	-Clinician checks if patient is comfortable with decision (if not comfortable, more time and deliberation may be required). -Patient and clinician determine timeline for follow-up. -Patient and clinician adjust decision/care plan as needed.

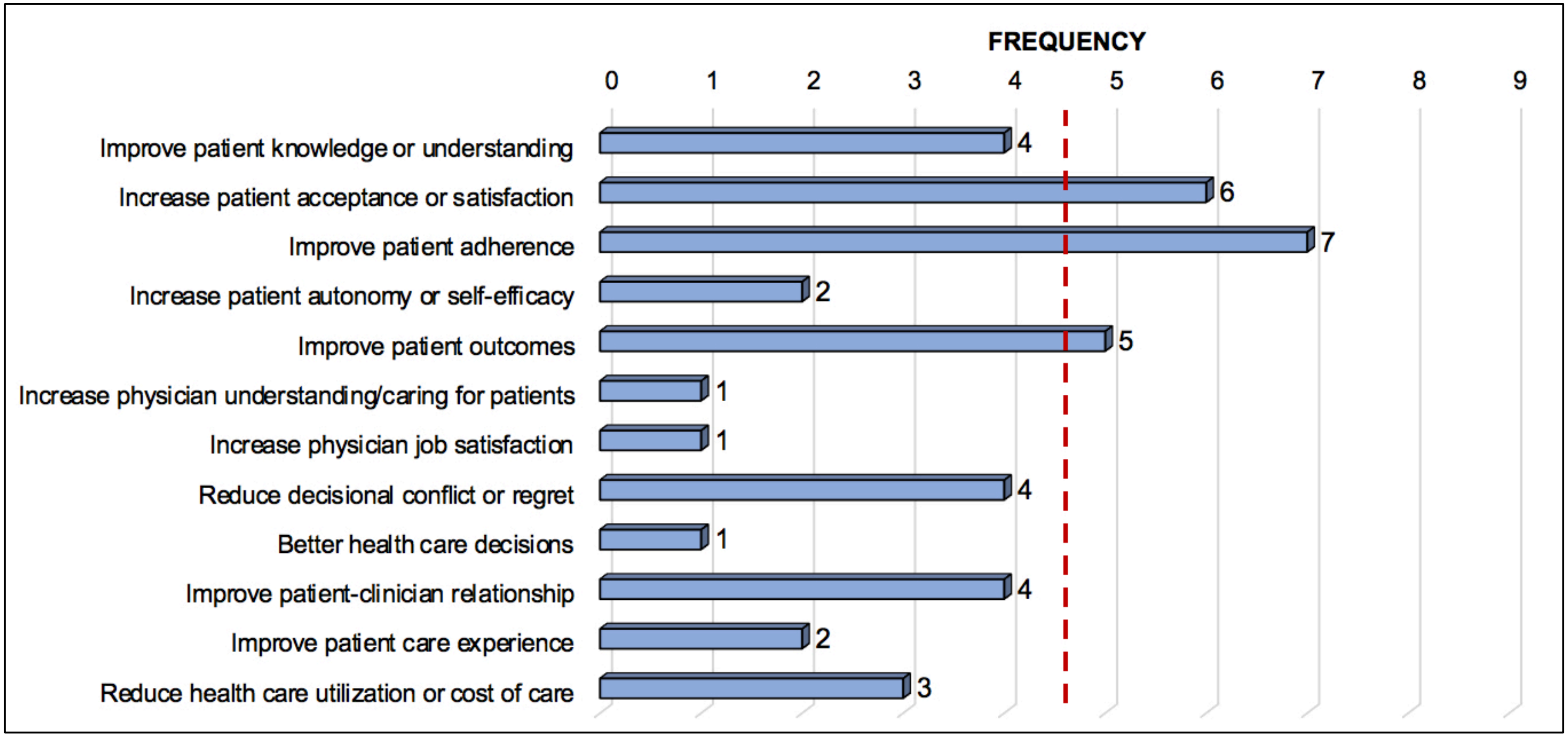
N=Number

5.5 Goals and Objectives of Shared Decision-making

Nine models from 11 publications provided information on goals and objectives of SDM.[1,12,170,186,189,191,196,197,201,204,212] One model was assessed as high quality, 6 were medium, and 1 was low. One was not assessed for quality because it was a Delphi study (no clear quality criteria for assessment). For all models, projected outcomes and benefits of SDM were taken as proxy for goals and objectives of the process. Discussion related to these concepts was limited, and none of the models extensively reviewed the conceptual link between SDM and projected outcomes or benefits.

Figure 5 lists the frequency of goals and objectives in the literature. I identified 12 unique goals and objectives. Three goals and objectives were common across models: improve patient outcomes, improve patient adherence, and increase patient acceptance or satisfaction. Three goals and objectives were included less than 50% of the time but were found in 44% of the models: improve patient-clinician relationship, reduce decisional conflict or regret, and improve patient knowledge or understanding. Nearly all of the models focused largely on benefits to patients after engaging in SDM, with the exception of one which included improved clinician job satisfaction as a potential goal of SDM.[189] Goals and objectives by model are provided in Appendix B.

Figure 5. Frequency of Goals and Objectives in Shared Decision-making Models



5.6 Responsibilities for Shared Decision-making

5.6.1 Clinician Responsibilities

Twenty-one models from 25 publications provided information on clinician responsibilities for SDM.[1,12,15,37,47,52,170,176,178,184,185,187,193-197,199-201,203,204,206,207,209] Three models were assessed as high quality, 11 were medium, and 5 were low. Two were not assessed for quality because they were Delphi studies (no clear quality criteria for assessment). I identified 22 unique clinician responsibilities, which are listed in Figure 6. The clinician responsibilities encompass the entire process of SDM, including the six common components. As previously noted, 38% of SDM models were clinician-driven, outlining the entire SDM process in terms of tasks for clinicians (e.g., clinician initiates conversation, clinician elicits preferences, clinician provides information). Only two responsibilities were in at least 50% of models reporting clinical responsibilities: eliciting patient health care preferences and sharing information (including information about options) with patients. These responsibilities align with the common components of patient values, preferences, and goals and information delivery/exchange. Clinician responsibilities by model are provided in Appendix B.

5.6.2 Patient Responsibilities

Eight models from nine publications provided information on patient responsibilities for SDM.[1,12,47,170,172,195,196,203,209] One model was assessed as high quality, six were assessed as medium, and one was assessed as low. From these models, I identified 10 unique responsibilities for patients. The relative infrequency of patient responsibilities compared to clinicians is most likely a consequence of 38% of the identified models being provider driven. As shown in Figure 7, only one patient responsibility was common: share information (e.g., symptoms, personal history) and health care preferences with clinicians. The overlap between patient and clinician responsibilities suggest that the SDM components of information exchange patient preferences/values/goals are joint obligations of both clinician and patient. Patient responsibilities by model are provided in Appendix B.

Figure 6. Frequency of Clinician Responsibilities in Shared Decision-making Models

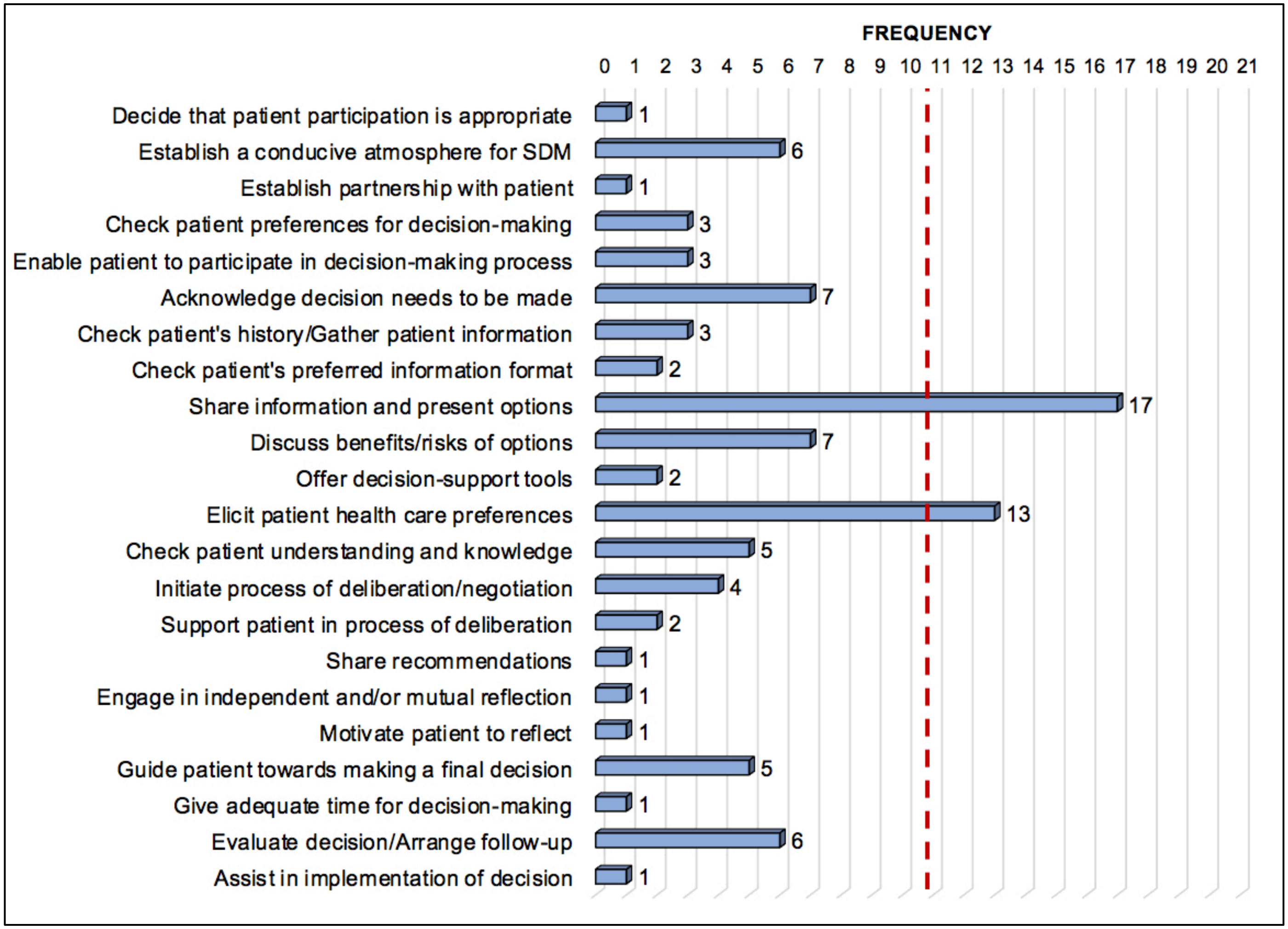
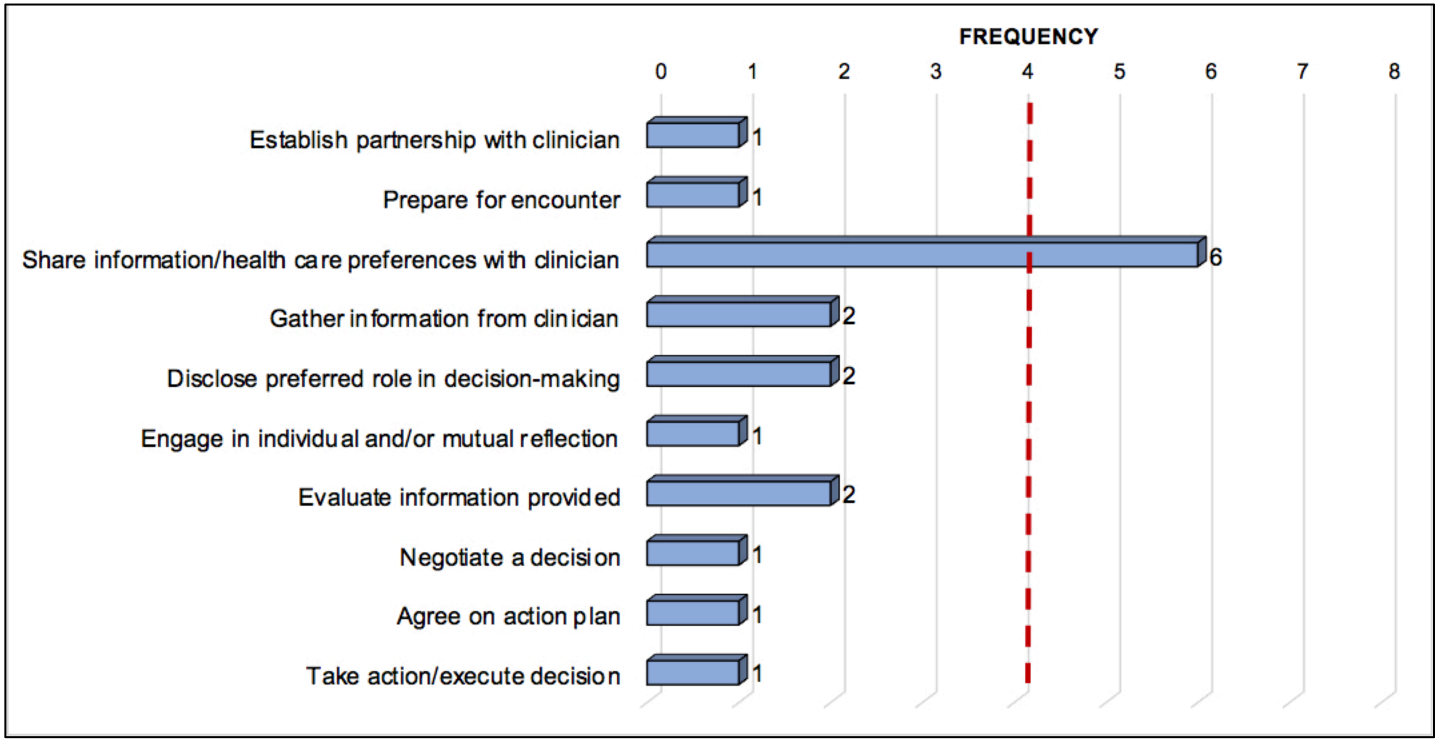


Figure 7. Frequency of Patient Responsibilities in Shared Decision-making Models



5.6 Empirical Studies of Shared Decision-making Models

There was insufficient evidence to assess the efficacy of SDM models and the extent to which the components, goals/objectives, and responsibilities are supported by empirical evidence. Ten studies from 13 publications tested the efficacy of SDM models.[175,179-181,183,186,188,194,201,202,208,212,214] Seven studies were RCTs (of which four were clustered RCTs), one study was a CCT, one study was an observational study, and one study was qualitative. Study quality was a significant concern. Five clinical trials and the observational study were rated as low quality due to concerns about risk of bias from attrition, selection, or selective reporting.[181,183,188,194,201,202,214]

All of the studies used SDM models that were created or adapted by study investigators and not based on a single existing SDM framework. Consequently, I was unable to match these models with other theoretical frameworks. All of the clinical trials compared SDM to usual care. One RCT also compared SDM to clinician-led decision-making. Six studies focused on SDM in the context of mental health care; three in inpatient mental health clinics, [179-181,183,202] and three in a community mental health clinic.[175,186,212,214] Sample sizes were small to moderate size, ranging from 24 to 408 participants.

None of the identified studies compared different SDM models to each other or examined the importance of individual components. Nine studies reported SDM process-related outcomes (e.g., satisfaction, knowledge), seven reported patient health outcomes, and five reported health care utilization. However, there was little overlap between the measures used. Overall, findings were mixed with some studies finding no difference between SDM and usual care groups in most outcomes measured. Only one CCT found differences favoring SDM in nearly all outcomes measured; however, the study was assessed as low quality due to potential bias from participant selection and attrition, and selective reporting.[202] Appendix B provides information on the findings for each study.

5.7 Assessment of Confidence in Evidence and Process Model for Shared Decision-making

Table 10 summarizes the assessment of confidence in findings. While there is moderate confidence in findings for the common components identified in the literature, there is only low confidence in the findings about the responsibilities patient and clinicians have in SDM and very low confidence in the findings about the goals and objectives of the models. Study quality was a moderate concern for all findings as most models were assessed as medium quality. There were moderate to serious concerns about relevance, coherence, and adequacy of data for the findings on goals/objectives and responsibilities due to variation in the evidence base and limited reporting in the literature.

Table 10. Assessment of Confidence in Evidence

Finding	Overall Assessment
The common components of SDM are acknowledging that there is a decision to be made and there are options; patient preferences, values, or goals; information delivery/exchange; deliberation,	Overall Assessment: Moderate confidence *Methodological Limitations:* Moderate concerns due to quality assessment of relevant studies. *Relevance:* No to very minor concerns.

making a decision; and post-decision evaluation and follow-up.	*Coherence:* Minor concerns due to variation in the literature. *Adequacy:* No to very minor concerns.
The primary goals and objectives of SDM are to improve patient outcomes, improve patient adherence, and increase patient acceptance or satisfaction.	Overall Assessment: Very low confidence *Methodological Limitations:* Moderate concerns due to quality assessment of relevant studies. *Relevance:* Serious concerns as findings are based on limited subset of evidence base. *Coherence:* Serious concerns due to variation in the literature. *Adequacy:* Serious concerns due to lack of reporting in literature.
In SDM, clinicians have the responsibility to elicit patient health care preferences and share information, including information about options, with patients. In SDM, patients have the responsibility to share information (e.g., symptoms, personal history) and health care preferences with clinicians.	Overall Assessment: Low confidence *Methodological Limitations:* Moderate concerns due to quality assessment of relevant studies. *Relevance:* Moderate concerns as findings are based on limited subset of evidence base. *Coherence:* Moderate concerns due to variation in the literature for both patient and clinician responsibilities. *Adequacy:* Serious concerns due to lack of reporting on patient responsibilities.

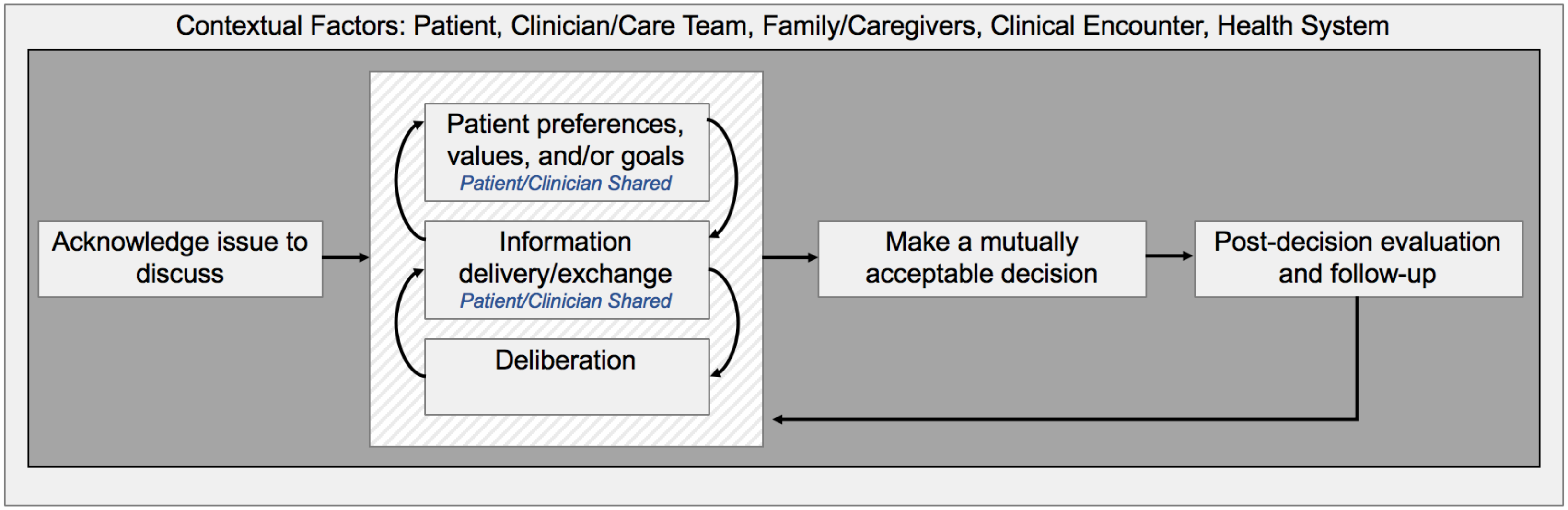
SDM=Shared Decision-Making

I was not able to assess the extent to which SDM models and their component components, goals/objectives, and responsibilities are supported in the empirical literature; however, there is sufficient confidence in evidence regarding the identification of common components to inform a process model of SDM. Figure 8 depicts an SDM process made of the six common components I identified in the literature. The process is defined within the clinician-patient dyad as only one publication explicitly outlined a team-based model of SDM. However, as noted by the majority of models found in the literature, care team members and family/caregivers may participate in the SDM process. Both are listed as contextual factors within the model.

Based on the operational definitions (Table 9), the discussion of patient preferences, values and/or goals; information delivery/exchange; and deliberation are depicted as non-linear as these processes may feed into one another (e.g., information delivery from clinician may cause patients to express additional preferences, deliberation may result in in more information exchange). Post-decision evaluation and follow-up may lead to re-engaging in the process of deliberation (and consequently discussion of preferences and information exchange/delivery). The process is housed within a broader set of contextual factors (from the patient, clinician, caregiver/supports, clinical encounter, and health system); all of which may influence the process.

Given the limitations of the data related to goals/objectives I have not included any expected outcomes for the process. However, with the overlap between patient and clinician responsibilities related to information exchange and patient preferences, values, and goals, the model includes a notation that these steps are the shared responsibility of patient and clinician.

Figure 8. Common Component Process Model for Shared Decision-making



CHAPTER 6: PREFERENCES OF MILLENNIAL WOMEN

The purpose of the interviews was to examine the health care decision-making preferences of millennial women when considering the variables of clinical severity (Aim 2) and time with clinicians (Aim 3). I conducted 35 interviews with millennial women residing in Minnesota. Ten of the 35 women were recruited from the Minnesota State Fair. The remaining women were recruited from the University of Minnesota-Twin Cities campus. A qualitative methodology was used to determine preferences and understand the underlying motivations behind these preferences. The findings from the interviews are summarized below.

6.1 Participant Characteristics

The characteristics of interview participants are provided in Table 11. The mean age of participants was 25. Approximately 29% of the participants identified as non-White and 9% were of Hispanic ethnicity. Almost 50% of participants had a bachelor's degree. All of the participants with a high school diploma or some college were in the process of obtaining a bachelor's degree. The mean interview length was 46 minutes (range: 29 to 71 minutes). Of the three clinical conditions used for the card sort exercise, the most commonly experienced condition was painful periods (57%). Few participants sought medical care for painful periods, instead opting to use over-the-counter medication. There was limited experience with polycystic ovary syndrome (PCOS) and ovarian cysts among participants.

Table 11. Participant Characteristics

Mean Age (Range)	25 (18-36)
Race % (N)	
White	71% (25)
Black or African American	3% (1)
Asian	17% (6)
Multiracial	3% (1)
Other	6% (2)
Hispanic Ethnicity % (N)	
Yes	9% (3)
No	91% (32)
Education % (N)	
High school diploma or GED	6% (2)
Some college, no degree	26% (9)
Bachelor's degree	46% (16)
Graduate or professional degree	23% (8)
Clinical Experiences % (N)	
Painful Periods	57% (20)
PCOS	3% (1)
Ovarian Cysts	11% (4)

6.1.1 Previous Health Care Decision-making Experiences

The introductory interview asked participants about their previous health care decision-making experiences. The purpose of this was to prepare participants to forecast their preferences in the card sort exercise. This also allowed me to establish a context for decision-making preferences identified during the card sort.

During the narrative interview, 12 participants (34%) discussed experiences related to birth control, including the insertion or removal of intrauterine devices, and 4 (11%) discussed experiences related to pap smears, including having an abnormal pap smear. Two participants discussed experiences related to ovarian cysts, and one shared an experience related to PCOS. The remaining participants discussed a range of clinical issues (e.g., vaginal infection or discomfort, chronic pelvic pain, amenorrhea).

When asked about the decision-making process for the experience they shared, 21 participants (60%) stated that they had made the decisions, 11 (31%) stated that the clinician had made the decisions, and 3 (9%) stated that the decisions were shared between them and the clinicians. Twenty-three participants (66%) felt that they had sufficient time with their clinician. Participants' expectations of clinicians during these encounters included that the clinician treat them with respect, be free of judgement, listen to and address their concerns, and provide accurate clinical information.

6.1.2 Baseline Health Care Decision-making Preferences

In the first part of the interview, participants were also presented with the card sort choices to determine their baseline health care decision-making preferences (without considering a specific clinical scenario). The card statements (shown in Table 5) represented passive, passive-shared, shared, active-shared, and active decision-making styles. When presented with the choices, the majority of participants (25, 71%) selected active-shared as the decision-making style that best reflected their preferences in general. Of these 25, 7 participants stated that shared decision-making (SDM) was also a preferred decision-making style. Agency over one's body and health care decisions was a primary motivating factor. Participants voiced the desire to make decisions over their own bodies. As one participant indicated:

> *"Since these are decisions about my body and **I'm the one who knows my body, I should be making the final decisions**."*
> Kristy, Age 22 (PA14)

Past experiences and mistrust of clinicians also played a role in forming a strong sense of personal agency in participants. Participants cited poor previous experiences when seeking medical care as a reason to retain control over their health care decisions. Dawn, who had an experience where a male clinician dismissed her pain stated:

> "*Well, **I've had some bad experiences with doctors, so I don't always trust their like final treatment plan**. So, if I feel like more needs to be done, I probably trust my own opinion more and try and fight for it. If I don't feel like they're doing it right."*
> Dawn, Age 19 (PA 27)

However, participants also recognized the expertise of clinicians and the importance of receiving medical information from them. Those who favored the active-shared approach, generally viewed the role of a clinician as providing information so that patients could make informed decisions. In explaining the role of the clinician, one participant commented:

> *"I think just the idea that I'm the one deciding what happens to my body or what goes into my body or anything like that. I would I want to be the decision maker, but I do know that I'm not an expert and so I you know, **I think the role of a doctor is, or any health care provider, is to inform their patients and educate and, you know, give the patient's all the information that they need to know to make that decision**."*
> Stacey, Age 25 (PA18)

6.2 Decision-making Preferences and Clinical Severity (Aim 2)

The goal of Aim 2 was to examine how decision-making preferences were influenced by clinical severity. Table 12 shows the five decision-making styles (active, active-shared, shared, passive, passive-shared) and the number of women who preferred the style (ranked the choice first in the card sort) for the clinical scenarios. For painful periods, 25 women (71%) selected active-shared as their most preferred decision-making style. This was consistent with the discussion of baseline health care decision-making preferences during the introductory interview.

However, for both PCOS and recurring ovarian cysts, the more preferred decision-making style was SDM. This indicates that as the scenarios became more severe some participants were willing to share power with clinicians and shift away from their baseline preference. However, most participants do not want to give most (passive-shared) or all (passive) decision-making power to clinicians.

Preferences became more diffuse as clinical severity increased from painful periods to PCOS. For painful periods, 32 women (91%) preferred either active-shared or SDM. For PCOS, 28 women (80%) preferred active-shared or SDM, three preferred active (9%), and four (11%) preferred passive-shared. From PCOS to recurring ovarian cysts, preference for active-shared or shared increased, with 30 women (86%) preferring one of the two decision-making styles. The number of women who preferred active decision-making decreased to one (3%). One participant most preferred a passive decision-making approach for recurring ovarian cysts, the only instance where any participant ranked passive decision-making as most preferred.

Table 12. Number of Women Who Preferred Each Decision-Making Style by Scenario

	Active N (%)	**Active-Shared N (%)**	**Shared N (%)**	**Passive-Shared N (%)**	**Passive N (%)**
Painful Periods	2 (6%)	25 (71%)	7 (20%)	1 (3%)	0 (0%)
PCOS	3 (9%)	11 (31%)	17 (49%)	4 (11%)	0 (0%)
Recurring Ovarian Cysts	1 (3%)	14 (40%)	16 (46%)	3 (9%)	1 (3%)

During the card sort exercise, each decision-making style was ranked from 1 to 5, with a ranking of 1 indicating that the decision-making style was most preferred. Examining the mean rankings provides insight into the deliberation of participants. As shown in Table 13, there is an inflection point at participants' third preference where they are choosing to either retain all decision-making power or cede some power to clinicians. For painful periods, participants most preferred active-shared followed by SDM. When faced with the choice of making the decision themselves or ceding some power to clinicians, participants ranked active decision-making third over passive-shared. This changes when clinical severity is increased. For both PCOS and recurring ovarian cysts, participants ranked passive-shared third, opting to share power with clinicians over making decisions themselves. Passive decision-making was the least preferred choice for all three scenarios.

Table 13. Mean Ranking for Each Decision-making Style by Scenario

	Active	Active-Shared	Shared	Passive-Shared	Passive
Painful Periods	3	1	2	4	5
PCOS	4	2	1	3	5
Recurring Ovarian Cysts	4	2	1	3	5

In examining the motivations behind decision-making preferences, a central tension emerged: the trade-off between personal agency and information asymmetry as clinical severity increased. These themes were consistent regardless of age and previous clinical experiences. Below I discuss participant views on both personal agency and information asymmetry, and how participants considered the trade-off between these factors as clinical severity increased.

6.2.1 Role of Personal Agency

Consistent with the themes that emerged during the discussion of general decision-making preferences, all participants expressed the importance of personal agency. Control over one’s body and health care decisions were central themes across interviews. Participants felt that health care decisions were personal and that they were in the best position to determine was best for them. For example, one participant discussed the personal nature of decisions around birth control:

> *“But, I think, **especially when you're talking about birth control, it's a very personal thing** and it kind of depends on what you're comfortable with, and how you can follow a treatment regimen.”*
>
> Claudia, Age 27 (PA 2, Painful Periods)

Another participant commented on the personal nature of making health care decisions and the importance of having control over their own body:

> *"Yeah, again, I think all health, but women's health in particular, and actually nutrition, lifestyle stuff in particular is, I just think is so personal* ***. People should always have control or input on their own bodies and their own health*** *."*
>
> Mary Anne, Age 34 (PA 15, PCOS)

The importance of personal agency over decisions was emphasized in the consideration of potential side effects and lifestyle changes. Participants stated that since they were the ones experiencing the side effects, they should be active participants in health care decision-making. Likewise, participants frequently discussed that they would be responsible for implementing any lifestyle changes and that they knew best what they could manage. One participant commented on the importance of being in control if there was potential for negative side effects:

> *"…* ***I want to be the one who's in control of that especially if it's a potentially negative side effect*** *, and I know my doctor would of course want to minimize that, but I still know my body better because I'm in it."*
>
> Stacey, Age 25 (PA 18, Painful Periods)

Another participant spoke to the responsibility required for patients make lifestyle changes:

> *"And* ***anytime lifestyle changes is a recommendation, that requires the patient to take on a whole lot of responsibility.*** *Either responsibility for making lifestyle changes or responsibility for acknowledging that there's been medical advice given that you're not following or choosing not to do or unable to do for a whole host of reasons..."*
>
> Mallory, Age 35 (PA 12, PCOS)

For many respondents, mistrust of clinicians was also an underlying factor in the desire to maintain control over health care decisions. This mistrust sometimes stemmed from a previous negative experience where the participant felt diminished by a clinician. Jessi who discussed that she felt dismissed by clinicians when trying to discuss mental health and period-related pain shared:

> *"And this doctor, whenever I would try to discuss about women's health, like painful periods, cramping, and like heavy flow, once in a while I also miss a period, they just would brush it off and be insensitive…And* ***it's actually really traumatizing for me because I actually have nightmares sometimes, and it makes me really nervous to go to a new provider****…"*
>
> Jessi, Age 23 (PA20, Painful Periods)

Several participants also expressed that their mistrust was rooted in the historic barriers and stigma women have faced when seeking care. Kristy who did not have direct experience with PCOS, but had read about women's difficulty with seeking care for PCOS commented:

> *"****I personally feel like the medical field has failed women with PCOS****, so I wouldn't be really interested in sharing much responsibility because of that previous knowledge in my head."*
>
> Kristy, Age 22 (PA14, PCOS)

Like Kristy, Abby spoke to a general understanding of the difficulty and barriers women may face when seeking health care, specifically commenting on pain management:

> *"****I know women historically are not believed when they're in pain****, and so with the leaving pain management up to my doctor, just seems like something that I would not want to do in this case."*
>
> Abby, Age 21 (PA23, Recurring Ovarian Cysts)

6.2.2 Role of Information Asymmetry

While participants desired agency over their health care decisions, all but one also acknowledged the importance of clinician expertise. Communication with clinicians to receive health care information was considered essential, even when participants did not want to yield most or all decision-making power to clinicians. Participants who preferred active-shared or shared saw their role as a decision-maker to filter and contextualize the information clinicians provided in terms of their personal needs and preferences. For example, one participant acknowledged the importance of obtaining a clinician’s opinion given that they were not an expert in gynecological issues:

> *“…I feel* ***like gynecological issues is not an area of my expertise. And so, I would want their opinion*** *knowing that there would be side effects for each I would want to weigh those side effects against what side effects I could handle.”*
>
> Shannon, Age 34 (PA8, Painful Periods)

Another participant commented that the objective of seeking medical care was to get the expertise of medical professionals:

> *“I guess because this is just a more complicated case, where if you aren't knowledgeable about what you were just diagnosed with and how to treat it, then* ***I think the reason that you go to the doctor is to get their expertise****.”*
>
> Blair, Age 23 (PA5, PCOS)

6.2.3 Tradeoff Between Personal Agency and Information Asymmetry

The theme of a tradeoff between a desire for agency over decisions and the information asymmetry between patient and clinician also emerged during the discussion of preferences. Severity played a significant role when considering this trade-off. Participants viewed painful periods as a less severe situation and consequently valued retaining agency over decisions. For example, Serena who had previous experience with painful cramps and heavy menstrual bleeding commented on the relative low severity of painful periods:

> *"Okay. I think I put the fact that I want the final decision about this treatment, specifically, is that like I said, I don't really, like I said,* ***I could be wrong, but I mean, painful periods suck, but they're not life-threatening****."*
>
> Serena, Age 22 (PA1)

Another participant indicated retaining agency over health care decisions was preferred for the painful period scenario due to the low severity and focus on pain management:

> *"Placing the final decision on me,* ***I feel a lot more comfortable with situations like this because it's not life or death. It's only going to be about my pain which of course is important to manage but it's not a huge weighted decision I have to make****. I don't feel it's necessarily for my doctor to share responsibility for that decision."*
>
> Jenny, Age 27 (PA6)

Moving from considering decisions for painful periods to decisions regarding PCOS, there was a shift towards wanting more input from clinicians. Participants were concerned about the dual diagnosis of PCOS and pre-diabetes and spoke about the fear and anxiety that they would feel. For some, this resulted in moving from active-shared to passive-shared, giving clinicians most of the decision-making power. The largest shift, however, was towards a preference for SDM. Participants expressed a greater desire for discussion with clinicians and collaboration to form consensus about treatment under the PCOS scenario than under the painful period scenario. SDM remained the most preferred choice for recurring ovarian cysts. Participants cited the importance of communication and collaboration to merge their viewpoint with that of the clinician. One participant commented on the importance of having consensus and clinician agreement, stating:

> *"I think the share responsibility was just I really want to be able to kind of get to a consensus about what the issue is. I feel a little bit less powerful in this matter, just because I feel the consequences are so severe.* ***I want to make sure that the physician agrees with that decision, and we just get to the best treatment option for me together****."*
>
> Georgina, Age 24 (PA25)

Another participant discussed the importance of open communication and understanding respective viewpoints:

> *"…I still think I'm* ***sharing the responsibility is the best here, that open communication and really understanding where each other are coming from in our opinions****."*
>
> Vanessa, Age 20 (PA22)

A number of participants also preferred active-shared decision making for the recurring ovarian cysts scenario; choosing to retain more decision-making power than clinicians. However, while participants had a favorable view of making decisions with input from clinicians, there were less favorable towards making the decisions completely by themselves when discussing recurring ovarian cysts. Concerns about information asymmetry and surgery made it less likely for participants to want to participate in active decision-making for ovarian cysts compared to painful periods or PCOS. One participant commented the importance of acknowledging their lack of personal knowledge about ovarian cysts:

> *"And then the very last one is that I prefer to make the final decision, because I know nothing. And* ***I still have to recognize that I know nothing about this****."*
>
> Serena, Age 22 (PA1)

Another participant discussed that they would not want to leave all decisions to the clinician, but the possibility of surgery did require clinician input:

> *"I would not leave all decisions regarding my treatment to the doctor. But I think with this one actually I would put the bottom one as I prefer to make the final decision about what treatment I will receive, partly because* ***I can't make an informed decision about surgery. I always need to have doctors involved with that****."*
>
> Mallory, Age 25 (PA 12)

6.3 Decision-making Preferences and Time (Aim 3)

The goal of Aim 3 was to examine how decision-making preferences were influenced by time with clinicians. There was not consensus amongst participants regarding the role of time in the formation of decision-making preferences; however, all participants emphasized the importance of time across all three clinical scenarios. Sufficient time was viewed as necessary component of a satisfactory and informative clinical encounter that allows patients to participate in health care decision-making. More complex and severe clinical situations underscored the importance of time to facilitate patient involvement in health care decision-making. Samantha, a participant who had previous experience with an ovarian cyst, commented on the role of time in making her feel like she was equally involved in decision-making:

> *"…I wish there was more time with health care providers,* ***because when they do have more time…my experience walking away from the appointment is so much better, and I feel like I've had a more equal share in my health care decision-making versus when I feel that appointment was rushed.*** *I don't feel like my questions were answered, and I feel like ultimately, I have to decide based on some literature maybe they printed out for me, what I'm going to do. And I don't have as much of an equal conversation that I would like…"*
>
> Samantha, Age 29 (PA33)

The idea of have insufficient time during an appointment did not usually change participants preferred decision-making style. Participants maintained a desire to participate in health care decision-making regardless of time. However, insufficient time did change their expectations for how the clinician would approach decision-making with them. Participants stated that with limited time they would feel pressured to give more power to the clinician and give less time to their own needs and preferences; forfeiting their personal agency. This was especially a concern when considering severe clinical conditions like recurring ovarian cysts. For example, one participant commented that insufficient time would give clinicians the power to create a treatment plan without her input:

> *"My guess would end up that my doctor would make the final decision and seriously consider my opinion because of the time crunch. Because my guess is that they'd be pressuring me to do it and they'd be like, 'Well, let's do this. I hear that you're saying this, but let's try this.'* ***So, I feel like with the time it makes me have less time to think about my decision that I would want to make and it gives them...that provider that power to say, 'No, this is what we're going to do.'"***
>
> Shannon, Age 34 (PA8)

Another participant stated that insufficient time would force her to make decisions for complex situations without considering her preferences:

> *“I think because the situation is really complex, it's going to take time for the doctor to explain this to me and for the doctor to lay out possible plans, possible treatments to me. If we don't have enough time for the appointment, I may not be able to express my own history and my preference.* ***I would kind of be forced to choose from one of the options without setting my own needs and without communicating effectively with the provider to come up with something that suits me the most****.”*
>
> Felicity, Age 24 (PA34)

While time was valued regardless of preferred decision-making style, it was considered especially important to those who preferred SDM. There was consensus that a shared approach would require sufficient time with clinicians in order to be successful due to the level of discussion required. Without sufficient time, participants stated that they would not be able to communicate their needs or preferences to clinicians. Kirsten, a participant who had a previous experience where a clinician did not fully inform her of her treatment choices, emphasized time pressure as a barrier to sharing responsibility for health care decisions:

> *“****Like the shared responsibility and being able to control your treatment, is only possible if the doctor's not pressing you for time, or the doctor is not pressed for time.*** *Like, yeah. So, there's less control when the doctors rushed, and you don't feel like you can really have a say in things, when there's no time to discuss what those options are.”*
>
> Kirsten, Age 26 (PA11)

Abby, a participant who stated that she would feel less satisfied with her decisions if there was insufficient time, noted the importance of time to support a shared approach:

> *“I think in this case. it would be again* ***hard like the longest conversation is the shared responsibility that places a lot of time burden on the discussion****, but that would ultimately be really important to me to have the shared responsibility.”*

Abby, Age 21 (PA23)

As the clinical severity of scenarios increased, participants considered how they would work around the barrier of a time-limited clinical encounter to achieve their preferred decision-making style. Several participants stated that they would address the issue of time pressure by scheduling follow-up appointments or going home to think about options before making decisions. One participant discussed that she would make a second appointment if she did not fully understand her diagnosis or treatment options:

> *"I feel like this is a…slightly more serious situation. I think I will still take my time and then make sure that I'm understanding, I'm fully understanding the situation, and I'm understanding the diagnosis that's given to me.* ***So yeah, time does play a factor but think regardless…I would be, if I need to, I will make a second appointment to actually understand the syndrome and the kind of complications and the treatment, the possible treatments****."*
>
> Molly, Age 25 (PA26, PCOS)

Another participant indicated that she would pursue multiple follow-up appoints if there was insufficient time for discussion:

> ***"I think the less time that I had in any particular appointment, the more appointments I would have to come in for really because I think I would need time to really thoroughly discuss that with my doctor****… Yeah, if any one appointment wasn't long enough, I would have to come back because I would need time to be able to have a full discussion with them."*
>
> Kit, Age 22 (PA13, Recurring Ovarian Cysts)

6.4 Additional Factors Influencing Decision-making Preferences

In addition to clinical severity and time, the interviews highlighted three additional factors that could influence preferences for health care decision-making: familiarity with clinician, clinician gender, and race and ethnicity.

6.4.1 Familiarity with Clinician

The interview guide included a probe about clinician familiarity. There was mixed response regarding the role of familiarity with clinicians in forming health care decision-making preferences. For some participants, familiarity was considered useful because it fosters trust, but was not a factor in terms of their decision-making preferences. For example, one participant commented that familiarity would make her more comfortable, but she would not change her decision-making preferences:

> *"It would **definitely make me feel more comfortable and I definitely have more trust for them**, but I would still probably keep it in the same order."*
>
> Melody, Age 18 (PA21)

However, for others, the trust created from familiarity would make them more willing to share some, but not all, decision-making power with clinicians. For instance, Julie indicated that she would consider a shift to SDM with clinicians as she became more familiar with them:

> *"I think **the more familiar I become with a doctor; I would probably lay a little bit more trust in them.** So, I might consider a different event such as potentially shared responsibility or some other scenario like that. But it will also depend on the medical situation."*
>
> Julie, Age 21 (PA16)

Another participant stated that familiarity with the clinician made her more open to sharing decision-making power.

> *"**I would be more interested in sharing responsibility with a practitioner that I am familiar with**, just overall, because they know my history and things of that sort, and we've already created a good relationship."*
>
> Kristy, Age 22 (PA14)

6.4.2 Clinician Gender

Five participants spoke to the role of clinician gender in influencing their ability or willingness to participate in discussions about health care decisions. Participants stated that during previous clinical encounters, having a male clinician made them feel uncomfortable or awkward when discussing their concerns. They felt more comfortable sharing with a female clinician than a male clinician. This was partially due to the fact that participants believed that female clinicians were in a better position to understand women's health issues or take their concerns seriously. Vanessa, a participant who had a male pediatrician shared that she switched to a female clinician when able to select her own clinician:

> *"I'm not quite sure if that was just a quirk I had as a kid, if **having a male doctor freaked me out. But I just never felt comfortable with him, I never felt like I could say everything on my mind to get the help that I needed.** So, I switched to a female provider last year."*
>
> Vanessa, Age 20 (PA 22)

Blair, who had a previous experience where a male clinician dismissed her pain, commented that she would not be able to share as much with a male clinician compared to a female clinician:

> *"Especially personally,* ***like with a male doctor, I would not be able to share as much.*** *Even if I told myself I was going to, I would not be able to share as much about my concerns as I could if it was a female doctor who could actually physically understand what that is like, I guess."*
>
> Blair, Age 23 (PA5)

Dawn also spoke to feeling more comfortable sharing information with a female clinician and stated she felt that female clinicians were more likely to believe her pain:

> *"Like when I'm trying to choose a physician****, I definitely prefer women, because I feel like they understand more...like they're more likely to be…like believe you or your pain****."*
>
> Dawn, Age 19 (PA27)

6.4.3 Race and Ethnicity

Two participants specifically spoke to the biases they faced as Asian women seeking care and how those biases inform their decision-making preferences. Both participants stated that previous experiences with racism in clinical encounters or anticipated racial bias made them want to have more control over their health care decisions. One participant shared that she would not want a clinician to make decisions for her because of a previous experience where a clinician made race-based assumptions about her diet:

> *"Because sometimes like doctors will be biased based on their patient population…Actually like one particular doctor that basically was like, 'All my patients need this vitamin,' or whatever****. And that's based on the assumption that all Asians eat rice****…"*

Jessi, Age 23 (PA20)

The second participant spoke to the bias women of color face in general when seeking care:

> *"I don't like to put all my eggs in one basket…**especially because a lot of times women, especially brown women's perspective, is ignored** and I've experienced that before where if I say one thing, it's just overlooked…"*
>
> Julie, Age 21 (PA24)

6.5 Participant Views on Shared Decision-making

As part of the card sort exercise, each participant was asked to describe what SDM looked like for each clinical scenario. Descriptions of SDM largely aligned with the common components identified in Aim 1. When asked to describe what sharing responsibility for health care decisions looked like, most participants described a process where their opinions were considered with those of clinicians. This included discussion where there would be information exchange and a weighing of options. When it came to a final decision, there would either be consensus or a compromise where both parties felt comfortable. For example, Serena described SDM as discussing all options and making decisions together with the clinician:

> *"I feel like us making a shared decision and having shared responsibility would be, like, laying all the options out, talking about these options…us talking about possible pros and cons…I think having them state the pros, but then I also state what might be difficult for me to actually accomplish, that would be kind of the shared responsibility…**I think just kind of deciding that together, of course, is what I really think of when I think of that card.**"*
>
> Serena, Age 22 (PA1)

Another participant described SDM as a back and forth discussion between patient and clinician, resulting in a compromise:

> *"I guess I see that one, it's more of a conversation.* ***A little bit more back and forth between me and the doctor in terms of what the treatments entail. I also see that one I think as kind of coming to a compromise if need be****."*
>
> Caroline, Age 18 (PA16)

A third participant described SDM as a longer, detailed conversation where the doctor and patient act as a team and discuss the risks and benefits of treatment options.

> *"I would envision this being a longer conversation. Where I'm asking a lot of questions. The doctor's also giving me a lot more details on what all this means. What are the risks and benefits of the medications and treatment versus doing nothing. So, I guess I just envision this being a longer detailed conversation, where all my options are laid out. All the risks and benefits are laid out.* ***And I feel more like my doctor and I are a team and deciding a middle ground of the best option for me****."*
>
> Samantha, Age 29 *(*PA33)

However, while many preferred SDM across the scenarios, there was also concern about losing power with a shared approach. The idea of splitting decision-making power evenly between patient and clinician did not appeal to some participants. For instance, Claudia spoke with some reluctance about having an equal split in decision-making power with clinicians:

> *"I think it's such a personal thing that* ***I would want to have a bit more control than kind of splitting it 50/50****, I guess."*
>
> Claudia, Age 27 (PA2)

Feeling pushed or pressured to agree with clinicians during SDM was also a concern. One participant indicated that sharing decision-making power would still put the clinician in a position to be forceful about decisions:

> *"…A little bit more pushy. Still giving me room to make the decision, but enforcing it a little bit more. Which* ***I think would make me feel like I didn't have as much of a choice****…"*
>
> Blair, Age 23 (PA5)

6.6. Participant Descriptions of Active-Shared Decision-Making

Participants were asked to describe active-shared decision-making when they identified it as their most preferred decision-making style during the card sort exercise. Similar to the descriptions of SDM, descriptions of active-shared decision-making involved a step for information delivery from clinicians, including receiving recommendations from clinicians. As one participant described,

> *"So, to me it would mean* ***getting all the necessary information for my doctor, from my doctor, and then potentially getting an opinion on what perhaps he or she would do in my situation****."*
>
> Caroline, Age 18 (PA16)

However, compared to SDM there was less emphasis on information exchange or joint deliberation between patient and clinician. For example, Georgina described the active-shared interaction as having a conversation with their clinician about the decision and the available options and then making a decision based on what they felt was best for them,

> *"I've discussed these are the things that are happening, these are my symptoms, and then we've had a conversation about what that what the symptoms might mean, what could be possibly the health issue that I'm having.* ***Then from there, having all that information and [giving] me all these different options of what I***

> ***could do, and having that conversation. Then I'd be able to be like, "Okay, that's the one that I think would fit the best with the life that I'm living at the moment."***
>
> Georgina, Age 24 (PA 25)

Another participant echoed the idea that in active-shared decision-making, they would receive information from their clinician, including any recommendations, and make the decision based on their own needs, stating:

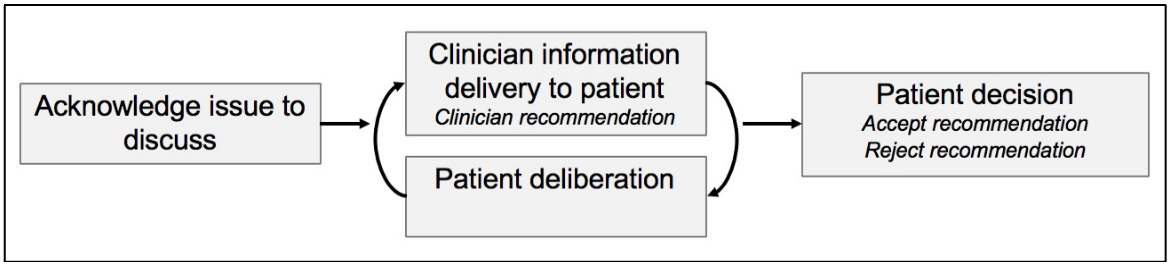
> *For me, it would be **my doctor telling me what they think is best for me** and everything that's going on, **but I would make like the final decision about what treatment option I would go for, because I would know what's best for me in this situation specifically**."*
>
> Dawn, Age 19 (PA27)

While clinician recommendations were identified as an important part of information delivery, participants noted that they could choose to not follow these recommendations. Final decisions are based on the patient's assessment of their own needs. This is distinct from SDM as a shared process emphasizes at minimum a mutually acceptable decision for both patient and clinician, and ideally consensus. As one participant described,

> *"…we'd go through the different options, and then probably narrow it down hopefully to a few, and then maybe talk about the pros and cons…And then, **I feel like they'd give a final recommendation of what they were thinking,** and then based on, of course, the final few little ones that we might have narrowed it down to**, I'd either confirm their recommended one or go along with one of the other ones that I was feeling a little bit better about.**"*
>
> Serena, Age 22 (PA1)

These descriptions provide an initial outline for an active-shared model of decision-making. Figure 9 illustrates the active-shared decision-making process based on participant descriptions. Like the SDM process outlined under Aim 1 (Figure 8), active-shared decision-making begins with acknowledging there is an issue to discuss. The next step of the process is information delivery from the clinician to the patient, which feeds patient deliberation. This can be a cyclical process as patient deliberation leads to more questions from patients and recommendations from clinicians about what option is best for the patient. Following information delivery and patient deliberation, the patient chooses to accept the clinician recommendation or reject the recommendation. Distinctive from SDM is that the patient is making the decision based on what they believe is best for them and the decision does not have to be mutually acceptable to the clinician.

Figure 9. Active-Shared Decision-making Process



6.7 Influence of Previous Experiences on Observed Themes

Themes regarding the role clinical severity were consistent regardless of participant characteristics or previous clinical experiences. While older and younger millennials could be at different life stages, I did not observe differences in preference motivation between them. I also did not observe differences in preference motivation between participants who had limited interactions with clinicians and participants who had more wide-ranging experience with the health care system (e.g., chronic conditions, surgical procedures).

The importance of personal agency, in particular, was consistent irrespective of previous clinical experiences. During the interviews, women who indicated they had limited experience making health care decisions during the introductory interview were just as likely to value agency over their bodies as women who indicated they had significant experience making health care decisions. Nearly all participants also spoke to the tradeoff between personal agency and information asymmetry when discussing their decision-making preferences. In addition, all participants valued additional time during clinical encounters to support participation in health care decision-making.

CHAPTER 7: DISCUSSION

The past decade has brought renewed attention to shared decision-making (SDM). SDM holds great promise, but there are clear research gaps that need to be addressed to advance implementation. The goal of this research was to address two gaps in the current evidence-base: 1) the “what” of SDM by conducting a literature review of SDM models, and 2) the “when” of SDM by examining the health care decision-making preferences of millennial women.

7.1 Defining the Process of Shared Decision-making

The systematic review executed under Aim 1 is a critical step forward in outlining the practice of SDM. The review represents an update and expansion of previous work.[6,26] I conducted a comprehensive search of the peer-review and gray literature, which allowed me to include models not considered in previous reviews such as those developed by both the Agency for Healthcare Research and Quality and NICE. I also assessed the quality of the SDM evidence-base as well as the confidence in findings. Findings for SDM components reached a moderate level of confidence in findings. There was low to very low confidence in findings for responsibilities and goals/objectives, and insufficient evidence to assess the efficacy of SDM models.

While there were limitations to the available evidence, I was able to propose a process model for SDM based on common components across models. I identified 20 unique components in 45 models. Previous reviews from

Makoul et al. (2006) and Bomhof-Roordink (2019) identified more components for SDM. These differences may be attributed to study methodology. The review from Makoul used less stringent exclusion criteria and included editorials and think-pieces.[6] The review from Bomhof-Roordink used Makoul's categorization as a starting point and then either combined and separated elements into different groupings.[26] Consequently, process components like information delivery/exchange where divided into multiple subcomponents like clinician expertise and patient questions.

Overall, I found that six SDM process components were common across models. These six components are: acknowledging that there is a decision to be made and there are options; patient preferences, values, or goals; information delivery/exchange, deliberation; making a decision; and post-decision evaluation and follow-up. Based on the available evidence, both the patient and the clinician have the responsibility of implementing two components: patient values, preferences, and goals and information delivery/exchange.

7.1.1 Implications for Shared Decision-making Policy and Practice

SDM should be adaptive to different circumstances, contexts and problems.[215] Hargraves et al. (2019) suggests that there are different modes of purposeful SDM that should be responsive to the problems of patients.[215] While there is not be a single one-size fits all approach to SDM, there needs to be consensus regarding the primary steps of the process if we are to measure quality of implementation and patient outcomes. The synthesis of SDM models in

Aim 1 is essential to making the practice accessible to the broader provider community. Lack of familiarity with SDM is an important barrier to implementing the process into routine clinical practice.[16] Smaller organizations and community clinicians may find SDM challenging, given the abundance of SDM publications and the variable quality of these publications. The findings from Aim 1 help address this barrier to uptake by outlining the minimum necessary process steps to conduct SDM for clinicians, health care organizations, and policymakers. The operational definitions synthesized as part of this review provide guidance on how each process step should be executed. By identifying common components, the Aim 1 findings also provide a foundation for developing a unified model of SDM for patient-centered care. A unified model is necessary as both implementation and evaluation require clear agreement within the field about what the process entails.

7.1.2 Review Limitations and Challenges

There are limitations to this review. While they are represented in the process model, I did not consider contextual factors that may influence SDM due to limited discussion of these factors in included models. I was also not able to include the expected outcomes of the SDM process. The SDM evidence base appears somewhat disjointed. There is literature on how contextual factors influence decision-making, but these factors are not discussed in the formation of SDM models. Similarly, studies considering SDM-related outcomes often focus on the use of decision aids, but do not link to a specific model or theory of practice for SDM. Without more attention to linking theoretical or process models to outcomes, it is unlikely that SDM implementation will reach its potential. In particular, clinicians can be skeptical about the evidence supporting SDM.[16] Consequently, it is important to demonstrate the value of the full SDM process, and not just tools used during information delivery/exchange. Health care organizations and clinicians may choose not to continue to invest in SDM processes as part of patient-centered care if we are unable to clearly link the practice to improved outcomes.

I encountered several challenges when examining the SDM literature. More transparency is needed in how SDM models are created and defined. A large proportion of the available literature on SDM models is narrative reviews. While these reviews are informative, there is a potential for bias due to non-systematic selection of included publications.

The research community also needs to better differentiate between studies that test a comprehensive SDM process and studies that test or validate decision aids in clinical settings. In some publications, study title and objectives suggested they were testing an SDM process, but the methods showed they were actually testing or validating a decision aid. If the intention is to promote SDM, studies should embed the testing of decision aids within a broader SDM process. Furthermore, publications that test an SDM process need to provide sufficient information on the model or process used. Lack of information on SDM in empirical studies of decision aids, in particular, hindered my ability to assess the efficacy of SDM models.

7.1.3 Future Research on Shared Decision-making

The systematic review provides a much-needed synthesis of SDM models available in the peer-reviewed and gray literature. This process should be considered iterative and periodic surveillance of the SDM literature should be conducted to determine when new updates are needed. Future empirical research efforts should include studies that not only compare SDM to usual care or other decision-making models, but also compare SDM models with different components. For example, SDM with asking patients about decision-making preferences compared to SDM without asking about preferences. There are clearly common components across available models, but the question remains whether the additional components identified would have added value to the SDM process and improve patient experience and outcomes.

A large proportion of included models were found to be clinician-driven, meaning that the process was outlined in terms of clinician actions (e.g., the clinician elicits preferences, the clinician provides information). If SDM is supposed to be a joint process between patient and clinician, we must move away from defining the process exclusively from the clinician viewpoint. Outlining the steps of SDM in a clinician-driven way reinforces a patriarchal view of the clinical encounter.

A critical step in moving away from this will be to more frequently include patients in the development of SDM models. SDM cannot support patients to make decisions and respect their perspectives if models remain focused on clinicians. Current studies on patient attitudes about and preferences for SDM may not provide sufficient evidence to derive a patient-driven SDM model without additional synthesis as well as patient focus groups or Delphi-process.

7.2 Millennial Women and Health Care Decision-making

The lack of patient perspectives represented in the literature identified in Aim 1 and the lack of SDM models specifically tailored to the needs of women highlights the value of the research conducted under Aims 2 and 3. It is important to incorporate patient perspectives into the discussion of how we implement and practice SDM. A patient-centered heath care system must consider the needs of all its patients, including young women.

A previous systematic review indicated that patient preferences for health care decision-making were shifting towards SDM in studies published post-2000.[8] My findings on the decision-making preferences of millennial women suggest that this trend may eventually progress towards a more active model of decision-making. Active-shared decision-making was the preferred decision-making style amongst interviewees at baseline and for painful periods. This suggests that the three-level model of decision-making preferences frequently used in research (passive, shared, active) is outdated.[8]

Active-shared decision-making is a hybrid decision-making model. The descriptions from participants were sufficient to outline key aspects of the process from the perspective of patients. In active-shared decision-making, participants wanted information from their clinician and a discussion of options, indicative of shared decision-making. However, they also wanted to keep decision-making power and were willing to reject clinician recommendations, indicative of active decision-making. Participants also appeared less invested in a deliberative process with clinicians compared to SDM. The findings from this research provide initial insight into what an active-shared process entails; however, additional research is needed to fully detail the active-shared model from the patient perspective and understand what contextual factors influence the process.

As clinical scenarios became more severe and complex, participant preferences moved from active-shared to SDM. Few participants wanted clinicians making their health care decisions and all participants spoke about the importance of being heard by their clinicians. The desire for agency for health care decisions was consistent across participants regardless of age or previous experiences. In addition, some participants were hesitant when discussing SDM. They expressed that clinician expertise was necessary, but wanted more power than the clinician over their health care decisions. This is may be indicative of a cultural shift in terms of expectations for clinical encounters amongst millennial women compared to previous generations that preferred to leave decisions in the hands of their clinicians.[30] More research is needed before we can fully determine the extent to which this shift occurs amongst millennial women.

There was not consensus amongst participants regarding the role of time in forming their decision-making preferences. Participants often commented that their decision-making preferences would remain the same regardless of time.

However, time is an inherent structural barrier to patient participation in health care decision-making. Participants noted that insufficient time would mostly likely force them to defer to their doctor and potentially ignore their own values and preferences. This is the antithesis of patient-centered care delivery. Several participants spoke about making follow-up appointments or phone calls if they had insufficient time during clinical encounters. Consequently, insufficient time during appointments may lead to greater health care utilization, among a sub-group of patients who are willing to attend multiple appointments to participate in health care decisions.

7.2.1 Implications for Clinical Practice

The findings from Aims 2 and 3 will help researchers and health care providers better understand not only how patient preferences may change under varying circumstances, but also why. This is especially important, as clinicians may dismiss the needs and preferences of patients if they feel that the underlying motivations are not important. This is especially true of female patients whose concerns tend to be taken less seriously.[23] While qualitative and preference-based research has limitations, my findings will ultimately help the health system better anticipate the needs of millennial women and interact with them in a way that is respectful to their decision-making preferences.

The interview findings indicate that clinicians need to prepare for not only SDM, but also active-shared decision-making. Efforts to identify best practices for SDM have increased over the past few years, especially with funding from the

Patient-Centered Outcomes Research Institute. However, there is little evidence that clinicians are prepared to encounter more actively engaged patients, especially when considering the continued resistance to SDM implementation amongst some clinicians.[16] Patients who favored active shared decision-making viewed clinicians as deliverers of information, not primary decision-makers. This is a large shift from the traditional medical model and will most likely require investments in training and support for clinicians.

It is possible that millennial clinicians will be more responsive to the needs of their generational peers and more open to patient participation in health care decision-making, given the current shifts created by millennial trainees.[106] This would allow for greater receptivity of active-shared decision-making within the medical community. None of the participants discussed the role of provider age or generation in discussing their health care decision-making preferences. More research is needed to determine if millennial clinicians view SDM or active patient engagement more favorably than other generations. Further research is also needed to determine if millennial patient-clinician concordance is more likely to facilitate SDM and active-shared decision-making.

The findings regarding the role of time and decision-making preferences shows that health care organizations need to find new ways to circumvent the barrier of time. In most health care organizations, it is extremely difficult to allot more time for clinical visits. Allowing patients to more easily email follow-up questions to clinicians may be one way to reduce time pressure during clinical encounters. For non-urgent situations, encouraging patients to go home and think about options may give patients the ability to remain in charge of their health care decisions even when there is not sufficient time during their appointments.

7.2.2 Study Limitations and Quality

There are limitations to this study. The accuracy of forecasting preferences amongst participants is unclear. However, the use of a qualitative methodology allowed for an in-depth examination of previous experiences and preference motivation, potentially correcting for forecasting errors. Interviewees self-selected to participate in interviews. Consequently, participants might have been predisposed to actively participate in health care decision-making. Outreach efforts to student groups were unsuccessful in increasing the enrollment of Black women, Native American women, and women of Hispanic ethnicity. In addition, non-college-educated women recruited at the Minnesota State Fair choose not to participate in interviews. Additional qualitative research is needed to understand the decision-making preferences and motivations of millennial women within these groups.

The use reflexivity and a second reviewer provide credibility and confirmability to my findings. Reflexivity allowed me to consider my role as both a millennial woman and a health services researcher and reflect on how these influenced the conduct and analysis of interviews. For example, I could often empathize and identify with participant experiences. I understood participants' fear of clinicians who dismissed their symptoms and their pain, having had experiences where my symptoms were not taken seriously by a clinician. In using reflexivity, I was able to consider whether my personal experiences were influencing my interpretation of data related to negative clinical experiences and mistrust of clinicians.

Likewise, as a health services researcher, I have encountered clinicians who are enthusiastic about patient-centered care and working with patients to make health care decisions. I have also encountered clinicians who question the ability of patients to participate in making health care decisions. Reflexivity allowed me to consider whether these clinician encounters and my role as a researcher influenced my interpretation of participants' experiences and attitudes about the health care system. My personal experiences and preferences towards active involvement in health care decision-making could have potentially influenced the interpretation of results. Using a second reviewer reduced the potential for bias in the identification and interpretation of themes and ensured that findings were not based on my personal preconceptions.

7.2.3 Future Research on Decision-making Preferences

The decision-making preferences of millennial women have not been extensively explored in the literature. Millennials are now the largest generation in the US.[22] Their health care needs and preferences should be a focus of future research, especially when considering the potential consequence of chronic disease prevalence for this population.[103] Millennial women should be a focus in future research given the gender bias they may face when seeking care.

Additional research is needed to determine the extent to which the themes identified in the interviews are applicable to non-college-educated millennial women. Patients with higher levels of education are more likely to prefer an active role in health care decision-making.[64,65] [66-68] All of the study participants valued personal agency in making health decisions. This theme did not vary between those who were recent high school graduates and those who had completed graduate education. Future research should focus on understanding how different socioeconomic variables including education intersect within the millennial generation and contribute to health care decision-making preferences.

Further research is also needed to explore the intersection between race, gender, and generation to form health care decision-making preferences. Only two participants spoke to the issue of race during the interviews. Both indicated that they were more likely to participate in health care decision-making because they anticipated experiencing racial bias in clinical encounters. Previous studies have shown that experiencing racial bias in clinical encounters can disempower patients.[77,78] Future research should examine the degree to which anticipation of bias may motivate millennial women of color to participate more in health care decision-making.

New research on decision-making preferences should also further explore the role of provider gender. Previous research suggests that women may prefer female gynecologists because female clinicians more often use a more patient-centered communication style.[216] Participant comments regarding clinician gender suggest that the desire for a female clinician may involve multiple factors including comfortability, previous negative experiences with male clinicians, and fear of being dismissed by male clinicians.

In addition, larger scale studies are needed to fully understand the extent to which the themes identified in this study are broadly applicable to all millennial women. Future research should include mixed-methods studies that combine survey methods with qualitative research. In addition, intergenerational studies will help determine the extent to which there are generational shifts in decision-making preferences among women.

7.3 Conclusion

SDM has the potential to improve the delivery of patient-centered care and ensure that patients are equal partners in health care decision-making. However, a common understanding of what the process entails and how it should be implemented is needed if we are to fully incorporate SDM in clinical practice as part of a patient-centered health care system. The systematic review in Aim 1 moves us closer to this goal by proposing a common component process model for SDM. However, the lack of studies focused on implementing an SDM process in clinical care is concerning given the investments made in SDM and patient-centered care research. It is likely that a large proportion of these resources have been used to study tools that support information delivery/exchange in SDM instead of SDM models. We must invest in studies that examine the impact of executing SDM in clinical care. Research examining implementation of SDM models will not only provide information on the ability of SDM to improve patient-outcomes, but also may provide a roadmap to successfully carrying out SDM across the health care system.

The prevalence of clinician driven SDM models is also concerning. SDM is a partnership between patient and clinician, yet existing models often do not consider the patient's role in implementing the process or patient decision-making preferences. Aims 2 and 3 provide valuable insight into the decision-making preferences of millennial women and their views on SDM. This is a significant contribution to the literature on patient decision-making preferences given the size of the millennial population. Millennial women are subject to generational (e.g., high potential for chronic disease, poor economic outlook, industry disruptors) and gender-based (e.g., bias) factors that make them a critical population for patient-centered care delivery. Clinicians and health care organizations will soon need to consider the needs of this population, if they are not already. Based on my findings, a major factor in the patient-clinician dynamic for this population will be the ability of clinicians work with patients who want more control over their health care decisions. Researchers and clinicians should take the preferences of millennial women seriously, as the goal of patient-centered care is to delivery care that is respectful of and responsive to individual needs of all patients.

BIBLIOGRAPHY

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 (1982).* 1997;44(5):681-692.
2. Joosten EA, DeFuentes-Merillas L, De Weert G, Sensky T, Van Der Staak C, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy and psychosomatics.* 2008;77(4):219-226.
3. Durand MA, Barr PJ, Walsh T, Elwyn G. Incentivizing shared decision making in the USA--where are we now? *Healthcare (Amsterdam, Netherlands).* 2015;3(2):97-101.
4. International Consortium for Health Outcomes Measurement (ICHOM). 2018; http://www.ichom.org/.
5. National Quality Forum. National Quality Partners Playbook™: Shared Decision Making in Healthcare. 2018.
6. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient education and counseling.* 2006;60(3):301-312.
7. Blumenthal-Barby J, Opel DJ, Dickert NW, et al. Potential Unintended Consequences Of Recent Shared Decision Making Policy Initiatives. *Health affairs (Project Hope).* 2019;38(11):1876-1881.
8. 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;86(1):9-18.
9. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? *BMJ (Clinical research ed).* 1999;319(7212):780-782.
10. Szasz TS, Hollender MH. A contribution to the philosophy of medicine; the basic models of the doctor-patient relationship. *AMA archives of internal medicine.* 1956;97(5):585-592.
11. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine.* 2012;366(9):780-781.
12. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social science & medicine (1982).* 1999;49(5):651-661.
13. 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 : an international journal of public participation in health care and health policy.* 2006;9(1):25-36.
14. Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in health care.* 2003;12(2):93-99.
15. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in

healthcare choices. *The British journal of general practice : the journal of the Royal College of General Practitioners.* 2000;50(460):892-899.

16. 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;73(3):526-535.
17. Moumjid N, Gafni A, Bremond A, Carrere MO. Shared decision making in the medical encounter: are we all talking about the same thing? *Medical decision making : an international journal of the Society for Medical Decision Making.* 2007;27(5):539-546.
18. Dabelea D, Mayer-Davis EJ, Saydah S, et al. Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *Jama.* 2014;311(17):1778-1786.
19. Hulsegge G, Picavet HS, Blokstra A, et al. Today's adult generations are less healthy than their predecessors: generation shifts in metabolic risk factors: the Doetinchem Cohort Study. *European journal of preventive cardiology.* 2014;21(9):1134-1144.
20. Ashman J, Rui P, Okeyode T. Characteristics of Office-based Physician Visits, 2014. *NCHS data brief.* 2017(292):1.
21. Rui P OT. National Ambulatory Medical Care Survey: 2015 State and National Summary Tables. 2015; https://www.cdc.gov/nchs/data/ahcd/namcs_summary/2015_namcs_web_tables.pdf.
22. Frey WH. The Millennial Generation. 2018; https://www.brookings.edu/wp-content/uploads/2018/01/2018-jan_brookings-metro_millennials-a-demographic-bridge-to-americas-diverse-future.pdf.
23. Bernstein B, Kane R. Physicians' attitudes toward female patients. *Med Care.* 1981;19(6):600-608.
24. Skimm Studies. Millennial Women are Worried About the Future of Their Reproductive Care. 2017; https://medium.com/@skimmstudies/skimm-studies-presents-millennial-women-are-worried-about-the-future-of-their-reproductive-care-458b741b8015.
25. Blanc X, Collet TH, Auer R, et al. Publication trends of shared decision making in 15 high impact medical journals: a full-text review with bibliometric analysis. *BMC medical informatics and decision making.* 2014;14:71.
26. Bomhof-Roordink H, Gartner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a systematic review. *BMJ open.* 2019;9(12):e031763.
27. Kriston L, Scholl I, Holzel L, Simon D, Loh A, Harter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient education and counseling.* 2010;80(1):94-99.
28. Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Med Care.* 2000;38(3):335-341.

29. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ (Clinical research ed).* 2000;321(7265):867-871.
30. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of general internal medicine.* 1989;4(1):23-30.
31. Stiggelbout AM, Kiebert GM. A role for the sick role. Patient preferences regarding information and participation in clinical decision-making. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 1997;157(4):383-389.
32. 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.* 2014;94(3):291-309.
33. Pieterse AH, Stiggelbout AM, Montori VM. Shared Decision Making and the Importance of Time. *Jama.* 2019;322(1):25-26.
34. Henderson LJ. Physician and patient as a social system. *New England journal of medicine.* 1935;212(18):819-823.
35. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *Jama.* 1992;267(16):2221-2226.
36. Gafni A, Charles C, Whelan T. The physician-patient encounter: the physician as a perfect agent for the patient versus the informed treatment decision-making model. *Social science & medicine (1982).* 1998;47(3):347-354.
37. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *Journal of general internal medicine.* 2012;27(10):1361-1367.
38. Parsons T. *The social system.* Psychology Press; 1991.
39. Institute of Medicine Committee on Quality of Health Care in A. In: *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington (DC): National Academies Press (US)
Copyright 2001 by the National Academy of Sciences. All rights reserved.; 2001.
40. Protection P, Act AC. Patient protection and affordable care act. *Public law.* 2010;111(148):1.
41. Shared Decision Making Project at University of Washington. Washington State Legislation. 2009; http://depts.washington.edu/shareddm/waleg.
42. Mayo Clinic. Shared Decision Making National Resource Center. 2017; http://shareddecisions.mayoclinic.org/.
43. National Quality Forum. Measure #007. NCQA Supplemental items for CAHPS® 4.0 Adult Questionnaire (CAHPS 4.0H). 2014; http://www.qualityforum.org/QPS/0007.
44. Lewis CL, Dalton AF, Drake L, et al. Developing and Evaluating a Clinic-Based Decision Aid Delivery System. *MDM Policy & Practice.* 2016;1(1):2381468316656850.

45. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implementation science : IS.* 2016;11:114.
46. President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research. *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship.* 1982.
47. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ (Clinical research ed).* 1999;319(7212):766-771.
48. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *The British journal of general practice : the journal of the Royal College of General Practitioners.* 1999;49(443):477-482.
49. Oshima Lee E, Emanuel EJ. Shared decision making to improve care and reduce costs. *The New England journal of medicine.* 2013;368(1):6-8.
50. Legare F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health affairs (Project Hope).* 2013;32(2):276-284.
51. Shay LA. Where is the evidence? A systematic review of shared decision making. 2015;35(1):114-131.
52. Elwyn G, Durand MA, Song J, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ (Clinical research ed).* 2017;359:j4891.
53. Peek ME, Lopez FY, Williams HS, et al. Development of a Conceptual Framework for Understanding Shared Decision making Among African-American LGBT Patients and their Clinicians. *Journal of general internal medicine.* 2016;31(6):677-687.
54. Agency for Healthcare Research and Quality. The SHARE Approach. 2014; http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html.
55. Department of Health and Human Services. Developing Measures of Shared Decision Making (R01), PA-16-424. 2016.
56. Byrne PS, Long BE. Doctors talking to patients: A study of the verbal behavior of general practitioners consulting in their surgeries. 1976.
57. Mechanic D. The functions and limitations of trust in the provision of medical care. *J Health Polit Policy Law.* 1998;23(4):661-686.
58. Lupton D. Doctors on the medical profession. *Sociology of Health & Illness.* 1997;19(4):480-497.
59. Krumholz HM, Barreto-Filho JA, Jones PG, Li Y, Spertus JA. Decision-making preferences among patients with an acute myocardial infarction. *JAMA internal medicine.* 2013;173(13):1252-1257.
60. Santema TB, Stoffer EA, Kunneman M, Koelemay MJ, Ubbink DT. What are the decision-making preferences of patients in vascular surgery? A mixed-methods study. *BMJ open.* 2017;7(2):e013272.

61. Marahrens L, Kern R, Ziemssen T, et al. Patients' preferences for involvement in the decision-making process for treating diabetic retinopathy. *BMC ophthalmology.* 2017;17(1):139.
62. Berger AM, Buzalko RJ, Kupzyk KA, Gardner BJ, Djalilova DM, Otte JL. Preferences and actual chemotherapy decision-making in the greater plains collaborative breast cancer study(). *Acta oncologica (Stockholm, Sweden).* 2017;56(12):1690-1697.
63. Eisenberg JM. Sociologic influences on decision-making by clinicians. *Annals of internal medicine.* 1979;90(6):957-964.
64. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient education and counseling.* 2006;60(2):102-114.
65. Singh JA, Sloan JA, Atherton PJ, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. *The American journal of managed care.* 2010;16(9):688-696.
66. Deber RB, Kraetschmer N, Urowitz S, Sharpe N. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health expectations : an international journal of public participation in health care and health policy.* 2007;10(3):248-258.
67. Smith SG, Pandit A, Rush SR, Wolf MS, Simon CJ. The Role of Patient Activation in Preferences for Shared Decision Making: Results From a National Survey of U.S. Adults. *Journal of Health Communication.* 2016;21(1):67-75.
68. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. *Journal of general internal medicine.* 2005;20(6):531-535.
69. Hubbard G, Kidd L, Donaghy E. Preferences for involvement in treatment decision making of patients with cancer: A review of the literature. *European Journal of Oncology Nursing.* 2008;12(4):299-318.
70. Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? *Health expectations : an international journal of public participation in health care and health policy.* 2004;7(4):317-326.
71. 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 (Project Hope).* 2012;31(5):1030-1038.
72. Sainio C, Lauri S, Eriksson E. Cancer patients' views and experiences of participation in care and decision making. *Nursing ethics.* 2001;8(2):97-113.
73. Waterworth S, Luker KA. Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of advanced nursing.* 1990;15(8):971-976.

74. van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social science & medicine (1982).* 2000;50(6):813-828.
75. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *American journal of public health.* 2004;94(12):2084-2090.
76. Johnson RL, Saha S, Arbelaez JJ, Beach MC, Cooper LA. Racial and ethnic differences in patient perceptions of bias and cultural competence in health care. *Journal of general internal medicine.* 2004;19(2):101-110.
77. Peek ME, Wilson SC, Gorawara-Bhat R, Odoms-Young A, Quinn MT, Chin MH. Barriers and facilitators to shared decision-making among African-Americans with diabetes. *Journal of general internal medicine.* 2009;24(10):1135-1139.
78. Peek ME, Odoms-Young A, Quinn MT, Gorawara-Bhat R, Wilson SC, Chin MH. Race and shared decision-making: perspectives of African-Americans with diabetes. *Social science & medicine (1982).* 2010;71(1):1-9.
79. Blanchard J, Nayar S, Lurie N. Patient-provider and patient-staff racial concordance and perceptions of mistreatment in the health care setting. *Journal of general internal medicine.* 2007;22(8):1184-1189.
80. Saha S, Komaromy M, Koepsell TD, Bindman AB. Patient-physician racial concordance and the perceived quality and use of health care. *Archives of internal medicine.* 1999;159(9):997-1004.
81. Cheraghi-Sohi S, Hole AR, Mead N, et al. What patients want from primary care consultations: a discrete choice experiment to identify patients' priorities. *Annals of family medicine.* 2008;6(2):107-115.
82. Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? *Archives of internal medicine.* 1996;156(13):1414-1420.
83. Ende J, Kazis L, Moskowitz MA. Preferences for autonomy when patients are physicians. *Journal of general internal medicine.* 1990;5(6):506-509.
84. Jayanti A, Neuvonen M, Wearden A, et al. Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates. *BMC nephrology.* 2015;16:189.
85. Mansell D, Poses RM, Kazis L, Duefield CA. Clinical factors that influence patients' desire for participation in decisions about illness. *Archives of internal medicine.* 2000;160(19):2991-2996.
86. Nease RF, Jr., Brooks WB. Patient desire for information and decision making in health care decisions: the Autonomy Preference Index and the Health Opinion Survey. *Journal of general internal medicine.* 1995;10(11):593-600.
87. Dehlendorf C, Diedrich J, Drey E, Postone A, Steinauer J. Preferences for decision-making about contraception and general health care among reproductive age women at an abortion clinic. *Patient education and counseling.* 2010;81(3):343-348.

88. Hamann J, Bieber C, Elwyn G, et al. How do patients from eastern and western Germany compare with regard to their preferences for shared decision making? *European journal of public health.* 2012;22(4):469-473.
89. Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. *European journal of public health.* 2005;15(4):355-360.
90. Rudell K, Myers L, Newman S. Preferences for involvement in medical decision making: comparing British and German views. *Psychology, health & medicine.* 2006;11(2):171-181; quiz 781-179.
91. Deledda G, Moretti F, Rimondini M, Zimmermann C. How patients want their doctor to communicate. A literature review on primary care patients' perspective. *Patient education and counseling.* 2013;90(3):297-306.
92. Ogden J, Bavalia K, Bull M, et al. "I want more time with my doctor": a quantitative study of time and the consultation. *Family practice.* 2004;21(5):479-483.
93. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Social science & medicine (1982).* 1988;27(11):1139-1145.
94. Tai-Seale M, McGuire TG, Zhang W. Time allocation in primary care office visits. *Health services research.* 2007;42(5):1871-1894.
95. Legare F, Stacey D, Turcotte S, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *The Cochrane database of systematic reviews.* 2014(9):Cd006732.
96. Svenson O, Edland A. Change of preferences under time pressure: Choices and judgements. *Scandinavian Journal of Psychology.* 1987;28(4):322-330.
97. Beisecker AE, Beisecker TD. Patient information-seeking behaviors when communicating with doctors. *Med Care.* 1990;28(1):19-28.
98. Vespa J. The changing economics and demographics of young adulthood: 1975–2016. *Washington, DC: US Department of Commerce, United States Census Bureau.* 2017;14.
99. Patten E, Fry R. How millennials today compare with their grandparents 50 years ago. *Pew Research Center.* 2015;19.
100. Credit Suisse. Global Wealth Report 2017. 2017; http://publications.credit-suisse.com/index.cfm/publikationen-shop/research-institute/global-wealth-report-2017-en/.
101. Ward BW, Schiller JS, Goodman RA. Multiple Chronic Conditions Among US Adults: A 2012 Update. *Preventing Chronic Disease.* 2014;11:E62.
102. American Psychological Association. Stress in America: Coping with Change. 2017; https://www.apa.org/news/press/releases/stress/2016/coping-with-change.pdf.
103. Blue Cross Blue Shield. *The Economic Consequences of Millennial Health.* 2019.
104. Piper LE. Generation Y in healthcare: leading millennials in an era of reform. *Frontiers of health services management.* 2012;29(1):16-28.

105. Olson ME. The "millennials": first year in practice. *Nursing outlook.* 2009;57(1):10-17.
106. Waljee JF, Chopra V, Saint S. Mentoring millennials. *JAMA.* 2018;319(15):1547-1548.
107. Cowan M. Millennial transformation for primary care. *Mil Med.* 2010;175(6):379-381.
108. Judge CP, Borrero S. Contraceptive decision making after the 2016 US presidential election. *American journal of obstetrics and gynecology.* 2017;217(1):89-90.
109. Rice C. The Trump effect? IUD visits rise after election. 2017; https://www.athenahealth.com/insight/trump-effect-iud-visits-rise-after-election.
110. Chang AM, Mumma B, Sease KL, Robey JL, Shofer FS, Hollander JE. Gender bias in cardiovascular testing persists after adjustment for presenting characteristics and cardiac risk. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine.* 2007;14(7):599-605.
111. Mackey C, Diercks DB. Gender Bias in the Management of Patients Still Exists. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine.* 2018.
112. As-Sanie S, Black R, Giudice LC, et al. Assessing research gaps and unmet needs in endometriosis. *American journal of obstetrics and gynecology.* 2019;221(2):86-94.
113. Arruda MS, Petta CA, Abrao MS, Benetti-Pinto CL. Time elapsed from onset of symptoms to diagnosis of endometriosis in a cohort study of Brazilian women. *Human reproduction (Oxford, England).* 2003;18(4):756-759.
114. Ballweg ML. Blaming the victim. The psychologizing of endometriosis. *Obstetrics and gynecology clinics of North America.* 1997;24(2):441-453.
115. Vaccarino V, Parsons L, Every NR, Barron HV, Krumholz HM. Sex-based differences in early mortality after myocardial infarction. National Registry of Myocardial Infarction 2 Participants. *The New England journal of medicine.* 1999;341(4):217-225.
116. Lichtman JH, Leifheit-Limson EC, Watanabe E, et al. Symptom recognition and healthcare experiences of young women with acute myocardial infarction. *Circulation Cardiovascular quality and outcomes.* 2015;8(2 Suppl 1):S31-38.
117. Vogel BA, Helmes AW, Hasenburg A. Concordance between patients' desired and actual decision-making roles in breast cancer care. *Psycho-oncology.* 2008;17(2):182-189.
118. Gerteis J ID, Deitz D, LeRoy L, Ricciardi R, Miller T, Basu J. *Multiple Chronic Conditions Chartbook. AHRQ Publications No, Q14-0038.* Rockville, MD: Agency for Healthcare Research and Quality; 2014.
119. Cox KJ. Counseling women with a previous cesarean birth: toward a shared decision-making partnership. *Journal of midwifery & women's health.* 2014;59(3):237-245.

120. Dugas M, Shorten A, Dube E, Wassef M, Bujold E, Chaillet N. Decision aid tools to support women's decision making in pregnancy and birth: a systematic review and meta-analysis. *Social science & medicine (1982).* 2012;74(12):1968-1978.
121. Gunn CM, Soley-Bori M, Battaglia TA, Cabral H, Kazis L. Shared Decision Making and the Use of Screening Mammography in Women Younger Than 50 Years of Age. *Journal of Health Communication.* 2015;20(9):1060-1066.
122. Lee BT, Chen C, Yueh JH, Nguyen MD, Lin SJ, Tobias AM. Computer-based learning module increases shared decision making in breast reconstruction. *Annals of surgical oncology.* 2010;17(3):738-743.
123. Mandelblatt J, Kreling B, Figeuriedo M, Feng S. What is the impact of shared decision making on treatment and outcomes for older women with breast cancer? *Journal of clinical oncology : official journal of the American Society of Clinical Oncology.* 2006;24(30):4908-4913.
124. Moore JE. Women's Voices in Maternity Care: The Triad of Shared Decision Making, Informed Consent, and Evidence-Based Practices. *The Journal of perinatal & neonatal nursing.* 2016;30(3):218-223.
125. Nicholas Z, Butow P, Tesson S, Boyle F. A systematic review of decision aids for patients making a decision about treatment for early breast cancer. *Breast (Edinburgh, Scotland).* 2016;26:31-45.
126. Scariati P, Nelson L, Watson L, Bedrick S, Eden KB. Impact of a decision aid on reducing uncertainty: pilot study of women in their 40s and screening mammography. *BMC medical informatics and decision making.* 2015;15:89.
127. Shorten A, Fagerlin A, Illuzzi J, et al. Developing an Internet-Based Decision Aid for Women Choosing Between Vaginal Birth After Cesarean and Planned Repeat Cesarean. *Journal of midwifery & women's health.* 2015;60(4):390-400.
128. Vortel MA, Adam S, Port-Thompson AV, Friedman JM, Grande SW, Birch PH. Comparing the ability of OPTION(12) and OPTION(5) to assess shared decision-making in genetic counselling. *Patient education and counseling.* 2016;99(10):1717-1723.
129. American College of Obstetricians and Gynecologists. FAQ046: Dysmenorrhea: Painful Periods. 2015; https://www.acog.org/Patients/FAQs/Dysmenorrhea-Painful-Periods?IsMobileSet=false. Accessed March 13, 2020.
130. Centers for Disease Control and Prevention. Key Statistics from the National Survey of Family Growth - C Listing. 2018; https://www.cdc.gov/nchs/nsfg/key_statistics/c.htm#contraception.
131. Kaloo P, Khazali S, Hoy D, Sadoon S. Management of Suspected Ovarian Masses in Premenopausal Women. *Green-Top Guideline.* 2011(62).
132. American College of Obstetricians and Gynecologists. FAQ075: Ovarian Cysts. 2017; https://www.acog.org/Patients/FAQs/Ovarian-Cysts.
133. Cahill D. PCOS. *BMJ clinical evidence.* 2009;2009.

134. Azziz R, Marin C, Hoq L, Badamgarav E, Song P. Health care-related economic burden of the polycystic ovary syndrome during the reproductive life span. *The Journal of clinical endocrinology and metabolism.* 2005;90(8):4650-4658.
135. Jason J. Polycystic ovary syndrome in the United States: clinical visit rates, characteristics, and associated health care costs. *Archives of internal medicine.* 2011;171(13):1209-1211.
136. Shea BJ, Grimshaw JM, Wells GA, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC medical research methodology.* 2007;7:10.
137. Baethge C, Goldbeck-Wood S, Mertens S. SANRA-a scale for the quality assessment of narrative review articles. *Research integrity and peer review.* 2019;4:5.
138. Sterne JAC, Savovic J, Page MJ, et al. RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ (Clinical research ed).* 2019;366:l4898.
139. Sterne JA, Hernan MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ (Clinical research ed).* 2016;355:i4919.
140. Lincoln YS, Guba EG. *Naturalistic inquiry.* Vol 75: Sage; 1985.
141. Ridgeway JL, Wang Z, Finney Rutten LJ, et al. Conceptualising paediatric health disparities: a metanarrative systematic review and unified conceptual framework. *BMJ open.* 2017;7(8):e015456.
142. Lewin S, Glenton C, Munthe-Kaas H, et al. Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). *PLoS medicine.* 2015;12(10):e1001895.
143. Britten N. Qualitative interviews in medical research. *BMJ (Clinical research ed).* 1995;311(6999):251-253.
144. Overcash JA. Narrative research: a viable methodology for clinical nursing. *Nursing forum.* 2004;39(1):15-22.
145. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *Journal of clinical epidemiology.* 1992;45(9):941-950.
146. Luniewski M, Reigle J, White B. Card sort: an assessment tool for the educational needs of patients with heart failure. *American journal of critical care : an official publication, American Association of Critical-Care Nurses.* 1999;8(5):297-302.
147. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Social science & medicine (1982).* 1994;39(2):279-289.
148. Jahrami H, Marnoch G, Gray AM. Use of card sort methodology in the testing of a clinical leadership competencies model. *Health services management research.* 2009;22(4):176-183.

149. Marshall MN. Sampling for qualitative research. *Family practice.* 1996;13(6):522-525.
150. Morse JM. *Qualitative nursing research: A contemporary dialogue.* Sage Publications; 1990.
151. Sandelowski M. Sample size in qualitative research. *Research in nursing & health.* 1995;18(2):179-183.
152. Minnesota Uo. D2D: The Driven to Discover Research Facility. 2017; http://d2d.umn.edu/.
153. Association of Reproductive Health Professionals. Patient Resources: Birth Control Method Match. 2017; http://www.arhp.org/MethodMatch/.
154. Planned Parenthood. All About Birth Control Methods. 2018; https://www.plannedparenthood.org/learn/birth-control.
155. US Department of Health and Human Services Office of Women's Health. Polycystic Ovary Syndrome. 2017; https://www.womenshealth.gov/a-z-topics/polycystic-ovary-syndrome.
156. NHS Choices. Ovarian Cyst. 2016; https://www.nhs.uk/conditions/ovarian-cyst/treatment/.
157. Legro RS, Arslanian SA, Ehrmann DA, et al. Diagnosis and treatment of polycystic ovary syndrome: an Endocrine Society clinical practice guideline. *The Journal of clinical endocrinology and metabolism.* 2013;98(12):4565-4592.
158. Williams T, Mortada R, Porter S. Diagnosis and Treatment of Polycystic Ovary Syndrome. *American family physician.* 2016;94(2):106-113.
159. Holloway I, Freshwater D. *Narrative research in nursing.* John Wiley & Sons; 2009.
160. Fraser H. Doing narrative research: Analysing personal stories line by line. *Qualitative Social Work.* 2004;3(2):179-201.
161. Greenhalgh T, Russell J, Swinglehurst D. Narrative methods in quality improvement research. *Quality & safety in health care.* 2005;14(6):443-449.
162. Peden-McAlpine C, Bliss D, Hill J. The experience of community-living women managing fecal incontinence. *Western journal of nursing research.* 2008;30(7):817-835.
163. Hibbard JH, Slovic P, Jewett JJ. Informing consumer decisions in health care: implications from decision-making research. *The Milbank quarterly.* 1997;75(3):395-414.
164. Loewenstein G. Projection bias in medical decision making. *Medical decision making : an international journal of the Society for Medical Decision Making.* 2005;25(1):96-105.
165. Eliott JA, Olver IN. End-of-life decision making is more than rational. *Communication & medicine.* 2005;2(1):21-34.
166. Neufeld A, Harrison MJ, Rempel GR, et al. Practical issues in using a card sort in a study of non-support and family caregiving. *Qualitative health research.* 2004;14(10):1418-1428.
167. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research.* 2005;15(9):1277-1288.

168. Elo S, Kyngas H. The qualitative content analysis process. *Journal of advanced nursing.* 2008;62(1):107-115.
169. Ortlipp M. Keeping and using reflective journals in the qualitative research process. *The qualitative report.* 2008;13(4):695-705.
170. Ballard-Reisch DS. A model of participative decision making for physician-patient interaction. *Health Communication.* 1990;2(2):91-104.
171. Callon W, Beach MC, Links AR, Wasserman C, Boss EF. An expanded framework to define and measure shared decision-making in dialogue: A 'top-down' and 'bottom-up' approach. *Patient Education & Counseling.* 2018;101(8):1368-1377.
172. Clayman ML, Gulbrandsen P, Morris MA. A patient in the clinic; a person in the world. Why shared decision making needs to center on the person rather than the medical encounter. *Patient education and counseling.* 2017;100(3):600-604.
173. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient care. *Patient education and counseling.* 2014;97(2):158-164.
174. Entwistle VA, Watt IS. Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient education and counseling.* 2006;63(3):268-278.
175. 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 Journal.* 2015;51(3):267-274.
176. Grad R, Legare F, Bell NR, et al. Shared decision making in preventive health care: What it is; what it is not. *Can Fam Physician.* 2017;63(9):682-684.
177. Groen van de Ven L, Smits C, Elwyn G, et al. Recognizing decision needs: first step for collaborative deliberation in dementia care networks. *Patient education and counseling.* 2017;100(7):1329-1337.
178. Hamann J, Heres S. Adapting shared decision making for individuals with severe mental illness. *Psychiatric Services.* 2014;65(12):1483-1486.
179. Ishii M, Okumura Y, Sugiyama N, et al. Efficacy of shared decision making on treatment satisfaction for patients with first-admission schizophrenia: Study protocol for a randomised controlled trial. *BMC Psychiatry Vol 14 2014, ArtID 111.* 2014;14.
180. Ishii M, Okumura Y, Sugiyama N, et al. Feasibility and efficacy of shared decision making for first-admission schizophrenia: a randomized clinical trial. *BMC psychiatry.* 2017;17(1):52. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/642/CN-01308642/frame.html https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5294770/pdf/12888_2017_Article_1218.pdf.
181. Joosten E, de Weert G, Sensky T, van der Staak C, de Jong C. Effect of shared decision-making on therapeutic alliance in addiction health care. *Patient Prefer Adherence.* 2008;2:277-285.
182. Joosten E, Jong C, Weert-van OG, Sensky T, Staak C. Shared decision-making: increases autonomy in substance-dependent patients. *Substance*

use & misuse. 2011;46(8):1037-1038. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/411/CN-00801411/frame.html https://www.tandfonline.com/doi/full/10.3109/10826084.2011.552931.

183. Joosten EAG, De Jong CAJ, De Weert-Van Oene GH, Sensky T, Van Der Staak CPF. Shared decision-making reduces drug use and psychiatric severity in substance-dependent patients. *Psychotherapy and Psychosomatics.* 2009;78(4):245-253.
184. Legare F, Stacey D, Gagnon S, et al. Validating a conceptual model for an inter-professional approach to shared decision making: A mixed methods study. *Journal of Evaluation in Clinical Practice.* 2011;17(4):554-564.
185. Legare F, Stacey D, Pouliot S, et al. Interprofessionalism and shared decision-making in primary care: A stepwise approach towards a new model. *Journal of Interprofessional Care.* 2011;25(1):18-25.
186. MJ M, GC F, MA V, E dB, CM vdF-C, AJTF B. Shared decision making in mental health care using routine outcome monitoring as a source of information: a cluster randomised controlled trial. *BMC psychiatry 15 (1) (no pagination), 2015 Article number: 313 Date of publication: 2015.* 2015. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/197/CN-01194197/frame.html https://bmcpsychiatry.biomedcentral.com/track/pdf/10.1186/s12888-015-0696-2.
187. Nieuwenhuijze MJ, Korstjens I, de Jonge A, de Vries R, Lagro-Janssen A. On speaking terms: a Delphi study on shared decision-making in maternity care. *BMC Pregnancy Childbirth.* 2014;14:223.
188. Paudel S, Sharma N, Joshi A, Randall M. Development of a shared decision making model in a community mental health center. *Community Mental Health Journal.* 2018;54(1):1-6.
189. Peek ME, Lopez FY, Williams H, et al. Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. *Journal of general internal medicine.* 2016;31(6):677-687.
190. Peek ME, Quinn MT, Gorawara-Bhat R, Odoms-Young A, Wilson SC, Chin MH. How is shared decision-making defined among African-Americans with diabetes? *Patient education and counseling.* 2008;72(3):450-458.
191. Rennke S, Yuan P, Monash B, et al. The SDM 3 Circle Model: A Literature Synthesis and Adaptation for Shared Decision Making in the Hospital. *J Hosp Med.* 2017;12(12):1001-1008.
192. Rubin MA. The collaborative autonomy model of medical decision-making. *Neurocrit Care.* 2014;20(2):311-318.
193. Rusiecki J, Schell J, Rothenberger S, Merriam S, McNeil M, Spagnoletti C. An Innovative Shared Decision-Making Curriculum for Internal Medicine Residents: Findings From the University of Pittsburgh Medical Center. *Acad Med.* 2018;93(6):937-942.
194. Sanders ARJ, Bensing JM, Magnee T, Verhaak P, de Wit NJ. The effectiveness of shared decision-making followed by positive

reinforcement on physical disability in the long-term follow-up of patients with nonspecific low back pain in primary care: a clustered randomised controlled trial. *BMC family practice.* 2018;19(1):102.

195. Shay L, Lafata JE. Understanding patient perceptions of shared decision making. *Patient education and counseling.* 2014;96(3):295-301.

196. Siminoff LA, Step MM. A communication model of shared decision making: Accounting for cancer treatment decisions. *Health Psychology.* 2005;24(4, Suppl):S99-S105.

197. Stiggelbout A, Pieterse A, De Haes J. Shared decision making: Concepts, evidence, and practice. *Patient education and counseling.* 2015;98(10):1172-1179.

198. Truglio-Londrigan M, Slyer JT. Shared Decision-Making for Nursing Practice: An Integrative Review. *Open Nurs J.* 2018;12:1-14.

199. van de Pol MH, Fluit CR, Lagro J, Slaats Y, Olde Rikkert MG, Lagro-Janssen AL. Shared decision making with frail older patients: Proposed teaching framework and practice recommendations. *Gerontology & Geriatrics Education.* 2017;38(4):482-495.

200. van de Pol MH, Fluit CR, Lagro J, Slaats YH, Olde Rikkert MG, Lagro-Janssen AL. Expert and patient consensus on a dynamic model for shared decision-making in frail older patients. *Patient education and counseling.* 2016;99(6):1069-1077.

201. Wilson S, Strub P, Buist A, et al. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American journal of respiratory and critical care medicine.* 2010;181(6):566-577. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/584/CN-00728584/frame.html https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2841026/pdf/AJRCCM1816566.pdf.

202. Zisman-Ilani Y, Roe D, Elwyn G, et al. Shared Decision Making for Psychiatric Rehabilitation Services Before Discharge from Psychiatric Hospitals. *Health Communication.* 2018:1-7.

203. Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model: sharing decision-making in chronic care. *Qualitative Health Research.* 2008;18(5):670-685.

204. Agency for Healthcare Research and Quality. SHARE Approach Workshop. 2016; https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/workshop/index.html. Accessed August 11, 2019.

205. Minnesota Shared Decision-Making Collaborative. Shared Decision-Making Implementation Roadmap. https://msdmc.org/pdf/MSDMCRoadmap.pdf. Accessed August 11, 2019.

206. National Institute for Health and Care Excellence (NICE). Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. Clinical guideline [CG138]. 2012;

https://www.nice.org.uk/guidance/cg138/chapter/1-Guidance. Accessed August 11, 2019.

207. Wexler R. Six Steps of Shared Decision Making. 2012; https://www.mainequalitycounts.org/image_upload/SixStepsSDM2.pdf. Accessed August 11, 2019.
208. Berger-Hoger B, Liethmann K, Muhlhauser I, Haastert B, Steckelberg A. Nurse-led coaching of shared decision-making for women with ductal carcinoma in situ in breast care centers: A cluster randomized controlled trial. *Int J Nurs Stud.* 2019;93:141-152.
209. Bomhof-Roordink H, Fischer MJ, van Duijn-Bakker N, et al. Shared decision making in oncology: A model based on patients', health care professionals', and researchers' views. *Psycho-oncology.* 2019;28(1):139-146.
210. Etingen B, Hill JN, Miller LJ, Schwartz A, LaVela SL, Jordan N. An Exploratory Pilot Study to Describe Shared Decision-Making for PTSD Treatment Planning: The Provider Perspective. *Mil Med.* 2019;184(Suppl 1):467-475.
211. Joseph-Williams N, Williams D, Wood F, et al. A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): Qualitative study. *Patient Education & Counseling.* 2019;102(10):1774-1785.
212. Metz MJ, Veerbeek MA, Twisk JWR, van der Feltz-Cornelis CM, de Beurs E, Beekman ATF. Shared decision-making in mental health care using routine outcome monitoring: results of a cluster randomised-controlled trial. *Soc Psychiatry Psychiatr Epidemiol.* 2019;54(2):209-219.
213. Ng CJ, Lee YK, Abdullah A, Abu Bakar AI, Tun Firzara AM, Tiew HW. Shared decision making: A dual-layer model to tackling multimorbidity in primary care. *Journal of Evaluation in Clinical Practice.* 2019;16:16.
214. Raue PJ, Schulberg HC, Bruce ML, et al. Effectiveness of Shared Decision-Making for Elderly Depressed Minority Primary Care Patients. *Am J Geriatr Psychiatry.* 2019;27(8):883-893.
215. Hargraves IG, Montori VM, Brito JP, et al. Purposeful SDM: A problem-based approach to caring for patients with shared decision making. *Patient Education & Counseling.* 2019;102(10):1786-1792.
216. Janssen SM, Lagro-Janssen AL. Physician's gender, communication style, patient preferences and patient satisfaction in gynecology and obstetrics: a systematic review. *Patient education and counseling.* 2012;89(2):221-226.

APPENDIX A: LITERATURE SEARCH STRATEGIES

Database: OVID Medline

1. Shared decision*.ti.
2. (involv* or consult* or prefer* or engage* or participat*).ti.
3. *Physician-Patient Relations/ or *Patient Participation/ or *Decision-making/ or *Clinical Decision-Making/
4. (patient decision* or decision making or informed decision*).ti.
5. (model* or framework* or process* or defin*).ti.
6. 2 and 3 and 5
7. 4 and 5
8. 1 or 6 or 7
9. limit 8 to (english language and yr="1982 - 2019")
10. limit 9 to (addresses or autobiography or bibliography or biography or case reports or clinical conference or comment or congresses or consensus development conference or consensus development conference, nih or dataset or dictionary or directory or editorial or "expression of concern" or festschrift or guideline or historical article or interactive tutorial or interview or lectures or legal cases or legislation or letter or news or newspaper article or periodical index or personal narratives or portraits or validation studies or video-audio media or webcasts)
11. 9 not 10

Database: OVID EMBASE

1. Shared decision*.ti. or *shared decision making/
2. *Patient Participation/ or *patient decision making/
3. (patient decision* or clinical decision* or informed decision*).ti.
4. (model* or framework* or defin*).ti.
5. 2 or 3
6. 4 and 5
7. 1 or 6
8. limit 7 to (english language and yr="1982 - 2019")
9. limit 8 to (abstract report or books or "book review" or chapter or conference abstract or "conference review" or editorial or letter or note or patent or reports or short survey or tombstone or book or book series or conference proceeding or trade journal)
10. 8 not 9

Database: PsychInfo

1. (*decision making/ or *client participation/) and (involv* or consult* or prefer* or engage* or participat*).ti.
2. (model* or framework* or defin*).ti.
3. 1 and 2
4. (Shared decision* or patient decision*).ti.
5. 3 or 4
6. limit 5 to yr="1982 - 2019"

7. limit 6 to (abstract collection or bibliography or chapter or clarification or "column/opinion" or "comment/reply" or dissertation or editorial or encyclopedia entry or interview or letter or obituary or poetry or publication information or review-book or review-media or review-software & other)
8. 6 not 7
9. limit 8 to english language

Database: CENTRAL
Precise search on shared decision-making terms

APPENDIX B: CHARACTERISTICS OF INCLUDED LITERATURE

Table B1. Characteristics of Included Articles

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
AHRQ 2016 US Gray Lit	None specified	▪ None reported	Yes	Yes	Yes	Medium
Ballard-Reisch 1990 US Narrative	None specified	▪ None reported	Yes	Yes	No	Medium
Berger-Höger 2019 30925280 Germany Cluster RCT	Ductal carcinoma in situ with treatment at breast care centers	▪ None reported	No	Yes	Yes	Medium
Bomhof-Roordink 2019 30346076 Netherlands Qualitative	Oncology	▪ None reported	Yes	No	Yes	High
Callon 2018 29550295 US Qualitative	None specified	▪ Holistic and respectful interpersonal emotional environment	Yes	No	No	Medium
Charles 1997 9032835 Charles 1999 10452420 Canada Narrative	Acute care	▪ Time constraints ▪ Clinician financial incentives	Yes	Yes	No	Medium
Clayman 2017	None specified	▪ None reported	Yes	No	No	Medium

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
27780646 Multi-Country Narrative						
Elwyn 2012 22618581 Elwyn 2017 29109079 Multi-country Narrative	None specified	▪ None reported	Yes	No	Yes	Medium
Elwyn 2000 11141876 Multi-country Qualitative	General practitioners	▪ Time constraints	No	No	Yes	High
Elwyn 2014 25175366 Multi-country Narrative	None specified	▪ Emotional state of participants ▪ Resources, constraints, and capabilities ▪ The range and accessibility of alternatives ▪ Social norms shaping the construction of preferences	No	No	No	Low
Entwistle 2006 16875797 UK Narrative	None specified	▪ Patient's views/feelings about clinician ▪ Clinician's view/feelings about patient	No	No	No	Medium
Etingen 2019 30901448 US Qualitative	PTSD for veterans	▪ None reported	Yes	Yes	No	Medium
Goscha 2015 25033796 US Qualitative	Medication decisions for severe and persistent chronic mental illness	▪ None reported	No	Yes	Yes	Medium
Grad 2017	None specified	▪ None reported	No	No	Yes	Low

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
28904031 Canada Narrative						
Groen van de Ven 2017 28238420 Netherlands Qualitative	Dementia care	▪ None reported	Yes	Yes	No	High
Hamann 2014 25756970 Germany Narrative	Patients with severe mental illness in mental health settings	▪ Best-choice decision-making (a better option clearly exists but also poses a risk that the patient will refuse)	No	No	Yes	Medium
Informed Medical Decisions Foundation 2012 US Gray Lit	None specified	▪ None reported	No	No	Yes	Low
Ishii 2017 28166757 Ishii 2014 26666295, Japan RCT	First-admission inpatients with schizophrenia at a psychiatric hospital	▪ None reported	No	Yes	No	High
Joosten 2008 19920974 Joosten 2009 19468259 Joosten 2011 21370962 Netherlands Cluster RCT	Inpatients with substance-related disorders	▪ None reported	No	Yes	No	Low
Joseph-Williams 2019 31351787	Routine clinical practice for kidney	▪ None reported	Yes	Yes	No	High

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
UK Qualitative	disease and breast cancer					
Legare 2011 20795835 Legare 2011 20695950 Multi-country Narrative	Interprofessional SDM for clinical primary care	▪ Social norms (cultural values, routines and policies within society, the health care team, and the patient-family team) ▪ Organizational routines (activities that exhibit four characteristics: memory, adaptation, values and rules) ▪ Institutional structure (state-level policies that constrain organizations and individuals, including elected officials, government agencies, the public administration, the legislature and the legal system)	Yes	Yes	Yes	Medium
Makoul 2006 16051459 US SR	None specified	▪ None reported	Yes	No	No	Low
Metz 2015 26666295 Metz 2019 30151651 Netherlands Cluster RCT	Mental health care organizations	▪ None reported	No	Yes	Yes	Medium
Minnesota Shared Decision-Making Collaborative US Gray Lit	Patients with serious mental illness in psychiatric hospitals	▪ None reported	Yes	Yes	No	Low

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
Montori 2006 16436159 US Narrative	Patients with poorly controlled asthma	▪ Encounter environment (should allow patients to point out the clinician's shortcomings or failures in understanding the patient's context) ▪ Time constraints ▪ Appointment availability	Yes	Yes	No	Medium
Ng 2019 31099120 Malaysia Narrative	Multi-morbidity	▪ None reported	No	Yes	No	Medium
NICE 2012 UK Gray Lit	Patients with chronic conditions	▪ None reported	Yes	Yes	Yes	High
Nieuwenhuijze 2014 25008286 Netherlands Delphi Study	Maternity care	▪ None Reported	No	No	Yes	Not Assessed
Paudel 2018 28378300 US Obs Study	Inpatients with substance-related disorders	▪ None reported	No	Yes	No	Low
Peek 2016 27008649 US SR	African American LGBT patients	▪ Physical (e.g., location, infrastructure, resources) and social (e.g., cultural, political) context in which people live, including service quality in health systems and interactions with clinicians. ▪ Environment (society, community, and clinic) ▪ Social identity	No	No	No	Medium

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
		▪ Perceptions of others ▪ Individual decision-making preferences ▪ Patient/clinician trust in each other and existing patient/clinician relationship				
Peek 2008 18684581 US Qualitative	African Americans with diabetes	▪ None reported	No	No	No	High
Raue 2019 30967321 US RCT	Elderly depressed patients	▪ None reported	No	Yes	Yes	High
Rennke 2017 29073314 US Narrative	Hospital inpatients	▪ Provider/team: Individual and team-based factors such as cognitions, behavior, and social features; includes both personal and professional characteristics. ▪ Patient/family: Personal characteristics (beliefs, attitudes, emotions, behaviors), illness history, and social features (e.g., culture, education, literacy, social supports). ▪ Medical context: Factors related to the disease and the potential ways to evaluate or manage it.	Yes	Yes	Yes	High
Rubin 2014 24233814 US Narrative	Neurologic critical care	▪ None reported	Yes	Yes	No	Medium

First Author Year PMID Country Article Type	**Population and/or Clinical Setting**	**Factors Influencing SDM Model**	**Includes Families or Caregivers**	**Includes Care Team**	**Clinician Driven**	**Quality**
Rusiecki 2018 29068819 US Obs Study	Internal medicine residents	▪ None reported	No	No	Yes	Medium
Sanders 2018 29954333 Netherlands Cluster RCT	Inpatients addicted to psychoactive substances	▪ None reported	No	No	Yes	Low
Shay 2014 25097150 US Qualitative	Primary care patients	▪ Ongoing, trusting relationship between patient and provider	No	No	No	Medium
Siminoff 2005 16045427 US Narrative	Patients with cancer	▪ Sociodemographic characteristics (gender, age, ethnicity, and social status) ▪ Personality traits ▪ Communication competence ▪ Communication climate: Real-time situational facts, perceptions, thoughts, and emotions during consultation. Consists of expressed emotional, cognitive, and decisional preferences of the communicators.	Yes	No	No	Medium
Stiggelbout 2015 26215573 Netherlands Narrative	None specified	▪ None reported	Yes	No	Yes	Medium
Towle 1999 10488010 Canada Narrative	None specified	▪ None reported	Yes	Yes	No	Medium

First Author Year PMID Country Article Type	Population and/or Clinical Setting	Factors Influencing SDM Model	Includes Families or Caregivers	Includes Care Team	Clinician Driven	Quality
Truglio-Londrigan 2018 29456779 US SR	Nursing in all health care settings	▪ Patient's emotional state, friends/family, home, community supports, and networks ▪ Patient age, gender, spiritual and cultural beliefs, education, life experiences, race ▪ Clinician's readiness and receptiveness to explore a patient's feelings and preferences, work environment ▪ Time constraints ▪ Acute or chronic illness ▪ Health system	Yes	Yes	No	High
van de Pol 2016 26763871 van de Pol 2017 28027017 Netherlands Delphi Study	Frail older patients with multiple morbidities	▪ Time constraints	Yes	Yes	Yes	Not Assessed
Wilson 2010 20019345 US RCT	Patients with serious mental illness at a community mental health center	▪ None reported	No	Yes	Yes	Low
Zoffmann 2008 18223158 Denmark Qualitative	Patients with poorly controlled diabetes	▪ None reported	No	No	No	Low
Zisman-Ilani 29393685 Israel CCT	Patients with non-chronic low back pain seeing general practitioners	▪ None reported	No	No	No	Low

AHRQ=Agency for Healthcare Research and Quality; CCT=Controlled Clinical Trial; LGBT=Lesbian, Gay, Bisexual, or Transgender; Lit=Literature; Narrative=Narrative Review; Obs=Observational; RCT=Randomized Controlled Trial; SDM=Shared Decision-making;

Table B2. Components Shared Decision-making Models: Six Common Components

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
AHRQ 2016 US Gray Lit Medium	**x**	**x**	**x**	**x**	**x**	**x**
Ballard-Reisch 1990 US Narrative Medium		**x**	**x**	**x**	**x**	**x**
Berger-Höger 2019 30925280 Germany Cluster RCT Medium	**x**	**x**	**x**		**x**	**x**
Bomhof-Roordink 2019 30346076 Netherlands Qualitative High	**x**	**x**	**x**	**x**	**x**	
Callon 2018 29550295 US Qualitative Medium	**x**	**x**	**x**	**x**	**x**	
Charles 1997 9032835	**x**	**x**	**x**	**x**	**x**	

Author Year PMID Country Article Type Quality	Acknowledge decision needs to be made	Patient health care preferences, values, and/or goals	Information delivery and exchange	Deliberation	Make decision	Post-decision evaluation and follow-up
Charles 1999 10452420 Canada Narrative Medium						
Clayman 2017 27780646 Multi-Country Narrative Medium			x	x	x	x
Elwyn 2012 22618581 Elwyn 2017 29109079 Multi-country Narrative Medium	x	x	x	x	x	x
Elwyn 2000 11141876 Multi-country Qualitative High	x	x	x	x	x	x
Elwyn 2014 25175366 Multi-country Narrative Low	x	x	x	x		
Etingen 2019 30901448 US Qualitative		x	x	x	x	x

Author Year PMID Country Article Type Quality	Acknowledge decision needs to be made	Patient health care preferences, values, and/or goals	Information delivery and exchange	Deliberation	Make decision	Post-decision evaluation and follow-up
Medium						
Entwistle 2006 16875797 UK Narrative Medium	x	x	x	x		x
Goscha 2015 25033796 US Qualitative Medium		x	x	x	x	x
Grad 2017 28904031 Canada Narrative Low	x	x	x	x		x
Groen van de Ven 2017 28238420 Netherlands Qualitative High	x	x	x	x		x
Hamann 2014 25756970 Germany Narrative Medium	x	x	x	x		
Informed Medical Decisions Foundation 2012 US Gray Lit	x	x	x	x	x	x

Author Year PMID Country Article Type Quality	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
Low						
Ishii 2017 28166757 Ishii 2014 26666295 Japan RCT High		x	x	x		
Joosten 2008 19920974 Joosten 2009 19468259 Joosten 2011 21370962 Netherlands Cluster RCT Low	x	x		x	x	x
Joseph-Williams 2019 31351787 UK Qualitative High	x	x	x	x	x	x
Legare 2011 20795835 Legare 2011 20695950 Multi-country Narrative Medium	x	x	x	x	x	x
Makoul 2006 16051459 US	x	x	x	x	x	x

Author Year PMID Country Article Type Quality	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
SR Low						
Metz 2015 26666295 Netherlands Cluster RCT Medium		**x**	**x**	**x**	**x**	**x**
Minnesota Shared Decision-Making Collaborative US Gray Lit Low	**x**	**x**	**x**	**x**	**x**	**x**
Montori 2006 16436159 US Narrative Medium		**x**	**x**	**x**	**x**	**x**
NICE 2012 UK Gray Lit High		**x**	**x**	**x**	**x**	
Ng 2019 31099120 Malaysia Narrative Medium		**x**	**x**	**x**	**x**	**x**
Paudel 2018 28378300 US Obs Study		**x**	**x**	**x**		**x**

Author Year PMID Country Article Type Quality	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
Low						
Peek 2016 27008649 US SR Medium			x	x	x	
Peek 2008 18684581 US Qualitative High			x		x	
Raue 2019 30967321 US RCT High	x	x	x		x	x
Rennke 2017 29073314 US Narrative High		x	x	x	x	x
Rubin 2014 24233814 US Narrative Medium	x	x	x	x	x	
Rusiecki 2018 29068819 US Obs Study	x	x	x	x	x	x

Author Year PMID Country Article Type Quality	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
Medium						
Sanders 2018 29954333 Netherlands Cluster RCT Low	x	x			x	x
Shay 2014 25097150 US Qualitative Medium			x		x	
Siminoff 2005 16045427 US Narrative Medium			x	x	x	
Stiggelbout 2015 26215573 Netherlands Narrative Medium	x	x	x	x	x	x
Truglio-Londrigan 2018 29456779 US SR High	x		x	x	x	x

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Acknowledge decision needs to be made**	**Patient health care preferences, values, and/or goals**	**Information delivery and exchange**	**Deliberation**	**Make decision**	**Post-decision evaluation and follow-up**
van de Pol 2016 26763871 van de Pol 2017 28027017 Netherlands Delphi Study Not Assessed	**x**	**x**	**x**	**x**		**x**
Wilson 2010 20019345 US RCT Low	**x**	**x**	**x**	**x**	**x**	**x**
Zisman-Ilani 29393685 Israel CCT Low	**x**	**x**	**x**	**x**	**x**	
FREQUENCY (N=42)*	27	36	40	37	34	29
PERCENT*	64%	86%	95%	88%	81%	69%

*Frequency and percent calculations based on all components

AHRQ=Agency for Healthcare Research and Quality; Lit=Literature; Narrative=Narrative Review; Obs=Observational; RCT=Randomized Controlled Trial

Table B3. Components Shared Decision-making Models: Other Components

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
AHRQ 2016 US Gray Lit Medium					**x**			**x**		**x**				**X**
Ballard-Reisch 1990 US Narrative Medium				**x**										**x**
Berger-Höger 2019 30925280 Germany Cluster RCT Medium														
Bomhof-Roordink 2019 30346076 Netherlands Qualitative High					**x**		**x**							
Callon 2018 29550295 US Qualitative Medium							**x**					**x**		
Charles 1997 9032835 Charles 1999 10452420							**x**			**x**	**x**			**x**

Author Year PMID Country Article Type Quality	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
Canada Narrative Medium														
Clayman 2017 27780646 Multi-Country Narrative Medium	**x**													**x**
Elwyn 2012 22618581 Elwyn 2017 29109079 Multi-country Narrative Medium									**x**			**x**		**x**
Elwyn 2000 11141876 Multi-country Qualitative High					**x**									
Elwyn 2014 25175366 Multi-country Narrative Low									**x**			**x**		
Entwistle 2006 16875797 UK						**x**					**x**			

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
Narrative Medium														
Etingen 2019 30901448 US Qualitative Medium														
Goscha 2015 25033796 US Qualitative Medium														
Grad 2017 28904031 Canada Narrative Low														
Groen van de Ven 2017 28238420 Netherlands Qualitative High					**x**				**x**	**x**		**x**		**x**
Hamann 2014 25756970 Germany Narrative Medium							**x**			**x**				

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
Informed Medical Decisions Foundation 2012 US Gray Lit Low								**x**						
Ishii 2017 28166757 Ishii 2014 26666295 Japan RCT High														
Joosten 2008 19920974 Joosten 2009 19468259 Joosten 2011 21370962 Netherlands Cluster RCT Low														
Joseph-Williams 2019 31351787 UK Qualitative High		**x**						**x**	**x**					**x**
Legare 2011							**x**		**x**					**x**

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
20795835 Legare 2011 20695950 Multi-country Narrative Medium														
Makoul 2006 16051459 US SR Low				**x**	**x**		**x**		**x**	**x**		**x**		**x**
Minnesota Shared Decision-Making Collaborative US Gray Lit Low								**x**						
Metz 2015 26666295 Netherlands Cluster RCT Medium					**x**									
Montori 2006 16436159 US Narrative Medium						**x**		**x**			**x**	**x**		**X**
NICE 2012								**x**						

Author Year PMID Country Article Type Quality	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
UK Gray Lit High														
Ng 2019 31099120 Malaysia Narrative Medium			**x**											
Paudel 2018 28378300 US Obs Study Low	**x**			**x**						**x**	**x**			
Peek 2016 27008649 US SR Medium											**x**			
Peek 2008 18684581 US Qualitative High							**x**							
Raue 2019 30967321 US RCT														**x**

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
High														
Rennke 2017 29073314 US Narrative High					x									x
Rubin 2014 24233814 US Narrative Medium							x			x				
Rusiecki 2018 29068819 US Obs Study Medium														x
Sanders 2018 29954333 Netherlands Cluster RCT Low					x			x						
Shay 2014 25097150 US Qualitative Medium							x				x	x	x	

Author **Year** **PMID** **Country** **Article Type** **Quality**	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
Siminoff 2005 16045427 US Narrative Medium					**x**						**x**			
Stiggelbout 2015 26215573 Netherlands Narrative Medium					**x**			**x**	**x**					
Truglio-Londrigan 2018 29456779 US SR High				**x**	**x**				**x**		**x**	**x**		**x**
van de Pol 2016 26763871 van de Pol 2017 28027017 Netherlands Delphi Study Not Assessed		**x**		**x**	**x**						**x**			
Wilson 2010 20019345 US RCT Low								**x**						

Author Year PMID Country Article Type Quality	**Encounter preparation (patient)**	**Encounter preparation (clinician)**	**Disease Prioritization**	**Discuss patient self-efficacy**	**Patient decision-making preferences**	**Clinician preferences**	**Clinician recommendation**	**Check understanding**	**Preference revision**	**Consensus-building**	**Trust**	**Respect**	**Patient self-advocacy**	**Iterative process**
Zisman-Ilani 29393685 Israel CCT Low														
FREQUENCY (N=42)*	2	2	1	5	12	2	9	9	8	7	9	8	1	14
PERCENT*	5%	5%	2%	12%	29%	5%	21%	21%	19%	17%	21%	19%	2%	33 %

*Frequency and percent calculations based on all components
AHRQ=Agency for Healthcare Research and Quality; CCT=Controlled Clinical Trial; Lit=Literature; Narrative=Narrative Review; Obs=Observational; RCT=Randomized Controlled Trial

Table B4. Goals and Objectives Outlined by Shared Decision-making Models

First Author Year PMID Country Article Type Quality	Improve Patient Knowledge or Understanding	Increase Patient Acceptance or Satisfaction	Improve Patient Adherence	Increase Patient Autonomy or Self-Efficacy	Improve Patient Outcomes	Increase Clinician Understanding/Caring for Patients	Increase Clinician Job Satisfaction	Reduce Decisional Conflict or Regret	Better Health Care Decisions	Improve Patient-Clinician Relationship	Improve Patient Care Experience	Reduce Health Care Utilization or Cost of Care
AHRQ 2016 US Gray Lit Medium	x	x	x					x		x	x	x
Ballard-Reisch 1990 US Narrative Medium	x	x	x					x				
Charles 1997 9032835 Charles 1999 10452420 Canada Narrative Medium	x			x								
Metz 2015 26666295 Netherlands Cluster RCT Medium			x		x			x		x		
Peek 2016 27008649 US SR Medium	x	x		x	x	x	x			x		

First Author Year PMID Country Article Type Quality	**Improve Patient Knowledge or Understanding**	**Increase Patient Acceptance or Satisfaction**	**Improve Patient Adherence**	**Increase Patient Autonomy or Self-Efficacy**	**Improve Patient Outcomes**	**Increase Clinician Understanding/Caring for Patients**	**Increase Clinician Job Satisfaction**	**Reduce Decisional Conflict or Regret**	**Better Health Care Decisions**	**Improve Patient-Clinician Relationship**	**Improve Patient Care Experience**	**Reduce Health Care Utilization or Cost of Care**
Rennke 2017 29073314 US Narrative High		**x**	**x**								**x**	
Siminoff 2005 16045427 US Narrative Medium		**x**	**x**		**x**			**x**				
Stiggelbout 2015 26215573 Netherlands Narrative Medium		**x**	**x**		**x**				**x**	**x**		**x**
Wilson 2010 20019345 US RCT Low			**x**		**x**							**x**
FREQUENCY (N=9)	4	6	7	2	5	1	1	4	1	4	2	3
PERCENT	44%	67%	78%	22%	56%	11%	11%	44%	11%	44%	22%	33%

AHRQ=Agency for Healthcare Research and Quality; Lit=Literature; Narrative=Narrative Review; RCT=Randomized Controlled Trial

Table B5. Responsibilities of Clinicians in Shared Decision-making Models

First Author Year PMID Country Article Type Quality	Decide that participation is appropriate	Establish a conducive atmosphere for SDM	Establish partnership with patient	Check patient preferences for decision-making	Enable patient to participate in decision-making process	Acknowledge decision needs to be made	Check patient's history/Gather patient information	Check patient's preferred information format	Share information/Present options	Discuss Benefits/risks of options	Offer decision-support tools	Elicit patient health care preferences	Check patient understanding and knowledge	Initiate process of deliberation/negotiation	Support patient in process of deliberation	Share recommendations	Engage in independent and/or mutual	Motivate patient to reflect	Guide patient towards making a final decision	Give adequate time for decision-making	Evaluate decision/Arrange follow-up	Assist in implementation of decision
AHRQ 2016 US Gray Lit Medium					x				x	x		x									x	
Ballard-Reisch 1990 US Narrative Medium									x			x										
Bomhof-Roordink 2019 30346076 Netherlands Qualitative High		x			x												x			x		
Charles 1997 9032835 Charles 1999		x							x	x		x				x						

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Decide that participation is appropriate**	**Establish a conducive atmosphere for SDM**	**Establish partnership with patient**	**Check patient preferences for decision-making**	**Enable patient to participate in decision-making process**	**Acknowledge decision needs to be made**	**Check patient's history/Gather patient information**	**Check patient's preferred information format**	**Share information/Present options**	**Discuss Benefits/risks of options**	**Offer decision-support tools**	**Elicit patient health care preferences**	**Check patient understanding and knowledge**	**Initiate process of deliberation/negotiation**	**Support patient in process of deliberation**	**Share recommendations**	**Engage in independent and/or mutual**	**Motivate patient to reflect**	**Guide patient towards making a final decision**	**Give adequate time for decision-making**	**Evaluate decision/Arrange follow-up**	**Assist in implementation of decision**
10452420 Canada Narrative Medium																						
Elwyn 2012 22618581 Elwyn 2017 29109079 Multi-country Narrative Medium						x			x	x	x	x	x						x			
Elwyn 2000 11141876 Multi-country Qualitative High				x		x		x	x			x	x						x		x	
Grad 2017 28904031						x			x			x							x		x	

First Author Year PMID Country Article Type Quality	Decide that participation is appropriate	Establish a conducive atmosphere for SDM	Establish partnership with patient	Check patient preferences for decision-making	Enable patient to participate in decision-making process	Acknowledge decision needs to be made	Check patient's history/Gather patient information	Check patient's preferred information format	Share information/Present options	Discuss Benefits/risks of options	Offer decision-support tools	Elicit patient health care preferences	Check patient understanding and knowledge	Initiate process of deliberation/negotiation	Support patient in process of deliberation	Share recommendations	Engage in independent and/or mutual	Motivate patient to reflect	Guide patient towards making a final decision	Give adequate time for decision-making	Evaluate decision/Arrange follow-up	Assist in implementation of decision
Canada Narrative Low																						
Hamann 2014 25756970 Germany Narrative Medium	x													x								
Informed Medical Decisions Foundation 2012 US Gray Lit Low					x				x	x				x	x							x
Legare 2011 20795835 Legare 2011 20695950						x																

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Decide that participation is appropriate**	**Establish a conducive atmosphere for SDM**	**Establish partnership with patient**	**Check patient preferences for decision-making**	**Enable patient to participate in decision-making process**	**Acknowledge decision needs to be made**	**Check patient's history/Gather patient information**	**Check patient's preferred information format**	**Share information/Present options**	**Discuss Benefits/risks of options**	**Offer decision-support tools**	**Elicit patient health care preferences**	**Check patient understanding and knowledge**	**Initiate process of deliberation/negotiation**	**Support patient in process of deliberation**	**Share recommendations**	**Engage in independent and/or mutual**	**Motivate patient to reflect**	**Guide patient towards making a final decision**	**Give adequate time for decision-making**	**Evaluate decision/Arrange follow-up**	**Assist in implementation of decision**
Multi-country Narrative Medium																						
NICE 2012 UK Gray Lit High		**x**							**x**	**x**	**x**	**x**	**x**							**x**		
Nieuwenhuijze 2014 25008286 Netherlands Delphi Study Not Assessed		**x**			**x**				**x**			**x**							**x**			
Shay 2014 25097150 US Qualitative Medium									**x**													

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Decide that participation is appropriate**	**Establish a conducive atmosphere for SDM**	**Establish partnership with patient**	**Check patient preferences for decision-making**	**Enable patient to participate in decision-making process**	**Acknowledge decision needs to be made**	**Check patient's history/Gather patient information**	**Check patient's preferred information format**	**Share information/Present options**	**Discuss Benefits/risks of options**	**Offer decision-support tools**	**Elicit patient health care preferences**	**Check patient understanding and knowledge**	**Initiate process of deliberation/negotiation**	**Support patient in process of deliberation**	**Share recommendations**	**Engage in independent and/or mutual**	**Motivate patient to reflect**	**Guide patient towards making a final decision**	**Give adequate time for decision-making**	**Evaluate decision/Arrange follow-up**	**Assist in implementation of decision**
Siminoff 2005 16045427 US Narrative Medium		**x**																				
Rusiecki 2018 29068819 US Obs Study Medium						**x**			**x**			**x**	**x**	**x**								
Sanders 2018 29954333 Netherlands Cluster RCT Low				**x**					**x**			**x**	**x**									
Stiggelbout 2015 26215573 Netherlands				**x**		**x**			**x**	**x**					**x**							

First Author Year PMID Country Article Type Quality	**Decide that participation is appropriate**	**Establish a conducive atmosphere for SDM**	**Establish partnership with patient**	**Check patient preferences for decision-making**	**Enable patient to participate in decision-making process**	**Acknowledge decision needs to be made**	**Check patient's history/Gather patient information**	**Check patient's preferred information format**	**Share information/Present options**	**Discuss Benefits/risks of options**	**Offer decision-support tools**	**Elicit patient health care preferences**	**Check patient understanding and knowledge**	**Initiate process of deliberation/negotiation**	**Support patient in process of deliberation**	**Share recommendations**	**Engage in independent and/or mutual**	**Motivate patient to reflect**	**Guide patient towards making a final decision**	**Give adequate time for decision-making**	**Evaluate decision/Arrange follow-up**	**Assist in implementation of decision**
Narrative Medium																						
Towle 1999 10488010 Canada Narrative Medium		**x**	**x**					**x**	**x**	**x**		**x**									**x**	
van de Pol 2016 26763871 van de Pol 2017 28027017 Netherlands Delphi Study Not Assessed							**x**		**x**			**x**							**x**		**x**	
Wilson 2010 20019345 US RCT						**x**	**x**		**x**					**x**							**x**	

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Decide that participation is appropriate**	**Establish a conducive atmosphere for SDM**	**Establish partnership with patient**	**Check patient preferences for decision-making**	**Enable patient to participate in decision-making process**	**Acknowledge decision needs to be made**	**Check patient's history/Gather patient information**	**Check patient's preferred information format**	**Share information/Present options**	**Discuss Benefits/risks of options**	**Offer decision-support tools**	**Elicit patient health care preferences**	**Check patient understanding and knowledge**	**Initiate process of deliberation/negotiation**	**Support patient in process of deliberation**	**Share recommendations**	**Engage in independent and/or mutual reflection**	**Motivate patient to reflect**	**Guide patient towards making a final decision**	**Give adequate time for decision-making**	**Evaluate decision/Arrange follow-up**	**Assist in implementation of decision**
Low																						
Zoffmann 2008 18223158 Denmark Qualitative Low							**x**										**x**	**x**				
FREQUENCY (N=21)	1	6	1	3	3	7	3	2	17	7	2	13	5	4	2	1	1	1	5	1	6	1
PERCENT	5%	29%	5%	14%	14%	33%	14%	10%	81%	33%	10%	62%	24%	19%	10%	5%	5%	5%	24%	5%	29%	5%

AHRQ=Agency for Healthcare Research and Quality; Lit=Literature; Narrative=Narrative Review; RCT=Randomized Controlled Trial

Table B6. Responsibilities of Patients in Shared Decision-making Models

First Author Year PMID Article Type Quality	Establish partnership with clinician	Prepare for encounter	Share information/health care preferences with clinician	Gather information from clinician	Disclose preferred role in decision-making	Engage in individual and/or mutual reflection	Evaluate information provided	Negotiate a decision	Agree on action plan	Take action/execute decision
Ballard-Reisch 1990 US Narrative Medium			x	x						
Bomhof-Roordink 2019 30346076 Netherlands Qualitative High			x				x			
Charles 1997 9032835 Charles 1999 10452420 Canada Narrative Medium			x							
Clayman 2017 27780646 Multi-Country Narrative Medium		x		x		x				x
Shay 2014 25097150 US Qualitative			x							

Medium										
Siminoff 2005 16045427 US Narrative Medium					**x**					
Towle 1999 10488010 Canada Narrative Medium	**x**		**x**		**x**		**x**	**x**	**x**	
Zoffmann 2008 18223158 Denmark Qualitative Low			**x**							
FREQUENCY (N=8)	1	1	6	2	2	1	2	1	1	1
PERCENT	13%	13%	75%	25%	25%	13%	25%	13%	13%	13%

Narrative=Narrative Review

Table B7. Results of Studies Examining Shared Decision-making Interventions: Randomized and Controlled Clinical Trials

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
Berger-Höger 2019 30925280 Germany Cluster RCT Medium	SDM vs. Usual Care N=67 Women with ductal carcinoma in situ at breast cancer centers Age 58 100% Female Race NR 27% Upper Secondary School or Higher	Multifocal APProach to the sharing' IN Shared Decision-Making, Patient Questionnaire Mean (95% CI) End of Consultation	3.87 (3.78, 3.96)	3.82 (3.68, 3.96)	Cluster mean difference (95% CI) 0.05 (-0.10, 0.20)
		Decisional Conflict Scale, Patient Mean (95% CI) End of Consultation	6.44 (2.22, 10.66)	6.47 (0.00, 13.37)	Cluster mean difference (95% CI) 0.03 (-7.24, 7.17)
Ishii 2017 28166757 Ishii 2014 26666295 Japan RCT High	SDM vs. Usual Care N=24 Acute psychiatric ward Patients with schizophrenia with first inpatient admission 39 years 32% Female Race NR Education NR	Client Satisfaction Questionnaire (CSQ-8-J) Mean Score (SD) Discharge	23.7 (3.9)	22.1 (3.7)	Adjusted Treatment Effect (95% CI) -0.8 (-4.2, 2.6)
		Drug Attitude Inventory-10 (DAI-10, Japanese Version) Mean Score (SD) Discharge	3.8 (3.7)	2.3 (4.8)	Adjusted Treatment Effect (95% CI) -1.1 (-4.4, 2.3)
		Global Assessment of Functioning (GAF) Mean Score (SD) Discharge	55.6 (11.2)	47.8 (18.9)	Adjusted Treatment Effect (95% CI) 4.0 (-13.0, 20.0)
		Average Length of Stay Mean (SD) Discharge	66.7 (40.4)	66.5 (17.4)	Adjusted Treatment Effect (95% CI) -1.7 (-43.6, 40.9)

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
		Number of patients who received psychiatric treatment within 30 days prior to follow-up 6 months	8	9	Adjusted Risk Difference (95% CI) 22.1 (-24.9, 70.1)
Joosten 2008 19920974 Netherlands Cluster RCT Low	SDM vs. Control (motivational interviewing) N=227 Inpatient treatment facility Individuals with substance-related disorder requiring inpatient treatment 41 years 24% Female Race NR 11.5 years	Helping Alliance Questionnaire (HAQ), Patient Total Mean (SD) 3 months (end of treatment)	46.6 (4.7)	47.5 (6.3)	p= 0.42
		Helping Alliance Questionnaire (HAQ), Clinician Total Mean (SD) 3 months (end of treatment)	42.6 (4.2)	39.4 (6.0)	p=0.01
		Helping Alliance Questionnaire (HAQ), Difference between patient and clinician scores 3 months (end of treatment)	3.7 (5.4)	7.0 (7.3)	p=0.02
Joosten 2009 19468259 Netherlands Cluster RCT Low	SDM vs. Control (motivational interviewing) N=227 Inpatient treatment facility	Days of primary substance use Mean (SD) 6 months (3 months post-treatment)	3.2 (8.6)	3.2 (7.3)	p=0.75
		Patients who are substance dependent % 6 months (3 months post-treatment)	52%	48%	p=0.68
		EQ-5D Utility Score 6 months (3 months post-treatment)	NR	NR	p=0.98

First Author Year PMID Country Article Type Quality	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	Measure Timepoint	SDM	Comparator	p-value Summary Statistic
	Individuals with substance-related disorder requiring inpatient treatment 40 years 28% Female Race NR 11.4 years	EuropASI Total Score Mean (SD) 6 months (3 months post-treatment)	NR	NR	p=0.18
		EuropASI Physical Health Subscale Mean (SD) 6 months (3 months post-treatment)	1.6 (1.9)	2.0 (2.1)	p=0.35
		EuropASI Work, Education and Income Subscale Mean (SD) 6 months (3 months post-treatment)	2.7 (2.0)	2.7 (2.1)	p=0.94
		EuropASI Alcohol Subscale Mean (SD) 6 months	3.1 (2.4)	3.6 (2.5)	p=0.1
		EuropASI Drugs Subscale Mean (SD) 6 months (3 months post-treatment)	1.6 (2.2)	2.3 (2.8)	p<0.01
		EuropASI Legal Subscale Mean (SD)	0.2 (0.7)	0.6 (1.4)	p=0.70
		EuropASI Family/Social Relations Subscale Mean (SD) 6 months (3 months post-treatment)	2.0 (1.9)	2.7 (2.3)	p=0.46
		EuropASI Psychological/Emotional Problems Subscale Mean (SD) 6 months (3 months post-treatment)	3.0 (2.3)	4.0 (2.5)	p=0.02

First Author Year PMID Country Article Type Quality	Comparison Baseline N Setting Participant Characteristics Clinical Condition Mean Age % Female Race	Measure Timepoint	SDM	Comparator	p-value Summary Statistic
		EuropASI Gambling Subscale Mean (SD) 6 months (3 months post-treatment)	0.1 (0.7)	0.1 (0.5)	p=0.34
Metz 2015 26666295 Metz 2019 30151651 Netherlands Cluster RCT Medium	SDM vs. Usual Care N=186 Patients at mental health care organizations (range of diagnoses) 47 years 60% Female Race NR 64% Secondary School or Higher	Decisional Conflict Scale Mean Score (SD) 6 months	33.03 (19.32)	33.18 (16.52)	p=0.72 Effect Size=0.07
		Working Alliance Inventory Short Form (WAI-S) Patient Mean Total Score (SD) 6 months	3.54 (0.90)	3.57 (0.89)	p=0.87 Effect Size=-0.03
		Outcome Questionnaire Mean Score (SD) 6 months	78.07 (31.08)	71.69 (24.73)	p=0.83 Effect Size=-0.05
		Manchester Short Quality of Life Measurement Mean Score (SD) 6 months	4.30 (0.94)	4.35 (0.94)	p=0.07 Effect Size=-0.42
		SDM-Q-9, Patient Mean Score (SD) 6 months	64.39 (24.88)	65.22 (23.94)	p=0.83 Effect Size=-0.03
		SDM-Q-9, Clinician Mean Score (SD) 6 months	75.78 (16.22)	69.61 (18.92)	p=0.12 Effect Size=0.31
Raue 2019 30967321 US RCT	SDM vs. Usual Care N=202	Adherence Level Mean (SD) 12 weeks	0.18 (0.03)	0.10 (0.03)	p=0.15

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
High	Elderly depressed patients seeking primary care 72 years 81% Female 55% White Education NR	Satisfaction with Decision Scale Mean (SD) 1 week	3.06 (0.18)	3.1 (0.34)	p=0.93
		24-item Hamilton Depression Rating Scale Mean (SD) 12 weeks	12.9 (0.8)	12.0 (0.9)	OR (95% CI) Treatment x Time 0.88 (−2.40, 4.17)
Sanders 2018 29954333 Netherlands Cluster RCT Low	SDM vs. Usual Care N=226 Primary Care Non-specific low back pain 45 years 53% Female Race NR 33% College/University	Involved in Decision-making? 1=no, 2=mostly no, 3=mostly yes, 4=yes Mean (SD) Unclear (post-consultation)	2.92 (1.12)	2.44 (1.23)	p=0.005
		Roland-Morris Disability Questionnaire Mean (SD) 2 weeks (post-consultation)	4.1 (5.3)	4.3 (4.8)	0.789
		Roland-Morris Disability Questionnaire Mean (SD) 26 weeks (post-consultation)	2.0 (3.7)	2.0 (3.6)	p=0.95 Mean Difference (95% CI) -0.23 (−1.26, 0.791)
		Pain Visual Analogue Scale Mean (SD) 2 weeks (post-consultation)	18.9 (21.7)	20.3 (20.9)	p=0.68
		Pain Visual Analogue Scale Mean (SD) 26 weeks (post-consultation)	13.6 (17.3)	16.3 (21.2)	p=0.39

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
					Mean Difference (95% CI) -1.12 (-6.13, 3.89)
		Adequate Relief (yes/no) N (%) 2 weeks (post-consultation)	70 (81%)	62 (81%)	p=0.89
		Adequate Relief (yes/no) N (%) 26 weeks (post-consultation)	35 (66%)	32 (64%)	p=0.83 OR (95% CI) 1.12 (0.51, 1.57)
		Absenteeism (days) Mean (SD) 2 weeks (post-consultation)	1.47 (3.35)	2.05 (4.03)	p=0.34
		Telephone consultations (per patient) Mean (SD) 2 weeks (post-consultation)	0.35 (0.71)	0.29 (0.60)	p=0.57
		Practice consultations (per patient) Mean (SD) 2 weeks (post-consultation)	0.21 (0.51)	0.11 (0.39)	p=0.13
		Practice consultations (per patient) Mean (SD) 26 weeks (post-consultation)	1.11 (0.45)	1.10 (0.38)	p=0.83 Rate Ratio (95% CI) 1.01 (0.88, 1.17)
Wilson 2010 20019345 US	SDM vs. Usual Care N=408	Fill/refill Adherence Continuous medication acquisition index	0.67	0.46	p<0.0001

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
RCT Low	Outpatient Care Patients with poorly controlled asthma 46 years 57% Female 61% White 37% 4-year College Degree or Higher	12 months			
		Asthma-Related Quality of Life Five-item Symptom Subscale of the Juniper Mini Asthma Quality of Life Questionnaire Mean 12 months	5.5	5.1	p<0.01
		Annual asthma-related Visits Mean visits per year 12 months	1/year	1.4/year	p=0.016
		Asthma Therapy Assessment Questionnaire (ATAQ) Odds of reporting no asthma control problems 12 months	NR	NR	p=0.002
		Lung Function Adjusted mean percent predicted FEV1 12 months	76.50%	73.10%	p=0.007 OR (95% CI) 1.9 (1.3, 2.9)
Wilson 2010 20019345 US RCT Low	SDM vs. Clinician Decision-making N=408 Outpatient are	Fill/refill Adherence Continuous medication acquisition index 12 months	0.67	0.59	p=0.03
		Asthma-Related Quality of Life Five-item Symptom Subscale of the	5.5	5.4	p=0.33

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
	Patients with poorly controlled asthma 46 years 56% Female 62% White 38% 4-year College Degree or Higher	Juniper Mini Asthma Quality of Life Questionnaire Mean 12 months			
		Annual asthma-related Visits Mean visits per year 12 months	1/year	1.1/year	p=0.97
		Lung Function Adjusted mean percent predicted FEV1 12 months	76.50%	75.80%	p=0.47
		Patient-Perceived Roles in Treatment Decision Making 5-point scale Mean (SD) After First Session	3.1 (0.6)	2.5 (0.9)	p<0.0001
Zisman-Ilani 29393685 Israel CCT Low	SDM vs. Usual Care N=101 Psychiatric hospitals Patients with Serious Mental Illness 37 years 43% Female Race NR	SDM-Q-9 Mean (SD) After choosing rehabilitation plan (timing unknown)	87.73 (7.68)	47.11 (25.59)	p<0.001
		Decision Self-Efficacy Scale Mean (SD) After choosing rehabilitation plan (timing unknown)	85.38 (11.0)	49.38 (24.16)	p<0.001
		Decision Attitude Scale (DAS) Mean (SD)	4.12 (0.33)	3.09 (0.72)	p<0.001

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Comparison** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**SDM**	**Comparator**	**p-value** **Summary Statistic**
	12.4 years	After choosing rehabilitation plan (timing unknown)			
		Patient Knowledge about the Rehabilitation Services and Process instrument Mean (SD) After choosing rehabilitation plan (timing unknown)	11.50 (3.48)	5.36 (3.73)	p<0.001
		The Hope Scale 6-12 months post-discharge	NR	NR	p< 0.001
		The Recovery Assessment Scale (RAS) 6-12 months post-discharge	NR	NR	p< 0.001
		Use of psychiatric rehabilitation services N (%) 6-12 months post-discharge	35/44 (79.5%)	14/40 (35%)	p<0.001
		Rehospitalization rate N (%) 6-12 months post-discharge	1/45 (2.2%)	4/40 (10%)	p> 0.05

CCT=Controlled Clinical Trial; CI=Confidence Interval; EuropASI=European Addiction Severity Index; FEV1= Forced Expiratory Volume, First Second; NR=Not Reported; OR=Odds Ratio; RCT=Randomized Controlled Trial; SD=Standard Deviation; SDM=Shared Decision-Making; SDM-Q-9=9-item Shared Decision Making Questionnaire

Table B8. Results of Studies Examining Shared Decision-making Interventions: Observational Trials

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Intervention** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Measure** **Timepoint**	**Findings**	**p-value** **Summary Statistic**
Paudel 2018 28378300 US Obs Study Low	SDM Group Therapy Intervention N=22 Community Mental Health Clinic Severe and persistent mental illness 45-65 years 50% Female Race NR Education NR	Decisional Conflict Scale Mean 12 weeks (post-intervention)	Less decision conflict post-intervention: Pre-Intervention: 34.77 Post-Intervention 9.28	p=0.0001
		Satisfaction Survey on SDM (4 questions) 12 weeks (post-intervention)	2/3 of completers believed that SDM was helpful 2/3 disagreed that SDM was too difficult for them to understand 70%+ agreed they had gained something important from SDM Majority agreed they had learned something	NR

NR=Not Reported; Obs=Observational; SDM=Shared Decision-Making

Table B9. Results of Studies Examining Shared Decision-making Interventions: Qualitative Studies

First Author **Year** **PMID** **Country** **Article Type** **Quality**	**Intervention** **Baseline N** **Setting** **Participant Characteristics** Clinical Condition Mean Age % Female Race	**Timepoint**	**Topic**	**Findings**
Goscha 2015 25033796 US Qualitative Medium	SDM vs. Usual Care N=12 Severe chronic mental illness 45 years 42% Female 58% African American Education NR	9 months	Goal-Setting	Staff reported an increase in involvement in shared decision making when the client had a goal he/she wanted to achieve via the use of medications. Prior to SDM, many of these goals had never been verbalized.
			Client Involvement	Clients became more involved in using the SDM and participated more in the medication consultation when progress toward their stated goal was being made in subsequent visits.
			Information Exchange	Clients in the SDM group were more likely to disclose information with their prescriber such as substance use, side effects of the medications, and actual use of the medication.
			Interaction with Case Manager	With clients who were highly engaged with SDM, there tended to be the presence of a case manager who was actively involved in all phases of the shared decision-making process. For clients who were not actively engaged, there seemed to be a between client and case manager.
			Medication Use	For clients who were actively using personal medicines, these were often discussed during the medication consultation with their prescriber and incorporated into the shared decision to increase options toward goal attainment.

NR=Not Reported; SDM=Shared Decision-Making

APPENDIX C: EXCLUDED LITERATURE

Not on Shared Decision-Making[1-23]

1. Amblas-Novellas J, Espaulella J, Rexach L, et al. Frailty, severity, progression and shared decision-making: A pragmatic framework for the challenge of clinical complexity at the end of life. *European Geriatric Medicine.* 2015;6(2):189-194.
2. Auerbach LS. Childbirth in Tunisia. Implications of a decision-making model. *Social Science & Medicine.* 1982;16(16):1499-1506.
3. Ballard T, Yeo G, Loft S, Vancouver JB, Neal A. An integrative formal model of motivation and decision making: The MGPM. *J Appl Psychol.* 2016;101(9):1240-1265.
4. Balneaves LG, Long B. An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. *Journal of advanced nursing.* 1999;30(6):1321-1331.
5. Balneaves LG, Truant TL, Kelly M, Verhoef MJ, Davison BJ. Bridging the gap: decision-making processes of women with breast cancer using complementary and alternative medicine (CAM). *Support Care Cancer.* 2007;15(8):973-983.
6. Burton CD, Entwistle VA, Elliott AM, Krucien N, Porteous T, Ryan M. The value of different aspects of person-centred care: A series of discrete choice experiments in people with long-term conditions. *BMJ open.* 2017;7 (4) (no pagination)(e015689).
7. Calabro MD, Tukoski B. Participative ethical decision making. A model for primary care. *Adv Nurse Pract.* 2003;11(6):83-88.
8. Charles C, DeMaio S. Lay participation in health care decision making: a conceptual framework. *J Health Polit Policy Law.* 1993;18(4):881-904.
9. Coombes JA, Rowett D, Whitty JA, Cottrell NW. Using a structured, patient-centred, educational exchange to facilitate a shared conversation about stroke prevention medications. *Journal of Evaluation in Clinical Practice.* 2019.
10. DeKeyser Ganz F, Engelberg R, Torres N, Curtis JR. Development of a Model of Interprofessional Shared Clinical Decision Making in the ICU: A Mixed-Methods Study. *Crit Care Med.* 2016;44(4):680-689.
11. Elwyn G, Miron-Shatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations.* 2010;13(2):139-147.
12. Golanowski M, Beaudry D, Kurz L, Laffey WJ, Hook ML. Interdisciplinary shared decision-making: taking shared governance to the next level. *Nurs Adm Q.* 2007;31(4):341-353.
13. Hamilton J. The collaborative model of doctor-patient consultation--is it always culturally appropriate? What do doctors and patients need to know to make it work in intercultural contexts? *Med Teach.* 2009;31(2):163-165.
14. Holzmueller CG, Wu AW, Pronovost PJ. A framework for encouraging patient engagement in medical decision making. *J Patient Saf.* 2012;8(4):161-164.

15. Johnson MO. The shifting landscape of health care: toward a model of health care empowerment. *American journal of public health.* 2011;101(2):265-270.
16. Kamal RN, Lindsay SE, Eppler SL. Patients Should Define Value in Health Care: A Conceptual Framework. *Journal of Hand Surgery.* 2018.
17. Lequerica AH, Kortte K. Therapeutic engagement: a proposed model of engagement in medical rehabilitation. *Am J Phys Med Rehabil.* 2010;89(5):415-422.
18. Moreau A, Carol L, Dedianne MC, et al. What perceptions do patients have of decision making (DM)? Toward an integrative patient-centered care model. A qualitative study using focus-group interviews. *Patient Education & Counseling.* 2012;87(2):206-211.
19. Rutten G, van Vugt HA, de Weerdt I, de Koning E. Implementation of a Structured Diabetes Consultation Model to Facilitate a Person-Centered Approach: Results From a Nationwide Dutch Study. *Diabetes Care.* 2018;41(4):688-695.
20. Treichler EB, Spaulding WD. Beyond shared decision-making: Collaboration in the age of recovery from serious mental illness. *American Journal of Orthopsychiatry.* 2017;87(5):567-574.
21. Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. *Eur J Gen Pract.* 2003;9(2):62-65.
22. Wilson JH, Hobbs H. Therapeutic partnership. A model for clinical practice. *Journal of psychosocial nursing and mental health services.* 1995;33(2):27-30.
23. Witt J, Elwyn G, Wood F, Brain K. Decision making and coping in healthcare: the Coping in Deliberation (CODE) framework. *Patient Education & Counseling.* 2012;88(2):256-261.

Shared Decision-Making Tool Only[24-74]

24. Al-Itejawi HH, van Uden-Kraan CF, Vis AN, et al. Development of a patient decision aid for the treatment of localised prostate cancer: A participatory design approach. *Journal of Clinical Nursing.* 2016;25(7-8):1131-1144.
25. Alden DL, Friend J, Fraenkel L, Jibaja-Weiss M. The effects of culturally targeted patient decision aids on medical consultation preparation for Hispanic women in the U.S.: Results from four randomized experiments. *Social Science and Medicine.* 2018;212:17-25.
26. Athale A, Giguere A, Barbara A, Krassova S, Iorio A. Developing a two-sided intervention to facilitate shared decision-making in haemophilia: decision boxes for clinicians and patient decision aids for patients. *Haemophilia.* 2014;20(6):800-806.
27. Baik D, Cho H, Masterson Creber RM. Examining Interventions Designed to Support Shared Decision Making and Subsequent Patient Outcomes in Palliative Care: A Systematic Review of the Literature. *Am J Hosp Palliat Care.* 2018:1049909118783688.
28. Barr PJ, Forcino RC, Dannenberg MD, et al. Healthcare Options for People Experiencing Depression (HOPE*D): The development and pilot

testing of an encounter-based decision aid for use in primary care. *BMJ open.* 2019;9 (4) (no pagination)(e025375).

29. Barrett PH, Beck A, Schmid K, Fireman B, Brown JB. Treatment decisions about lumbar herniated disk in a shared decision-making program. *Jt Comm J Qual Improv.* 2002;28(5):211-219.
30. Barry MJ, Cherkin DC, Chang Y, Fowler FJ, Jr., Skates S. A randomized trial of a multimedia shared decision-making program for men facing a treatment decision for benign prostatic hyperplasia. *Disease Management and Clinical Outcomes.* 1997;1(1):5-14.
31. Bieber C, Müller K, Blumenstiel K, et al. A shared decision-making communication training program for physicians treating fibromyalgia patients: effects of a randomized controlled trial. *Journal of psychosomatic research.* 2008;64(1):13-20.
32. Bieber C, Müller K, Blumenstiel K, et al. Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient education and counseling.* 2006;63(3):357-366.
33. Buhse S, Kuniss N, Liethmann K, Muller UA, Lehmann T, Muhlhauser I. Informed shared decision-making programme for patients with type 2 diabetes in primary care: cluster randomised controlled trial. *BMJ open.* 2018;8(12):e024004.
34. Chhatriwalla AK, Decker C, Gialde E, et al. Developing and Testing a Personalized, Evidence-Based, Shared Decision-Making Tool for Stent Selection in Percutaneous Coronary Intervention Using a Pre-Post Study Design. *Circulation Cardiovascular Quality & Outcomes.* 2019;12(2):e005139.
35. Collinsworth A, Brown R, Sjames C, stanford R, Alemayehu D, Priest E. The impact of patient education and shared decision making on hospital readmissions for COPD. *International journal of COPD.* 2018;13:1325-1332.
36. Cupples ME, Cole JA, Hart ND, Heron N, McKinley MC, Tully MA. Shared decision-making (SHARE-D) for healthy behaviour change: a feasibility study in general practice. *BJGP open.* 2018;2(2):bjgpopen18X101517.
37. Deinzer A, Veelken R, Kohnen R, Schmieder R. Is a shared decision-making approach effective in improving hypertension management? *Journal of clinical hypertension (greenwich, conn).* 2009;11(5):266-270. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/761/CN-00721761/frame.html.
38. Doll JA, Jones WS, Lokhnygina Y, et al. PREPARED Study: A Study of Shared Decision-Making for Coronary Artery Disease. *Circulation Cardiovascular Quality & Outcomes.* 2019;12(2):e005244.
39. Durif-Bruckert C, Roux P, Morelle M, Mignotte H, Faure C, Moumjid-Ferdjaoui N. Shared decision-making in medical encounters regarding breast cancer treatment: The contribution of methodological triangulation. *European Journal of Cancer Care.* 2015;24(4):461-472.

40. Fagan HB, Fournakis NA, Jurkovitz C, et al. Telephone-Based Shared Decision-making for Lung Cancer Screening in Primary Care. *J Cancer Educ.* 2019;09:09.
41. Finnerty M, Austin E, Chen Q, et al. Implementation and Use of a Client-Facing Web-Based Shared Decision-Making System (MyCHOIS-CommonGround) in Two Specialty Mental Health Clinics. *Community Mental Health Journal.* 2019;55(4):641-650.
42. Finnerty MT, Layman DM, Chen Q, et al. Use of a Web-Based Shared Decision-Making Program: Impact on Ongoing Treatment Engagement and Antipsychotic Adherence. *Psychiatric Services.* 2018;69(12):1215-1221.
43. Fortnum D, Smolonogov T, Walker R, Kairaitis L, Pugh D. 'My kidneys, my choice, decision aid': supporting shared decision making. *J.* 2015;41(2):81-87.
44. Hahlweg P, Witzel I, Muller V, Elwyn G, Durand MA, Scholl I. Adaptation and qualitative evaluation of encounter decision aids in breast cancer care. *Archives of Gynecology and Obstetrics.* 2019.
45. Hamann J, Cohen R, Leucht S, Busch R, Kissling W. Shared decision making and long-term outcome in schizophrenia treatment. *Journal of clinical psychiatry.* 2007;68(7):992-997. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/045/CN-00700045/frame.html http://www.psychiatrist.com/jcp/article/pages/2007/v68n07/v68n0703.aspx.
46. Hamann J, Holzhuter F, Stecher L, Heres S. Shared decision making PLUS-A cluster-randomized trial with inpatients suffering from schizophrenia (SDM-PLUS). *BMC Psychiatry Vol 17 2017, ArtID 78.* 2017;17.
47. Hamann J, Langer B, Winkler V, et al. Shared decision making for in-patients with schizophrenia. *Acta psychiatrica scandinavica.* 2006;114(4):265-273. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/148/CN-00572148/frame.html https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1600-0447.2006.00798.x.
48. Harcourt D, Griffiths C, Baker E, Hansen E, White P, Clarke A. The acceptability of PEGASUS: An intervention to facilitate shared decision-making with women contemplating breast reconstruction. *Psychology, health & medicine.* 2016;21(2):248-253.
49. Harter M, Buchholz A, Nicolai J, et al. Shared decision making and the use of decision aids: A cluster-randomized study on the efficacy of a training in an oncology setting. *Deutsches Arzteblatt International.* 2015;112(40):672-689.
50. Härter M, Buchholz A, Nicolai J, et al. Shared Decision Making and the Use of Decision Aids. *Deutsches arzteblatt international.* 2015;112(40):672-679. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/496/CN-01259496/frame.html https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4640071/pdf/Dtsch_Arztebl_Int-112-0672.pdf.

51. Holt K, Kimport K, Kuppermann M, Fitzpatrick J, Steinauer J, Dehlendorf C. Patient-provider communication before and after implementation of the contraceptive decision support tool My Birth Control. *Patient Education and Counseling.* 2019.
52. Jacklin S, Maskrey N, Chapman S. Improving Shared Decision Making Between Patients and Clinicians: Design and Development of a Virtual Patient Simulation Tool. *JMIR Med Educ.* 2018;4(2):e10088.
53. Lin PJ, Fang SY, Kuo YL. Development and Usability Testing of a Decision Support App for Women Considering Breast Reconstruction Surgery. *Journal of cancer education : the official journal of the American Association for Cancer Education.* 2019;28.
54. Mangla M, Cha TD, Dorrwachter JM, et al. Increasing the use of patient decision AIDS in orthopaedic care: Results of a quality improvement project. *BMJ Quality and Safety.* 2018;27(5):347-354.
55. Mazzone PJ, Tenenbaum A, Seeley M, et al. Impact of a Lung Cancer Screening Counseling and Shared Decision-Making Visit. *Chest.* 2017;151(3):572-578.
56. McCarus SD, Wiercinski K, Heidrich N. Shared Decision-Making to Improve Patient Engagement in Minimally Invasive Hysterectomy. *Surg Technol Int.* 2019;34:265-268.
57. McLellan C, O'Neil AI, Cameron M, et al. Facilitating Informed Treatment Decisions in Acne: A Pilot Study of a Patient Decision Aid. *Journal of cutaneous medicine and surgery.* 2019;23(1):117-118.
58. Metz M, Elfeddali I, Veerbeek M, de Beurs E, Beekman A, van der Feltz-Cornelis C. Effectiveness of a multi-facetted blended eHealth intervention during intake supporting patients and clinicians in Shared Decision Making: A cluster randomised controlled trial in a specialist mental health outpatient setting. *PLoS ONE.* 2018;13(6):e0199795.
59. Moin T, Duru OK, Turk N, et al. Effectiveness of Shared Decision-making for Diabetes Prevention: 12-Month Results from the Prediabetes Informed Decision and Education (PRIDE) Trial. *Journal of general internal medicine.* 2019;30:30.
60. Myers RE, Leader AE, Censits JH, et al. Decision Support and Shared Decision Making About Active Surveillance Versus Active Treatment Among Men Diagnosed with Low-Risk Prostate Cancer: a Pilot Study. *J Cancer Educ.* 2018;33(1):180-185.
61. Owens OL, Kim S, Tavakoli AS. Are decision aids leading to shared prostate cancer screening decisions among African-American men?: iDecide. *Cancer Causes and Control.* 2019;30(7):713-719.
62. Paraskeva N, Clarke A, Grover R, Hamilton S, Withey S, Harcourt D. Facilitating shared decision-making with breast augmentation patients: Acceptability of the PEGASUS intervention. *J Plast Reconstr Aesthet Surg.* 2017;70(2):203-208.
63. Patel S, Ngunjiri A, Hee S, et al. Primum non nocere: shared informed decision making in low back pain - A pilot cluster randomised trial. *BMC musculoskeletal disorders.* 2014;15(1 // () *Wolfson Foundation*).

http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/373/CN-01022373/frame.html https://bmcmusculoskeletdisord.biomedcentral.com/track/pdf/10.1186/1471-2474-15-282.

64. Roosmalen M, Stalmeier P, Verhoef L, et al. Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. *Journal of clinical oncology.* 2004;22(16):3293-3301. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/444/CN-00481444/frame.html.
65. Schaffer JT, Hess EP, Hollander JE, et al. Impact of a Shared Decision Making Intervention on Health Care Utilization: a Secondary Analysis of the Chest Pain Choice Multicenter Randomized Trial. *Academic emergency medicine.* 2018;25(3):293-300.
66. Shorten A, Shorten B, Fagerlin A, et al. A Study to Assess the Feasibility of Implementing a Web-Based Decision Aid for Birth after Cesarean to Increase Opportunities for Shared Decision Making in Ethnically Diverse Settings. *Journal of midwifery & women's health.* 2019;64(1):78-87.
67. Sondergaard SR, Madsen PH, Hilberg O, Jensen KM, Olling K, Steffensen KD. A prospective cohort study of shared decision making in lung cancer diagnostics: Impact of using a patient decision aid. *Patient Education & Counseling.* 2019;16:16.
68. Sowan AK, Beraya AR, Carrola A, Reed C. Effect of a Multimedia Patient Decision Aid to Supplement the Informed Consent Process of a Peripherally Inserted Central Venous Catheter Procedure: Pre-Post Quasi-Experimental Study. *JMIR Med Inform.* 2018;6(4):e11056.
69. Speck RM, Neuman MD, Resnick KS, Mellers BA, Fleisher LA. Anticipated regret in shared decision-making: a randomized experimental study. *Perioper Med (Lond).* 2016;5:5.
70. Tinsel I, Buchholz A, Vach W, et al. Shared decision-making in antihypertensive therapy: a cluster randomised controlled trial. *BMC family practice.* 2013;14:135. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/167/CN-00921167/frame.html https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3847233/pdf/1471-2296-14-135.pdf.
71. Vilkins AL, Sahara M, Till SR, et al. Effects of Shared Decision Making on Opioid Prescribing After Hysterectomy. *Obstet Gynecol.* 2019;10:10.
72. Wise MR, Sadler L, Shorten B, van der Westhuizen K, Shorten A. Birth choices for women in a 'Positive Birth after Caesarean' clinic: Randomised trial of alternative shared decision support strategies. *Aust N Z J Obstet Gynaecol.* 2019;18:18.
73. Yamaguchi S, Taneda A, Matsunaga A, et al. Efficacy of a peer-led, recovery-oriented shared decision-making system: a pilot randomized controlled trial. *Psychiatric services (washington, DC).* 2017;68(12):1307-1311. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/340/CN-01442340/frame.html.

74. Ye S, Leppin AL, Chan AY, et al. An Informatics Approach to Implement Support for Shared Decision Making for Primary Prevention Statin Therapy. *MDM Policy & Practice.* 2018;3(1):2381468318777752.

Other Shared Decision-Making[75-233]

75. Abraham TH, Wright P, White P, Booth BM, Cucciare MA. Feasibility and acceptability of shared decision-making to promote alcohol behavior change among women veterans: Results from focus groups. *Journal of Addictive Diseases.* 2017;36(4):252-263.
76. Adams JR, Drake RE. Shared Decision-Making and Evidence-Based Practice. *Community Mental Health Journal.* 2006;42(1):87-105.
77. Adekpedjou R, Stacey D, Briere N, et al. Engaging Caregivers in Health-Related Housing Decisions for Older Adults With Cognitive Impairment: A Cluster Randomized Trial. *The Gerontologist.* 2019;16.
78. Afshar K, Bunch TJ. Return-to-Play in 2017 and the Role of Shared Decision-Making in Patients with Inherited and Acquired Channelopathies and Cardiomyopathies. *Curr Treat Options Cardiovasc Med.* 2017;19(10):75.
79. Albrecht KJ, Nashan D, Meiss F, Bengel J, Reuter K. Shared decision making in dermato-oncology: preference for involvement of melanoma patients. *Melanoma Res.* 2014;24(1):68-74.
80. Alden DL, Friend J, Schapira M, Stiggelbout A. Cultural targeting and tailoring of shared decision making technology: A theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups. *Social Science & Medicine.* 2014;105:1-8.
81. Alegria M, Nakash O, Johnson K, et al. Effectiveness of the DECIDE interventions on shared decision making and perceived quality of care in behavioral health with multicultural patients a randomized clinical trial. *JAMA psychiatry.* 2018;75(4):325-335.
82. Alegria M, Nakash O, Johnson K, et al. Effectiveness of the DECIDE interventions on shared decision making and perceived quality of care in behavioral health with multicultural patients a randomized clinical trial. *JAMA psychiatry.* 2018;75(4):325-335.
83. Alguera-Lara V, Dowsey MM, Ride J, Kinder S, Castle D. Shared decision making in mental health: The importance for current clinical practice. *Australasian Psychiatry.* 2017;25(6):578-582.
84. Alvarez K, Wang Y, Alegria M, et al. Psychometrics of shared decision making and communication as patient centered measures for two language groups. *Psychological Assessment.* 2016;28(9):1074-1086.
85. Ammentorp J, Wolderslund M, Timmermann C, et al. How participatory action research changed our view of the challenges of shared decision-making training. *Patient Education & Counseling.* 2018;101(4):639-646.
86. Amundsen A, Nordoy T, Lingen KE, Sorlie T, Bergvik S. Is patient behavior during consultation associated with shared decision-making? A study of patients' questions, cues and concerns in relation to observed

shared decision-making in a cancer outpatient clinic. *Patient Education & Counseling.* 2018;101(3):399-405.

87. Aoki Y, Takaesu Y, Inoue M, et al. Seven-day shared decision making for outpatients with first episode of mood disorders among university students: A randomized controlled trial. *Psychiatry Res.* 2019;281:112531.
88. Armstrong MJ. Shared decision-making in stroke: an evolving approach to improved patient care. *Stroke vasc.* 2017;2(2):84-87.
89. Bae JM. Shared decision making: relevant concepts and facilitating strategies. *Epidemiol Health.* 2017;39:e2017048.
90. Ballesteros J, Moral E, Brieva L, Ruiz-Beato E, Prefasi D, Maurino J. Psychometric properties of the SDM-Q-9 questionnaire for shared decision-making in multiple sclerosis: Item response theory modelling and confirmatory factor analysis. *Health and Quality of Life Outcomes Vol 15 2017, ArtID 79.* 2017;15.
91. Bansback N, Bell M, Spooner L, Pompeo A, Han PK, Harrison M. Communicating uncertainty in benefits and harms: A review of patient decision support interventions. *The Patient: Patient-Centered Outcomes Research.* 2017;10(3):311-319.
92. Barker C, Dunn S, Moore GP, Reszel J, Lemyre B, Daboval T. Shared decision making during antenatal counselling for anticipated extremely preterm birth. *Paediatr child health.* 2019;24(4):240-249.
93. Barr PJ, Elwyn G. Measurement challenges in shared decision making: Putting the 'patient' in patient-reported measures. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2016;19(5):993-1001.
94. Barr PJ, Forcino RC, Thompson R, et al. Evaluating CollaboRATE in a clinical setting: Analysis of mode effects on scores, response rates and costs of data collection. *BMJ open.* 2017;7 (3) (no pagination)(e014681).
95. Barr PJ, O'Malley AJ, Tsulukidze M, Gionfriddo MR, Montori V, Elwyn G. The psychometric properties of Observer OPTION5, an observer measure of shared decision making. *Patient education and counseling.* 2015;98(8):970-976.
96. Barr PJ, Thompson R, Walsh T, Grande SW, Ozanne EM, Elwyn G. The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process. *Journal of Medical Internet Research.* 2014;16(1):142-155.
97. Barr PJ, Thompson R, Walsh T, Grande SW, Ozanne EM, Elwyn G. "The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process": Correction. *Journal of Medical Internet Research.* 2015;17(2):1-2.
98. Bartlett JA, Peterson JA. Psychometric evaluation of the shared decision-making instrument-revised. *Western journal of nursing research.* 2013;35(2):193-213.
99. Berger-Hoger B, Liethmann K, Muhlhauser I, Steckelberg A. Implementation of shared decision-making in oncology: development and

pilot study of a nurse-led decision-coaching programme for women with ductal carcinoma in situ. *BMC Med Inf Decis Mak.* 2017;17(1):160.

100. Bernstein J, Kupperman E, Kandel LA, Ahn J. Shared Decision Making, Fast and Slow: Implications for Informed Consent, Resource Utilization, and Patient Satisfaction in Orthopaedic Surgery. *J Am Acad Orthop Surg.* 2016;24(7):495-502.
101. Beyene LS, Severinsson E, Saetre Hansen B, Rortveit K. Being in a space of sharing decision-making for dignified mental care. *Journal of psychiatric and mental health nursing.* 2019;25.
102. Bouniols N, Leclere B, Moret L. Evaluating the quality of shared decision making during the patient-carer encounter: a systematic review of tools. *BMC Res Notes.* 2016;9:382.
103. Brock DW. The ideal of shared decision making between physicians and patients. *Kennedy Inst Ethics J.* 1991;1(1):28-47.
104. Brooks AT, Silverman L, Wallen GR. Shared decision making: A fundamental tenet in a conceptual framework of integrative healthcare delivery. *Integrative Medicine Insights.* 2012;2012(8):29-36.
105. Brown SL, Salmon P. Reconciling the theory and reality of shared decision-making: A "matching" approach to practitioner leadership. *Health Expectations.* 2019;22(3):275-283.
106. Bunn F, Goodman C, Russell B, et al. Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis. *BMC geriatr.* 2018;18(1):165.
107. Burton D, Blundell N, Jones M, Fraser A, Elwyn G. Shared decision-making in cardiology: Do patients want it and do doctors provide it? *Patient education and counseling.* 2010;80(2):173-179.
108. Calderon C, Ferrando P, Carmona-Bayonas A, et al. Validation of SDM-Q-Doc Questionnaire to measure shared decision-making physician's perspective in oncology practice. *Clinical & translational oncology.* 2017:1-8. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/043/CN-01374043/frame.html https://link.springer.com/article/10.1007%2Fs12094-017-1671-9.
109. Caldwell JG. Evaluating attitudes of first-year residents to shared decision making. *Medical Education Online Vol 13 2008, ArtID 10.* 2008;13.
110. Callon W, Saha S, Wilson IB, et al. How does decision complexity affect shared decision making? An analysis of patient-provider antiretroviral initiation dialogue. *Patient Education & Counseling.* 2017;100(5):919-926.
111. Chambers-Evans J. The family as window onto the world of the patient: involving patients and families in the decision-making process. *Can J Nurs Res.* 2002;34(3):15-31.
112. Chin MH, Lopez FY, Nathan AG, Cook SC. Improving Shared Decision Making with LGBT Racial and Ethnic Minority Patients. *Journal of general internal medicine.* 2016;31(6):591-593.
113. Clapp JT, Arriaga AF, Murthy S, et al. Surgical Consultation as Social Process: Implications for Shared Decision Making. *Ann Surg.* 2017;12:12.

114. Clayman ML, Makoul G, Harper MM, Koby DG, Williams AR. Development of a shared decision making coding system for analysis of patient-healthcare provider encounters. *Patient education and counseling.* 2012;88(3):367-372.
115. Couet N, Labrecque M, Robitaille H, Turcotte S, Legare F. The impact of DECISION+2 on patient intention to engage in shared decision making: secondary analysis of a multicentre clustered randomized trial. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2015;18(6):2629-2637.
116. Coutu M-F, Legare F, Durand M-J, et al. Operationalizing a shared decision making model for work rehabilitation programs: A consensus process. *Journal of Occupational Rehabilitation.* 2015;25(1):141-152.
117. Cribb A, Entwistle VA. Shared decision making: Trade-offs between narrower and broader conceptions. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2011;14(2):210-219.
118. Davis S, Roudsari A, Raworth R, Courtney KL, MacKay L. Shared decision-making using personal health record technology: a scoping review at the crossroads. *J Am Med Inform Assoc.* 2017;24(4):857-866.
119. de Haes H. Dilemmas in patient centeredness and shared decision making: a case for vulnerability. *Patient education and counseling.* 2006;62(3):291-298.
120. Dehlendorf C, Reed R, Fitzpatrick J, Kuppermann M, Steinauer J, Kimport K. A mixed-methods study of provider perspectives on My Birth Control: a contraceptive decision support tool designed to facilitate shared decision making. *Contraception.* 2019;09:09.
121. Del Rio-Lanza AB, Suarez-Alvarez L, Suarez-Vazquez A, Vazquez-Casielles R. Information provision and attentive listening as determinants of patient perceptions of shared decision-making around chronic illnesses. *Springerplus.* 2016;5(1):1386.
122. DeMeester RH, Lopez FY, Moore JE, Cook SC, Chin MH. A model of organizational context and shared decision making: Application to LGBT racial and ethnic minority patients. *Journal of general internal medicine.* 2016;31(6):651-662.
123. Dolan JG. Shared decision-making--Transferring research into practice: The analytic hierarchy process (AHP). *Patient education and counseling.* 2008;73(3):418-425.
124. Durand MA, Barr PJ, Walsh T, Elwyn G. Incentivizing shared decision making in the USA--where are we now? *Healthcare (Amsterdam, Netherlands).* 2015;3(2):97-101.
125. Dy SM, Purnell TS. Key concepts relevant to quality of complex and shared decision-making in health care: A literature review. *Social Science & Medicine.* 2012;74(4):582-587.
126. Edwards A, Elwyn G. Inside the black box of shared decision making: Distinguishing between the process of involvement and who makes the

decision. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2006;9(4):307-320.

127. Edwards A, Elwyn G, Hood K, et al. Patient-based outcome results from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. *Family practice.* 2004;21(4):347-354.
128. Eliacin J, Salyers MP, Kukla M, Matthias MS. Patients' understanding of shared decision making in a mental health setting. *Qualitative Health Research.* 2015;25(5):668-678.
129. Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters. *Patient education and counseling.* 2013;93(1):102-107.
130. Elwyn G, Cochran N, Pignone M. Shared Decision Making-The Importance of Diagnosing Preferences. *JAMA internal medicine.* 2017;177(9):1239-1240.
131. Elwyn G, Edwards A, Gwyn R, Grol R. Towards a feasible model for shared decision making: focus group study with general practice registrars. *BMJ (Clinical research ed).* 1999;319(7212):753-756.
132. Elwyn G, Edwards A, Hood K, et al. 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;21(4):337-346.
133. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *The British journal of general practice : the journal of the Royal College of General Practitioners.* 1999;49(443):477-482.
134. Elwyn G, Edwards A, Mowle S, et al. Measuring the involvement of patients in shared decision-making: a systematic review of instruments. *Patient education and counseling.* 2001;43(1):5-22.
135. Elwyn G, Edwards A, Wensing M, Hibbs R, Wilkinson C, Grol R. Shared decision making observed in clinical practice: Visual displays of communication sequence and patterns. *Journal of Evaluation in Clinical Practice.* 2001;7(2):211-221.
136. Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in health care.* 2003;12(2):93-99.
137. Elwyn G, Frosch D, Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implementation Science.* 2009;4:75.
138. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implementation science : IS.* 2016;11:114.
139. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *BMJ: British Medical Journal.* 2006;333(7565):417.

140. Elwyn G, Tsulukidze M, Edwards A, Legare F, Newcombe R. Using a 'talk' model of shared decision making to propose an observation-based measure: Observer OPTION^{5 Item}. *Patient education and counseling.* 2013;93(2):265-271.
141. Epstein RM, Gramling RE. What is shared in shared decision making? Complex decisions when the evidence is unclear. *Medical Care Research and Review.* 2013;70(1, Suppl):94S-112S.
142. Frosch DL, Legare F, Fishbein M, Elwyn G. Adjuncts or adversaries to shared decision-making? Applying the Integrative Model of behavior to the role and design of decision support interventions in healthcare interactions. *Implementation Science.* 2009;4:73.
143. Gafni A, Charles C, Whelan T. The physician-patient encounter: the physician as a perfect agent for the patient versus the informed treatment decision-making model. *Social science & medicine (1982).* 1998;47(3):347-354.
144. Geiger F, Kasper J. Of blind men and elephants: suggesting SDM-MASS as a compound measure for shared decision making integrating patient, physician and observer views. *Z.* 2012;106(4):284-289.
145. Gillick MR. Re-engineering shared decision-making. *J Med Ethics.* 2015;41(9):785-788.
146. Gioia D, Autrey S, Drapalski AL, Glynn S, Cohen AN, Dixon LB. Veterans' views of a shared decision-making process: A qualitative substudy of REORDER. *American Journal of Psychiatric Rehabilitation.* 2014;17(4):348-364.
147. Gonzalez SC, Preiss RM, Allende-Richter S. Contraceptive Shared Decision-Making: An Innovative Approach in Adolescent and Young Adults Contraceptive Counseling. *Clin Pediatr (Phila).* 2019;58(4):466-469.
148. Goodwin JS, Nishi S, Zhou J, Kuo YF. Use of the Shared Decision-Making Visit for Lung Cancer Screening Among Medicare Enrollees. *JAMA internal medicine.* 2019;179(5):716-718.
149. Goossensen A, Zijlstra P, Koopmanschap M. Measuring shared decision making processes in psychiatry: Skills versus patient satisfaction. *Patient education and counseling.* 2007;67(1-2):50-56.
150. Groen-van de Ven L, Smits C, de Graaff F, et al. Involvement of people with dementia in making decisions about their lives: a qualitative study that appraises shared decision-making concerning daycare. *BMJ open.* 2017;7(11):e018337.
151. Groen-van de Ven L, Smits C, Span M, et al. The challenges of shared decision making in dementia care networks. *Int Psychogeriatr.* 2018;30(6):843-857.
152. Gulbrandsen P, Clayman ML, Beach MC, et al. Shared decision-making as an existential journey: Aiming for restored autonomous capacity. *Patient education and counseling.* 2016;99(9):1505-1510.
153. Gustavsson E, Sandman L. Health-care needs and shared decision-making in priority-setting. *Med Health Care Philos.* 2015;18(1):13-22.

154. Gwyn R, Elwyn G. When is a shared decision not (quite) a shared decision? Negotiating preferences in a general practice encounter. *Social Science & Medicine.* 1999;49(4):437-447.
155. Haesebaert J, Adekpedjou R, Croteau J, Robitaille H, Legare F. Shared decision-making experienced by Canadians facing health care decisions: a Web-based survey. *CMAJ Open.* 2019;7(2):E210-E216.
156. Hamann J, Kohl S, McCabe R, et al. 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;51(4):617-625.
157. Hamann J, Mendel R, Buhner M, et al. How should patients behave to facilitate shared decision making-The doctors' view. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2012;15(4):360-366.
158. Hargraves I, LeBlanc A, Shah ND, Montori VM. Shared Decision Making: The Need For Patient-Clinician Conversation, Not Just Information. *Health affairs (Project Hope).* 2016;35(4):627-629.
159. Hargraves IG, Montori VM, Brito JP, et al. Purposeful SDM: A problem-based approach to caring for patients with shared decision making. *Patient Education & Counseling.* 2019;102(10):1786-1792.
160. Henselmans I, van Laarhoven HWM, de Haes H, et al. Training for Medical Oncologists on Shared Decision-Making About Palliative Chemotherapy: a Randomized Controlled Trial. *Oncologist.* 2019;24(2):259-265.
161. Herlitz A. Comparativism and the Grounds for Person-Centered Care and Shared Decision Making. *J Clin Ethics.* 2017;28(4):269-278.
162. Hess EP, Grudzen CR, Thomson R, Raja AS, Carpenter CR. Shared Decision-making in the Emergency Department: Respecting Patient Autonomy When Seconds Count. *Academic Emergency Medicine.* 2015;22(7):856-864.
163. Hessinger JD, London MJ, Baer SM. Evaluation of a shared decision-making intervention on the utilization of evidence-based psychotherapy in a VA outpatient PTSD clinic. *Psychol Serv.* 2018;15(4):437-441.
164. Hoffmann TC, Bennett S, Tomsett C, Del Mar C. Brief training of student clinicians in shared decision making: A single-blind randomized controlled trial. *Journal of general internal medicine.* 2014;29(6):844-849.
165. Holmes-Rovner M, Kelly-Blake K, Dwamena F, et al. Shared Decision Making Guidance Reminders in Practice (SDM-GRIP). *Patient education and counseling.* 2011;85(2):219-224.
166. Hopmans W, Damman OC, Senan S, Hartemink KJ, Smit EF, Timmermans DR. A patient perspective on shared decision making in stage I non-small cell lung cancer: a mixed methods study. *BMC Cancer.* 2015;15:959.
167. Hyde C, Dunn KM, Higginbottom A, Chew-Graham CA. Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations. *Health Expectations: An*

International Journal of Public Participation in Health Care & Health Policy. 2017;20(2):298-308.

168. Kasper J, Hoffmann F, Heesen C, Kopke S, Geiger F. MAPPIN'SDM--the multifocal approach to sharing in shared decision making.[Erratum appears in PLoS One. 2012;7(6). doi:10.1371/annotation/3e489f03-e7e7-4b41-827e-caa85bb06466]. *PLoS ONE.* 2012;7(4):e34849.
169. Kasper J, Legare F, Scheibler F, Geiger F. Turning signals into meaning-'Shared decision making' meets communication theory. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2012;15(1):3-11.
170. Kriston L, Scholl I, Holzel L, Simon D, Loh A, Harter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient education and counseling.* 2010;80(1):94-99.
171. Kunneman M, Gionfriddo MR, Toloza FJ, et al. Humanistic communication in the evaluation of shared decision making: A systematic review. *Patient education and counseling.* 2019;102(3):452-466.
172. Landmark AMD, Ofstad EH, Svennevig J. Eliciting patient preferences in shared decision-making (SDM): Comparing conversation analysis and SDM measurements. *Patient education and counseling.* 2017;100(11):2081-2087.
173. Légaré F, Guerrier M, Nadeau C, Rhéaume C, Turcotte S, Labrecque M. Impact of DECISION + 2 on patient and physician assessment of shared decision making implementation in the context of antibiotics use for acute respiratory infections. *Implementation science.* 2013;8:144.
174. Legare F, Moumjid-Ferdjaoui N, Drolet R, et al. Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group. *J Contin Educ Health Prof.* 2013;33(4):267-273.
175. Legare F, Turcotte S, Robitaille H, et al. Some but not all dyadic measures in shared decision making research have satisfactory psychometric properties. *Journal of clinical epidemiology.* 2012;65(12):1310-1320.
176. Lenzen SA, Daniels R, van Bokhoven MA, van der Weijden T, Beurskens A. Development of a conversation approach for practice nurses aimed at making shared decisions on goals and action plans with primary care patients. *BMC health services research.* 2018;18(1):891.
177. Lewis KB, Stacey D, Squires JE, Carroll S. Shared decision-making models acknowledging an interprofessional approach: A theory analysis to inform nursing practice. *Research and Theory for Nursing Practice: An International Journal.* 2016;30(1):26-43.
178. Lown BA, Clark WD, Hanson JL. Mutual influence in shared decision making: a collaborative study of patients and physicians.[Erratum appears in Health Expect. 2009 Sep;12(3):343]. *Health Expectations.* 2009;12(2):160-174.

179. Mahmood S, Hazes JMW, Veldt P, et al. The development and evaluation of a personalized training in shared decision making skills for rheumatologists. *The Journal of rheumatology.* 2019;01.

180. Mahmoodi N, Sargeant S. Shared decision-making - Rhetoric and reality: Women's experiences and perceptions of adjuvant treatment decision-making for breast cancer. *J Health Psychol.* 2017:1359105316689141.

181. Matthias MS, Salyers MP, Frankel RM. Re-thinking shared decision-making: Context matters. *Patient education and counseling.* 2013;91(2):176-179.

182. Melbourne E, Sinclair K, Durand M-A, Legare F, Elwyn G. Developing a dyadic OPTION scale to measure perceptions of shared decision making. *Patient education and counseling.* 2010;78(2):177-183.

183. Moore G, Reszel J, Daboval T, Lemyre B, Barker C, Dunn S. Qualitative evaluation of a guideline supporting shared decision making for extreme preterm birth. *J Matern Fetal Neonatal Med.* 2018:1-9.

184. Moumjid N, Gafni A, Bremond A, Carrere MO. Shared decision making in the medical encounter: are we all talking about the same thing? *Medical decision making : an international journal of the Society for Medical Decision Making.* 2007;27(5):539-546.

185. Murray E, Charles C, Gafni A. Shared decision-making in primary care: tailoring the Charles et al. model to fit the context of general practice. *Patient Education & Counseling.* 2006;62(2):205-211.

186. Murray K, Yasso S, Schomburg R, et al. Journey of Excellence: Implementing a Shared Decision-Making Model. *Am.* 2016;116(4):50-56.

187. Muscat DM, Shepherd HL, Morony S, et al. Can adults with low literacy understand shared decision making questions? A qualitative investigation. *Patient education and counseling.* 2016;99(11):1796-1802.

188. Ng HH. Intersectionality and Shared Decision Making in LGBTQ Health. *LGBT health.* 2016;3(5):325-326.

189. Nicolai J, Moshagen M, Eich W, Bieber C. The OPTION scale for the assessment of shared decision making (SDM): Methodological issues. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen.* 2012;106(4):264-271.

190. Noseworthy PA, Brito JP, Kunneman M, et al. Shared decision-making in atrial fibrillation: navigating complex issues in partnership with the patient. *J Interv Card Electrophysiol.* 2018;17:17.

191. Obeidat RF, Homish GG, Lally RM. Shared decision making among individuals with cancer in non-western cultures: A literature review. *Oncology Nursing Forum.* 2013;40(5):454-463.

192. Olomu A, Hart-Davidson W, Luo Z, Kelly-Blake K, Holmes-Rovner M. Implementing shared decision making in federally qualified health centers, a quasi-experimental design study: the Office-Guidelines Applied to Practice (Office-GAP) program. *BMC health services research.* 2016;16(a):334.

193. Parimbelli E, Wilk S, Kingwell S, Andreev P, Michalowski W. Shared Decision-Making Ontology for a Healthcare Team Executing a Workflow,

an Instantiation for Metastatic Spinal Cord Compression Management. *AMIA Annu Symp Proc.* 2018;2018:877-886.

194. Pickrell W, Elwyn G, Smith P. Shared decision-making in epilepsy management. *Epilepsy & Behavior.* 2015;47:78-82.
195. Politi MC, Legare F. Physicians' reactions to uncertainty in the context of shared decision making. *Patient education and counseling.* 2010;80(2):155-157.
196. 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;91(2):167-175.
197. Rapaport S, Leshno M, Fink L. A design process for using normative models in shared decision making: A case study in the context of prenatal testing. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2014;17(6):863-875.
198. Ritter S, Stirnemann J, Breckwoldt J, et al. Shared Decision-Making Training in Internal Medicine: A Multisite Intervention Study. *J Grad Med Educ.* 2019;11(4 Suppl):146-151.
199. Robertson M, Moir J, Skelton J, Dowell J, Cowan S. When the business of sharing treatment decisions is not the same as shared decision making: A discourse analysis of decision sharing in general practice. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine.* 2011;15(1):78-95.
200. Rodenburg-Vandenbussche S, Pieterse AH, Kroonenberg PM, et al. Dutch Translation and Psychometric Testing of the 9-Item Shared Decision Making Questionnaire (SDM-Q-9) and Shared Decision Making Questionnaire-Physician Version (SDM-Q-Doc) in Primary and Secondary Care. *PLoS ONE.* 2015;10(7):e0132158.
201. Rood JA, Van Zuuren FJ, Stam F, van der Ploeg T, Huijgens PC, Verdonck-de Leeuw IM. Cognitive coping style (monitoring and blunting) and the need for information, information satisfaction and shared decision making among patients with haematological malignancies. *Psycho-oncology.* 2015;24(5):564-571.
202. Ruland CM, Bakken S. Developing, implementing, and evaluating decision support systems for shared decision making in patient care: a conceptual model and case illustration. *J Biomed Inform.* 2002;35(5-6):313-321.
203. Saba GW, Wong ST, Schillinger D, et al. Shared decision making and the experience of partnership in primary care. *Annals of family medicine.* 2006;4(1):54-62.
204. Sandman L. The concept of negotiation in shared decision making. *Health Care Analysis.* 2009;17(3):236-243.
205. Sandman L, Granger BB, Ekman I, Munthe C. Adherence, shared decision-making and patient autonomy. *Med Health Care Philos.* 2012;15(2):115-127.

206. Sandman L, Munthe C. Shared decision making, paternalism and patient choice. *Health Care Analysis.* 2010;18(1):60-84.
207. Scholl I, Koelewijn-van Loon M, Sepucha K, et al. Measurement of shared decision making - a review of instruments. *Z.* 2011;105(4):313-324.
208. Scholl I, Kriston L, Dirmaier J, Buchholz A, Harter M. Development and psychometric properties of the Shared Decision Making Questionnaire-Physician version (SDM-Q-DOC). *Patient education and counseling.* 2012;88(2):284-290.
209. Seal RP, Kynaston J, Elwyn G, Smith PE. Using an Option Grid in shared decision making. *Pract.* 2014;14(1):54-56.
210. Serrano V, Rodriguez-Gutierrez R, Hargraves I, Gionfriddo MR, Tamhane S, Montori VM. Shared decision-making in the care of individuals with diabetes. *Diabet Med.* 2016;33(6):742-751.
211. Sevdalis N, Harvey N. Predicting preferences: A neglected aspect of shared decision-making. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2006;9(3):245-251.
212. Siegel CA. Shared decision making in inflammatory bowel disease: helping patients understand the tradeoffs between treatment options. *Gut.* 2012;61(3):459-465.
213. Simon D, Loh A, Harter M. Measuring (shared) decision-making - A review of psychometric instruments. *Zeitschrift fur Arztliche Fortbildung und Qualitatssicherung.* 2007;101(4):259-267.
214. Simon D, Schorr G, Wirtz M, et al. Development and first validation of the shared decision-making questionnaire (SDM-Q). *Patient education and counseling.* 2006;63(3):319-327.
215. 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;80(2):164-172.
216. Stacey D, Murray MA, Legare F, Sandy D, Menard P, O'Connor A. Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy. *Worldviews Evid Based Nurs.* 2008;5(1):25-35.
217. Stalmeier PFM, Unic IJ, Verhoef LCG, Van Daal WAJ. Evaluation of a shared decision making program for women suspected to have a genetic predisposition to breast cancer: Preliminary results. *Medical Decision Making.* 1999;19(3):230-241.
218. Stamm A, Banerji J, Wolff E, et al. A decision aid versus shared decision making for prostate cancer screening: results of a randomized, controlled trial. *Canadian journal of urology.* 2017;24(4):8910-8917. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/763/CN-01569763/frame.html.
219. Thorne S, Oliffe JL, Stajduhar KI. Communicating shared decision-making: Cancer patient perspectives. *Patient education and counseling.* 2013;90(3):291-296.

220. Tonelli MR, Sullivan MD. Person-centred shared decision making. *Journal of Evaluation in Clinical Practice.* 2019;12:12.

221. Toupin-April K, Barton J, Fraenkel L, et al. Development of a Draft Core Set of Domains for Measuring Shared Decision Making in Osteoarthritis: An OMERACT Working Group on Shared Decision Making. *J Rheumatol.* 2015;42(12):2442-2447.

222. Towle A, Godolphin W, Grams G, LaMarre A. Putting informed and shared decision making into practice. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2006;9(4):321-332.

223. Tsulukidze M, Grande SW, Gionfriddo MR. Assessing Option Grid practicability and feasibility for facilitating shared decision making: An exploratory study. *Patient education and counseling.* 2015;98(7):871-877.

224. van Esch TEM, Brabers AEM, Hek K, van Dijk L, Verheij RA, de Jong JD. Does shared decision-making reduce antibiotic prescribing in primary care? *J Antimicrob Chemother.* 2018;73(11):3199-3205.

225. van Nistelrooij I, Visse M, Spekkink A, de Lange J. How shared is shared decision-making? A care-ethical view on the role of partner and family. *Journal of Medical Ethics: Journal of the Institute of Medical Ethics.* 2017;43(9):637-644.

226. Velligan DI, Roberts DL, Sierra C, Fredrick MM, Roach MJ. What patients with severe mental illness transitioning from hospital to community have to say about care and shared decision-making. *Issues in Mental Health Nursing.* 2016;37(6):400-405.

227. Vermunt N, Elwyn G, Westert G, Harmsen M, Olde Rikkert M, Meinders M. Goal setting is insufficiently recognised as an essential part of shared decision-making in the complex care of older patients: a framework analysis. *BMC family practice.* 2019;20(1):76.

228. Vortel MA, Adam S, Port-Thompson AV, Friedman JM, Grande SW, Birch PH. Comparing the ability of OPTION(12) and OPTION(5) to assess shared decision-making in genetic counselling. *Patient education and counseling.* 2016;99(10):1717-1723.

229. Widdershoven GA, Verheggen FW. Improving informed consent by implementing shared decisionmaking in health care. *IRB: A Review of Human Subjects Research.* 1999;21(4):1-4.

230. Wildeboer A, du Pon E, Schuling J, Haaijer-Ruskamp FM, Denig P. Views of general practice staff about the use of a patient-oriented treatment decision aid in shared decision making for patients with type 2 diabetes: A mixed-methods study. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy.* 2018;21(1):64-74.

231. Wollny A, Altiner A, Daubmann A, et al. Patient-centered communication and shared decision making to reduce HbA1c levels of patients with poorly controlled type 2 diabetes mellitus - results of the cluster-randomized controlled DEBATE trial. *BMC family practice.* 2019;20(1):87.

232. Wood F, Phillips K, Edwards A, Elwyn G. Working with interpreters: The challenges of introducing Option Grid patient decision aids. *Patient education and counseling.* 2017;100(3):456-464.
233. Wu TY, Chen CT, Huang YJ, Hou WH, Wang JD, Hsieh CL. Rasch Analysis of the 9-Item Shared Decision Making Questionnaire in Women With Breast Cancer. *Cancer Nurs.* 2018;19:19.

Publication Type[234-261]

234. Al JK. The impact of a decision aid on depressed patients' involvement in shared decision making: a pilot randomized controlled double-blinded study. *Value in health Conference: ISPOR 21st annual international meeting research Washington, DC united states Conference start: 20160521 Conference end: 20160525 Conference publication: (varpagings).* 2016;19(3):A19. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/612/CN-01266612/frame.html.
235. Armstrong MJ, Shulman LM, Vandigo J, Daniel Mullins C. Patient engagement and shared decision-making. *Neurology: Clinical Practice.* 2016;6(2):190-197.
236. Armstrong MJ, Shulman LM, Vandigo J, Mullins CD. Patient engagement and shared decision-making: What do they look like in neurology practice? *Neurol.* 2016;6(2):190-197.
237. Bahl R. Shared decision-making in selection of prosthetic aortic valve. *Open Heart.* 2015;2(1):e000269.
238. Beach MC, Sugarman J. Realizing Shared Decision-making in Practice. *Jama.* 2019;25:25.
239. Berger-Hoger B, Liethmann K, Muhlhauser I, Haastert B, Steckelberg A. Informed shared decision-making supported by decision coaches for women with ductal carcinoma in situ: study protocol for a cluster randomized controlled trial. *Trials.* 2015;16:452.
240. Buhse S, Muhlhauser I, Heller T, et al. An informed shared decision making programme on the prevention of myocardial infarction for patients with type 2 diabetes: randomised, controlled trial. *Diabetologia.* 2015;58(1 suppl. 1):S429-s430. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/921/CN-01106921/frame.html https://link.springer.com/content/pdf/10.1007%2Fs00125-015-3687-4.pdf.
241. Bunn F, Goodman C, Manthorpe J, et al. Supporting shared decision-making for older people with multiple health and social care needs: a protocol for a realist synthesis to inform integrated care models. *BMJ open.* 2017;7(2):e014026.
242. Camacho S. Evidence-Based and Patient-Centered Medicine with Shared Decision Improves Colonoscopy Efficacy in Poor Bowel Preparation Patients. *J Invest Surg.* 2018:1-2.
243. Case B, Qamer S, Gates E, Srichai MB. SHARED DECISION MAKING IN THE PREVENTION AND MANAGEMENT OF CARDIOVASCULAR DISEASE IN THE OUTPATIENT SETTING: a PILOT PROGRAM. *Journal of the american college of cardiology.* 2019;73(9):3038-.

244. Chor J, Stulberg DB, Tillman S. Shared Decision-Making Framework for Pelvic Examinations in Asymptomatic, Nonpregnant Patients. *Obstet Gynecol.* 2019;133(4):810-814.
245. Demiris G. Independence and shared decision making: the role of smart home technology in empowering older adults. *Conf Proc IEEE Eng Med Biol Soc.* 2009;2009:6432-6436.
246. Drake RE. Is Treatment Adherence the Goal of Shared Decision Making? *Psychiatric Services.* 2018;69(12):1195.
247. Fried TR. Communication About Treatment Options and Shared Decision Making in the Intensive Care Unit. *JAMA internal medicine.* 2019;179(5):684-685.
248. Goldman HH. Shared decision making: Roots in antiquity. *Psychiatric Services.* 2014;65(12):1399.
249. Goodwin JS, Nishi S, Kuo YF. Physicians' Responsibilities in Shared Decision Making for Lung Cancer Screening-Reply. *JAMA internal medicine.* 2019;179(7):995-996.
250. Groot G, Waldron T, Carr T, et al. Development of a program theory for shared decision-making: a realist review protocol. *Syst.* 2017;6(1):114.
251. Heathcote LC, Goldberg DS, Eccleston C, et al. Advancing shared decision making for symptom monitoring in people living beyond cancer. *Lancet Oncol.* 2018;19(10):e556-e563.
252. Huang R, Song X, Wu J, et al. Assessing the feasibility and quality of shared decision making in China: evaluating a clinical encounter intervention for Chinese patients. *Patient Prefer Adherence.* 2016;10:2341-2350.
253. Kopecky KE, Urbach D, Schwarze ML. Risk Calculators and Decision Aids Are Not Enough for Shared Decision Making. *JAMA Surg.* 2019;154(1):3-4.
254. Lucke JC. Enhancing shared decision-making in contraceptive consultations. *J Fam Plann Reprod Health Care.* 2017;43(2):126-127.
255. Miedany Y, Gaafary M, Youssef S, Palmer D. Shared decision making in standard rheumatology practice: from policy to practice. *Annals of the rheumatic diseases.* 2015;74:1002. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/869/CN-01128869/frame.html https://ard.bmj.com/content/74/Suppl_2/1002.1.
256. Mold JW. Facilitating shared decision making with patients. *American family physician.* 2006;74(7):1209-1210, 1212.
257. Perez RJ, Lara R-GI, Gonzalez SF, Pascual PJ, Villagran MJ. DECIDE study: effectiveness of shared decision making in treatment planning at discharge of inpatient with schizophrenia: half sample interim analysis, preliminary conclusions. *European psychiatry.* 2016;33:S278. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/390/CN-01160390/frame.html https://www.europsy-journal.com/article/S0924-9338(16)00746-X/fulltext.
258. Perez RJ, Pascual PJ, Lara R-GI, et al. DECIDE Study: effectiveness of shared decision-making in treatment planning at discharge of inpatient

with schizophrenia. Experience after 20 months of the study. *European psychiatry.* 2016;33:S617. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/376/CN-01160376/frame.html https://www.europsy-journal.com/article/S0924-9338(16)02311-7/fulltext.
259. Schofield T, Elwyn G, Edwards A, Visser A. Shared decision making. *Patient Education & Counseling.* 2003;50(3):229-230.
260. Theriault G, Bell NR, Grad R, Singh H, Szafran O. Teaching shared decision making: An essential competency. *Can Fam Physician.* 2019;65(7):514-516.
261. Van Laarhoven HWM, Henselmans I, Van Maarschalkerweerd P, et al. Training oncologists and preparing patients for shared decision making about palliative systemic treatment: results from the randomized controlled CHOICE study. *Annals of oncology.* 2018;29:viii548-.

Child/Adolescent Study[262]

262. Ludden T, Shade L, Reeves K, et al. Asthma dissemination around patient-centered treatments in North Carolina (ADAPT-NC): a cluster randomized control trial evaluating dissemination of an evidence-based shared decision-making intervention for asthma management. *J Asthma.* 2018:1-12.

Not in English[263-265]

263. Bieber C, Müller K, Blumenstiel K, et al. Shared decision making (SDM) with chronic pain patients. The patient as a partner in the medical decision making process. *Bundesgesundheitsblatt, gesundheitsforschung, gesundheitsschutz.* 2004;47(10):985-991. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/191/CN-00505191/frame.html.
264. Deinzer A, Babel H, Veelken R, Kohnen R, Schmieder R. Shared decision-making with hypertensive patients. Results of an implementation in Germany. *Deutsche medizinische wochenschrift (1946).* 2006;131(46):2592-2596. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/589/CN-00573589/frame.html https://www.thieme-connect.de/products/ejournals/abstract/10.1055/s-2006-956254.
265. Loh A, Simon D, Harter M. Effects of shared decision making in primary care of depressive patients - Better compliance and treatment effects. *Klinikarzt.* 2007;36(1):38-41. http://cochranelibrary-wiley.com/o/cochrane/clcentral/articles/186/CN-00712186/frame.html.

APPENDIX D: FINAL INTERVIEW GUIDE

GUIDE

Part I. Introductory Interview (20 minutes)

1. Thinking about your experiences with doctors or other health care providers (e.g., nurse, nurse practitioner, physician assistant, midwife), tell me about a situation where you discussed a gynecological issue, specifically about a treatment decision or in general.
    a. How long had you seen this medical provider?
    b. Did you have specific expectations when you went to the provider?
    c. How would you describe the decision-making process with the provider(s)?
        i. Who would you say made the decision(s) in this situation?
    d. How did time with the provider play a role in this situation?
        i. Did it influence the decision-making process, how you viewed the provider, or how you felt about the decision?

2. We have some options about how you could interact with your doctor or another health care provider to make decisions. **[GO OVER CARDS]**
    a. Do you have any questions about the cards?
    b. Just in general, which card or cards do you think best describes your preferences?
        i. Tell me more about why you picked this one/these.
    c. So, you selected **[X]**. Are there any times or circumstances you would go towards these other options?

Part II. Card-Sort Exercise (30 minutes)

1. For the next part, we're going to discuss three different medical situations: painful periods, polycystic ovary syndrome, and recurring ovarian cysts. Have you had any experience with any of these?
    a. If YES: What can you tell me about this experience?
        i. Did you seek medical care?
        ii. If yes, what was the process for discussion and making decisions with the provider(s)?
    b. If NO: *Move on #2*

2. I'm going to hand you this card that it has a brief paragraph describing **[clinical situation: painful periods, pcos/pre-diabetes, recurring ovarian cysts]**. Take your time and read it over and let me know if you have any questions.

3. So, you are thinking about **[clinical issue].** Looking at the choices we went over earlier, can you order these from the one you prefer the most to the one

you prefer the least? Take your time, there are no right or wrong answers. And if you feel comfortable, please think out loud as you do it.

a. It looks like your order of preference is [**SAY ORDER OUT LOUD].** Starting from your most preferred to least preferred, let's talk about why you selected this order. [**ASK ABOUT PLACEMENT FOR EACH CARD]**
b. [X] is the option you like the best in scenario. Tell me what that looks like to you in terms of this scenario.
c. You put the "share responsibility" option [X] in this order. Tell me about what "shared responsibility" means to you within this scenario.
d. [X] is the option you like the least in this scenario. Tell me what that looks like to you in terms of this scenario.
e. How would familiarity with the provider and time with the provider during the appointment be a factor in your preferences for this situation?

Part III. Wrap-Up (5 minutes)
We're almost done with the interview. We've talked about your experiences with health providers and how you would like to interact with providers to make decisions under different circumstances. Before we end, do you have anything else you want to share with about how you make decisions with health care providers or role of time in your interactions with them?

SCENARIOS

Painful Periods

You have been experiencing painful periods for the past two months. You have tried using over-the-counter pain medication and heating pads, but you are still experiencing pain. The doctor suggests starting hormonal birth control as a potential way to address the pain. Your options include birth control pills, patches, or rings. All of these options have different trade-offs, and you may experience side effects from each.

PCOS

You have had irregular periods, weight gain and severe breakouts. The doctor diagnoses you with polycystic ovary syndrome (PCOS) and pre-diabetes. Women with PCOS often have small ovarian cysts. Lifestyle changes and medication can manage symptoms, but PCOS can lead to complications during pregnancy or infertility. The doctor recommends that you lose weight and offers a referral to a nutritionist. Because you are pre-diabetic, the doctor wants you to consider taking medication to lower your blood sugar. You can also start hormonal birth control to regulate your period, but you may experience side effects from the medication.

Recurring Ovarian Cysts

You have been diagnosed with an ovarian cyst- a sac filled with fluid or tissue on an ovary-for the third time in the past 2 years. The doctor recommends taking over-the-counter medication for any pain and starting hormonal birth control to prevent cysts from recurring. Birth control will have side effects and will not reduce the size of your current cyst. Given the size of your cyst, the doctor would like you to consider a surgical option if it continues to grow over the next 2 months. If the cyst grows larger, there is a higher chance it will burst, which will cause internal bleeding and more pain.

CARD CHOICES

I prefer to make the final decision about which treatment I will receive.
I prefer to make the final decision about my treatment after seriously considering my doctor’s opinion.
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
I prefer to leave all decisions regarding my treatment to my doctor.