

Fall 9-1-2015

Design of a Patient-Centered and Clinically Integrated Patient Decision Aid

Sergey Motorny
Dakota State University

Follow this and additional works at: <https://scholar.dsu.edu/theses>

Recommended Citation

Motorny, Sergey, "Design of a Patient-Centered and Clinically Integrated Patient Decision Aid" (2015). *Masters Theses & Doctoral Dissertations*. 296.
<https://scholar.dsu.edu/theses/296>

This Dissertation is brought to you for free and open access by Beadle Scholar. It has been accepted for inclusion in Masters Theses & Doctoral Dissertations by an authorized administrator of Beadle Scholar. For more information, please contact repository@dsu.edu.

Design of a Patient-Centered and Clinically Integrated Patient Decision Aid

A dissertation submitted to Dakota State University in partial fulfillment
of the requirements for the degree of

Doctor of Science

in

Information Systems

September, 2015

By

Sergey Motorny

Dissertation Committee:

Surendra Sarnikar, PhD

Wayne Pauli, PhD

Stacey Berry, PhD

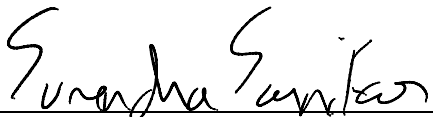


DISSERTATION APPROVAL FORM

This dissertation is approved as a credible and independent investigation by a candidate for the Doctor of Science in Information Systems degree and is acceptable for meeting the dissertation requirements for this degree. Acceptance of this dissertation does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department or university.

Student Name: Sergey Motorny

Dissertation Title: Design of a Patient-Centered and Clinically Integrated Patient Decision Aid

Dissertation Chair:  Date: 9/30/2015

Committee member:  Date: 9/30/2015

Committee member:  Date: 9/30/2015

ACKNOWLEDGMENT

Dissertation work has proven to be the most significant educational endeavor of my life. Its academic roots have given me an unexpectedly wide range of new insights on various aspects of life. I will remain forever grateful to everyone who has been involved with me in this process. Explicitly, I would like to thank my dissertation supervisor Dr. Surendra Sarnikar for his unfaltering guidance and rich insights. I would like to thank Dr. Wayne Pauli for his swift feedback and infinite optimism, Dr. Stacey Berry for her diligent reviews and motivating encouragements, and Dr. Cherie Noteboom for her collaboration and genuine interest.

I would like to thank everyone who has participated indirectly. Your roles have also been crucial. I thank my grandmother Vera, who passed away in 2010, for spending time with me as a child and being the motivation to improve medical treatment instruments through own difficult health care journey. I thank my wife Sarah for believing in my ability to complete this enormous task. I thank my parents for never doubting the value of education and investing in me so openheartedly. I thank my kids for reminding me that learning is a journey and not a destination.

I thank such researchers before me as Elwyn Glyn, PhD, Lesley F. Degner, PhD, Annette O'Connor, PhD, Peter A. Ubel, MD, and Judith Ann Kaprowy, MS, for laying the academic groundwork used in developing this patient decision aid framework and its first instantiation. At last but not least, I would like to thank Dakota State University for developing such a high-quality Information Systems program, which continues to attract talented faculty and students. Thank you Eric Brown, PhD, and Kevin Williams, PhD, for demonstrating that perseverance is one of key elements in successful educational pursuits.

ABSTRACT

One of the emerging trends of healthcare delivery is that of patient-centered medicine which promotes patient empowerment through sharing of medical decision making. Information technology is one of key enablers of patient-centered care and patient engagement in clinical decision making. One of the technological tools used to stimulate patient health care involvement is patient decision aids.

Hidden potential of patient decision aids has already been revealed. However, their real-world application remains lackluster. The lack of real-world use is two-fold. First problem is shortage of recognition that individual patients utilize different decision making strategies and that medical decision making highly emotional. Second problem is lack of practical utility needed to motivate physicians implement patient decision aids in their everyday clinical workflows.

Existing patient decision aids make generalized assumptions about their users and fail to satisfy the variability of individual information needs and decision making preferences known to literature. Clinical decision making is also an inherently emotional process. Existing patient decision aids rarely rely on official decision making theories, which consider the role of human emotions during the challenging process of medical treatment selection. Clinical integration of patient decision aids in everyday practice hinges on physician acceptance, which makes it critical to provide utility to practicing physicians. Patient decision aids can be used to streamline clinical encounters by improving patient-centeredness and facilitating the development of trusting patient-physician relationships while simultaneously decreasing the level of administrative burden.

This work investigates the influence of such patient attributes as individual preferences for shared decision making and personal information needs on the preferred format of decision making strategies and resulting quality of clinical decision making. Physician perceptions towards needed clinical utility are also studied. Framework for future patient decision aids is designed as a blueprint for creating individualized, theory-based, and clinically integrated treatment selection instruments. The designed framework is instantiated in the context of an end-stage renal disease treatment selection. The instrument is evaluated via a role playing experiment, and physicians are interviewed to measure clinical utility.

DECLARATION

I hereby certify that this dissertation constitutes my own product, that where the language of others is set forth, quotation marks so indicate, and that appropriate credit is given where I have used the language, ideas, expressions or writings of another.

I declare that the dissertation describes original work that has not previously been presented for the award of any other degree of any institution.

Signed,

A handwritten signature in black ink, appearing to read 'Sergey Motorny', written in a cursive style. The signature is positioned above a horizontal line.

Sergey Motorny

TABLE OF CONTENTS

DISSERTATION APPROVAL FORM.....	II
ACKNOWLEDGMENT	III
ABSTRACT	IV
DECLARATION	V
TABLE OF CONTENTS	VI
LIST OF TABLES.....	1
LIST OF FIGURES.....	3
INTRODUCTION	4
STATE OF HEALTH CARE	4
PATIENT-CENTERED MEDICINE	5
SHARED DECISION MAKING	5
PATIENT DECISION AIDS.....	6
PROBLEM STATEMENT.....	7
CONTRIBUTIONS OUTLINE	8
DISSERTATION STRUCTURE	9
POTENTIAL IMPACT	10
CHAPTER SUMMARY.....	11
LITERATURE REVIEW	12
INTERNATIONAL PATIENT DECISION AIDS STANDARDS	13
DECISION STRATEGIES: FOUR KINDS.....	13
DECISION MAKING PREFERENCES: FOUR PATIENT TYPES.....	14
Paternalistic Patient.....	15
Informed Patient	15
Collaborative Patient.....	16
Deliberative Patient.....	16
DECISION MAKING MODELS.....	17
Expected Utility Theory	17

Conflict Theory	17
Prospect Theory.....	18
Fuzzy Trace Theory	18
Differentiation and Consolidation Theory	18
Ecological Rationality Theory.....	19
Rational-emotional Decision Avoidance Theory	19
Affective Forecasting Theory.....	19
INFORMATION AND INFORMATION NEED	20
CONTROL PREFERENCES SCALE	21
DECISIONAL CONFLICT SCALE	23
CLINICAL INTEGRATION	23
IT-ENABLED PATIENT DECISION AIDS	25
Provisioning of Healthcare Information	26
Clarification of Personal Values	29
Support for Clinical Integration	30
Facilitation of Shared Decision Making	32
Emotional Adaptation Support.....	33
Framework Need	34
Potential Benefits of IT-based Patient Decision Aids and Framework-based Software Development	42
RESEARCH GAPS SUMMARY	43
CHAPTER SUMMARY.....	43
RESEARCH APPROACH	45
DESIGN SCIENCE.....	46
PROBLEM IDENTIFICATION AND MOTIVATION	48
SOLUTION OBJECTIVES.....	49
FRAMEWORK DESIGN	49
DEMONSTRATION	50
DATA COLLECTION.....	50
EVALUATION	51
CHAPTER SUMMARY.....	51
DESIGN OF A PATIENT-CENTERED AND CLINICALLY INTEGRATED PATIENT DECISION AID	53
FRAMEWORK OBJECTIVES	54

FRAMEWORK DIAGRAMS.....	55
EMOTIONAL ADAPTATION GATEWAY.....	58
DECISION STRATEGY GATEWAY.....	60
Coefficient x – Recording Preferences for Shared Decision Making.....	61
Patient Type (PT) Matrix.....	61
Strategy Type (ST) Matrix.....	62
Strategy Output (SO) Vector.....	63
INFORMATION NEED GATEWAY.....	64
Coefficient y - Recording Information Need Preferences.....	65
Information Selection (IS) Matrix.....	65
Amount of Information (AI) Matrix.....	66
Information Output (IO) Vector.....	67
WORKFLOW RECOMMENDATION GATEWAY.....	68
WORKFLOW RECOMMENDATION (WR) MATRIX.....	69
Workflow Output (WO) Vector.....	70
VALIDITY.....	71
Formative Validity.....	72
Summative Validity.....	75
DECISIONAL CONFLICT SCALE.....	75
CHAPTER SUMMARY.....	76

IMPLEMENTATION OF A PATIENT DECISION AID FOR DIALYSIS TREATMENT

SELECTION.....	78
CONDITION SELECTION.....	78
EXISTING INSTRUMENTS.....	79
HYPOTHESES.....	79
SERVER-SIDE AND CLIENT-SIDE PROGRAMMING.....	81
INSTANCE PROGRAMMING SELECTIONS.....	82
SESSION CONTROL.....	82
FILE ACCESS.....	83
RANDOMIZATION FUNCTION.....	83
CONDUCTING THE STUDY.....	83
Objectives.....	83
Participant Recruitment.....	84
Quantitative System Evaluation.....	84
An Invitation to Participate in a Study.....	84

Role Playing	85
Study Purpose.....	85
Your Objective	85
Begin Exercise	85
IMPLEMENTATION SCREENSHOTS	86
Information Need Gateway	87
Decision Strategy Gateway.....	88
WORKFLOW RECOMMENDATION GATEWAY	90
WORKFLOW RECOMMENDATION MODULES	91
Self-Education (Informative) Module	93
Clinical Team (Collaborative and Deliberative) Module.....	93
Expedited Decision (Paternalistic) Module	94
DEMONSTRATION OF FRAMEWORK-ASSISTED TREATMENT SELECTION.....	95
DEMONSTRATION OF FRAMEWORK-ASSISTED WORKFLOW RECOMMENDATION.....	97
QUALITATIVE SYSTEM EVALUATION.....	98
Hypothetical Scenario.....	99
Workflow Recommendation Gateway	100
Patient-Specific Clinical Steps for Informative Patient Type	100
Patient-Specific Clinical Steps for Passive/Paternalistic Patient Type.....	101
CHAPTER SUMMARY.....	102
STUDY RESULTS	104
QUANTITATIVE EXPERIMENT RESULTS.....	104
Hypothesis H1: Decision aids based on the proposed framework are better	105
Hypothesis H2: Decision aids based on the proposed framework better satisfy information needs	106
Hypothesis H3: Decision aids based on the proposed framework improve decision effectiveness.....	106
Hypothesis H4: Decision aids based on the proposed framework reduce decisional uncertainty	107
Hypothesis H5: Decision aids based on the proposed framework support more individual patient types.....	107
QUALITATIVE PHYSICIAN SURVEY RESULTS	108
CHAPTER SUMMARY.....	112
RESULTS DISCUSSION.....	114

DISCUSSION	114
CONTRIBUTIONS TO KNOWLEDGE	115
CONTRIBUTIONS TO PRACTICE	116
IMPACT	116
FUTURE IMPROVEMENT OF PATIENT ENGAGEMENT AND CLINICAL INTEGRATION	117
LIMITATIONS	117
CONCLUSION	118
REFERENCES	119
APPENDIX A: ADAPTATION EXERCISE	133
APPENDIX B: DECISIONAL CONFLICT SCALE	134
APPENDIX C: IPDAS CRITERIA CHECKLIST – CONTENT SECTION	135
APPENDIX D: ONLINE DIALYSIS TREATMENT SELECTORS.....	136
APPENDIX E: OPTION INSTRUMENT	140
APPENDIX F: DATA	145
APPENDIX G: INSTRUMENT SCREENSHOTS.....	147

LIST OF TABLES

Table 1. Attribute Comparisons of the Existing IT-enabled Patient Decision Aids	36
Table 2. Shortcomings, Objectives, and Features	55
Table 3. Manipulation of Patient Type (PT) Matrix	61
Table 4. Binary Representation of Patient Type (PT) Matrix	61
Table 5. Values of Strategy Type (ST) Matrix	62
Table 6. Binary Representation of Strategy Type (ST) Matrix	62
Table 7. Values of Strategy Output (SO) Vector	63
Table 8. Binary Representation of Strategy Output (SO) Vector	63
Table 9. Manipulation of Information (IS) Selection Matrix	65
Table 10. Binary Representation of IS Matrix.....	66
Table 11. Values of Amount of Information (AI) Matrix.....	66
Table 12. Binary Representation of Amount of Information (AI) Matrix	66
Table 13. Values of Information Output (IO) Vector.....	67
Table 14. Binary Representation of Information Output (IO) Vector.....	67
Table 15. Values of Workflow Recommendation (WR) Matrix	69
Table 16. Binary Representation of Workflow Recommendation Matrix	69
Table 17. Values of Workflow Output (WO) Vector.....	71
Table 18. Binary Representation of Workflow Output (WO) Vector.....	71
Table 19. Evaluation Methods	72
Table 20. Validity of Assumptions.....	73
Table 21. Existing Dialysis Treatment Selectors.....	79
Table 22. Hypotheses, Artifact Features, and Measurement.....	80
Table 23. Objectives and Attributes.....	91
Table 24. Demographics Summary of Study Participants	105
Table 25. Summary of Results for All Decision Maker Types.....	105

Table 26. Summary of Results per Decision Maker Type.....	107
Table 27. Summary of Results for All but Collaborative Decision Maker Types.....	108

LIST OF FIGURES

Figure 1. Control Preferences Scale. Informed Patient Type	23
Figure 2. Dissertation Steps. Design Science Research Methodology	47
Figure 3. Framework Activity Diagram	56
Figure 4. The Framework with a Layered View	56
Figure 5. Theoretical and Technical Building Blocks of the Framework	57
Figure 6. Use Case Diagram of Emotional Adaptation Gateway	59
Figure 7. Use Case Diagram of Decision Strategy Gateway	60
Figure 8. Use Case Diagram of Information Need Gateway	64
Figure 9. Use Case Diagram of Workflow Recommendation Gateway	68
Figure 10. Information Need Gateway. Risks and Benefits	87
Figure 11. Information Need Gateway	88
Figure 12. Implementation of Control Preferences Scale	89
Figure 13. Implementation of Recommend For Decision Strategy	90
Figure 14. Demonstration of Decision Strategy Gateway	95
Figure 15. Demonstration of Information Need Gateway	96
Figure 16. Demonstration of Workflow Recommendation Gateway	98
Figure 17. Activity Diagram of Workflow Recommendation Gateway	100
Figure 18. Informative Patient Characteristics	100
Figure 19. Paternalistic/Passive Patient Characteristics	101
Figure 20. Decisional Conflict Scale Data for All Patient Types	145
Figure 21. Decisional Conflict Scale Data for Informative Patient Type	146
Figure 22. Decisional Conflict Scale Data for Collaborative Patient Type	146
Figure 23. Decisional Conflict Scale Data for Paternalistic Patient Type	146

CHAPTER 1

INTRODUCTION

The introduction chapter is used for a broad overview of the dissertation research project. This chapter begins with listing some of the problems of the United States healthcare system and their possible solutions described in today's literature. Several previously outlined solutions to the listed healthcare shortcomings are patient-centered medicine and involvement in shared decision making. The chapter is continued via a discussion of the potential of patient decision aids to improve patient centeredness and sharing of medical treatment selections. Research problem is identified as a need to use the domain of information systems to further develop the field of patient decision aids. Motivation for the dissertation work is highlighted as a goal to advance the technology of patient decision aids technology and make meaningful contributions to the domains of software development, medical decision making, and clinical practice. The chapter is concluded with an outline of the following dissertation chapters.

State of Health Care

The United States' health care system has been experiencing changes in the areas of chronic illnesses and escalation of costs. The number of chronic illnesses has been on the rise, and the growth of health care spending has been out-pacing the annual growth of the US gross domestic product (Reinhardt, Hussey, & Anderson, 2004). The United States of America is known to spend more on health care than any country in the world, and the spending has been recorded to accelerate even in the times of economic contractions (Levit et al., 2003). Objective measures also reveal that regardless of high costs, the system fails to translate some of the already known medical discoveries into tangible quality improvements (Dougherty & Conway, 2008). One of the more recent attempts to address this failure recommends making physicians accountable for the health outcomes of their patients (Rowe, 2006). The prospect of physician accountability seems to carry potential for improving the quality without increasing costs (Caminiti et al., 2013). Combining physician accountability initiatives while

considering patient as a whole may be a better approach than focusing on a limited set of measures, which potentially cause to neglect the complexity of caring for the chronically ill patients (Snyder & Neubauer, 2007). Inclusion of patient-centered care in the physician accountability programs has been offered as a solution for improving quality, maintaining costs, and balancing short- and long-term health management goals, which still preserve patients' interests (Boyd et al., 2005). The concept of patient-centered medicine and its dependency on clinical decision-making protocols is described in a greater detail in the following section.

Patient-Centered Medicine

The idea of patient-centered medicine is not new. It has been on the forefront of many studies, conference proceedings, and journal articles for over a decade now (Epstein, Fiscella, Lesser, & Stange, 2010). Patient-centered medicine is geared to deliver care on a more personal level capable of improving patient satisfaction and quality of care without incurring additional costs (Epstein, et al., 2010). Institute of Medicine (IOM) defines patient-centered care as the one respecting and responsive to patients' individual needs, preferences, and values while using them as a guide for clinical decision making (Little et al., 2001). Patient-centered medicine tasks health care practitioners with knowing their patients as a person and not just as a list of attributes such as age, sex, and occupation. Patient-centered medicine obliges physicians to establish so-called healing relationships, which place their clients' interests above everything else. Patients acknowledge that they typically feel abandoned in the absence of such healing relationships (Quill & Cassel, 1995). Individually tailored information and shared decision making are viewed as the necessary premise to establishing healing relationships during office visits.

Shared Decision Making

Shared decision making is considered one of the new pinnacles of patient-centered medicine (Barry & Edgman-Levitan, 2012). Patient-centered providers need to educate patients in the roles they can play during the decision making processes and consequences of each of the available treatment options (Glyn Elwyn et al., 2009). Clinicians are called to shift their focuses from disease to patient management in order to align their clinical practices with the guidelines suggested by the Institute of Medicine.

Sharing of clinical decision making is affected by the patients' abilities to participate with the desired levels of involvement. Many patients express concerns about their failures to join the process of clinical decision making at the desired levels of involvement. Literature reveals that patients can be divided into four general categories based on their individual preferences for shared decision making (the categories are described in a greater detail in Chapter 2). It should not be assumed that shared decision making implies equal levels of individual involvement.

Involvement in shared decision making processes also depends upon the ability to satisfy patients' information needs. Patients reveal that information is the single most important variable affecting their abilities to become engaged in clinical decision making. Insufficiency of information or information overload lead to undue anxiety, which causes patients to abandon their desired roles of shared decision making.

Patient participation in clinical decision making also depends on their ability to control the highly-emotional state of health-related treatment selections. Many acute and chronic ailments share common psychological trajectories. For example, a shocking diagnosis may quickly weaken human capacity to retain information, think rationally, and arrive at fitting decisions.

Health information technology can be designed to support and facilitate the process of sharing the responsibility of clinical decision making (Epstein, et al., 2010). Using information technology to promote patient engagement is one of the most advertised topics of HIMSS (Healthcare Information and Management Systems Society) in 2015 where keynote speaker calls it a "3 Trillion Question" (himss.org, 2014). Properly designed health information technology, such as patient decision aids, can serve as a catalyst for producing the right mix of receptive healthcare practitioners, informed and involved patients, and lead to a well-coordinated patient-centered medicine.

Patient Decision Aids

Patient decision aids are instruments, which assist patients in arriving at informed, value-based health care decisions (Feldman-Stewart, O'Brien, et al., 2012) and serve as supplements rather than complete replacements of clinical consultations (D. Stacey et al., 2011). Patient decision aids are expected to play one of central roles in future health care delivery (Glyn Elwyn et al., 2009). Some of the predicted effects of patient decision aids are

increased patient comfort, knowledge, and involvement in shared decision making (F. Izquierdo, J. Gracia, M. Guerra, J. A. Blasco, & E. Andradas, 2011; M. D. Thomson & Hoffman-Goetz, 2007). When properly implemented, patient decision aids should stabilize treatment preferences, reduce decisional conflict, improve satisfaction rates, control levels of anxiety, and accelerate the speed clinical decision making (R. Evans et al., 2007; Holmes-Rovner et al., 2007). Patient decision aids can assist patients in clarifying personal values, understanding treatment options, and deliberating possible outcomes (Glyn Elwyn, et al., 2009; O'Connor et al., 2007).

International Patients Decision Aids Standards (IPDAS) is an existing framework, which was developed to serve as a reliable evaluation method of the quality of patient decision aids (Glyn Elwyn, et al., 2009). The framework consists of three main sections devoted to decision aid content, patient development process, and overall effectiveness. As an IPDAS critic, Bekker (Bekker, 2010) says that the framework's desire to meet all of the patients' needs with one resource reduces its effectiveness. Bekker calls for the need to investigate why certain components may even hinder the decision making process (Bekker, 2010).

Proliferation of patient decision aids in everyday practice heavily depends upon their acceptance by healthcare providers. Physicians need to rely on these instruments if patient decision aids are expected to have a positive effect on patient centeredness. Modern-day physicians are busy professionals whose technology acceptance hinges on its capacity to offer tangible improvements without increasing administrative burdens and decreasing professional autonomy.

Problem Statement

A problem is defined as the difference between a goal and the current state of a system (Hevner, March, Park, & Ram, 2004). In the case of patient decision aids, there are significant differences between the desired and existing rates of personalization, clinical utilization, and ability to correct the overwhelming effect of human emotions.

Existing patient decision aids make generalized assumptions about their users and fail to satisfy the variability of individual information needs and decision making preferences already known to literature. In order to increase comfort, knowledge, participation in the decision making process, and support for personal health-related decisions, patient decision

aids should be end-user individualized (J. G. Dolan & Frisina, 2002; Levine, Gafni, Markham, & MacFarlane, 1992; D. Stacey, et al., 2011). Individualization is especially important because patient decision aids are meant to support treatment selections lacking the medically apparent right or wrong answers (Harrison et al., 2009; Holmes-Rovner, 2007; Levine, et al., 1992).

As discussed earlier in this chapter, shared decision making depends upon the abilities of patients to satisfy their information needs and minimize the anxiety associated with the emotionally-charged times. Existing patient decision aids ignore the natural variation of personal information needs and individual desires for decision making autonomy. Extant patient decision aids also lack the ability to minimize human bias caused by poorly uncontrolled emotions and high levels of anxiety.

Existing patient decision aids lack clinical utility and tend to overlook the roles physicians play in their real-world acceptance. Physicians need instruments, which would assist them in refining their practices for better patient centeredness, but such tools must provide value without exposing them to additional administrative burdens and encroaching upon their professional autonomies.

In summary, an ideal patient decision aid should provide the means to control emotional bias, strive to engage on an individual level, and list treatment information in a personally meaningful way. Patient decision aids should also simultaneously appeal to healthcare providers if they are to become integrated into clinical practice (J. G. Dolan & Frisina, 2002; Levine, et al., 1992; D. Stacey, et al., 2011). The purpose of this research is to develop a patient decision aid framework, which takes into account such individual human characteristics as emotional states, preferences for decision making autonomy, and personal information needs. The framework offers a personalized treatment selection experience, which is tailored for the patient and improves the decision making quality by lowering the levels of decisional conflict. The framework also contains a workflow recommendation component, which assists healthcare providers in improving patient centeredness while respecting their professional autonomies and existing administrative burdens.

Contributions Outline

This research makes several important contributions. First, current shortcomings of patient decision aids are revealed and formulated in a way, which both the scientific and non-

scientific communities can comprehend. In order to close the stated limitations of patient decision aids, it is important to convey them together with a proposed solution to the entities, which will be directly involved in closing these deficiencies. This work makes it a priority to provide utility and deliver the message not only to scientists but also to software developers and physicians. Second, formal patient decision aid framework is developed, which applies information technology in order to improve the decision making process through individualization. One of the existing decision making theories, which recognizes the role of emotions in human decision making, is incorporated into the framework. The framework includes a component meant to provide value to practicing physicians and, thus, increase clinical utilization rates of patient decision aids. Third, live demonstration of the framework's effectiveness is presented via an instantiation of the first treatment selection prototype. Finally, the developed framework is evaluated statistically by staging an experiment and analyzing the respondents' subjective levels of the resulting decisional conflict. Qualitative data are solicited from the United States family physicians regarding the potential utility of the component aimed at improving patient centeredness of their clinical workflows. Quantitative and qualitative results are presented for the purpose of revealing both strengths and weaknesses of this framework and its first prototype instantiation.

Dissertation Structure

Structure of the remainder of this dissertations is as follows:

Chapter 2 is literature review. The chapter builds the base for the framework via an academic approach of literature review. Objectives of this chapter are to provide an overview of the existing theory and research in the areas of patient decision aids, decision making, engagement preferences, information needs, clinical practices, technology, and pre-validated instruments meant to reveal patient characteristics and evaluate quality of a decision making process.

Chapter 3 is research methodology. The chapter identifies the selected methodology, lists its advantages and disadvantages, and enumerates the steps needed to complete a full research cycle. Design Science research is named as the chosen research methodology. This chapter discusses research problem and motivation, solution objectives, framework design, demonstration, and evaluation as dictated by Design Science research methodology.

Chapter 4 is theory and artifact design. The chapter proposes and develops the solution

in the form of a patient decision aid framework meant to close the identified shortcomings and according to the stated objectives. The chapter contains diagrams, graphs, tables, and formulas, which an application developer can use as a template to program a new patient decision aid. The chapter details the framework's objectives, parameters, and assumptions. The text develops formal specifications and tests used to meet the objectives.

Chapter 5 is implementation. This chapter describes the first instantiation of a patient decision aid according to the developed framework. Disease-specific application is programmed, and human participation is solicited. Chapter 5 evaluates the application via a randomized experiment conducted with the help of human subjects at Dakota Stated University. The chapter elaborates experiment design, protocols, and validation methods. Research hypotheses are explicated and tabulated in conjunction with the artifact's features and experiment's evaluation methods.

Chapters 6 and 7 are results, discussion, and conclusion. The final two chapters are devoted to analyzing data, presenting results, reaching conclusions, and discussing the impact. The hypotheses are examined in their relation to the performed data analysis and their influence on specific artifact objectives. The results are highlighted and reviewed in their relation to the literature review topics. Based on the finds, the chapters makes objective inferences, draws conclusions, limitations, and suggests directions for further future research.

Potential Impact

Just as the case with the information systems discipline, potential impact of this research is multi-faceted and multi-disciplinary. Patient-centered electronic health, patient decision aids, decision support systems, and user experience design are only some of the potential recipient domains of this dissertation work. Application developers, user experience designers, health care administrators, researchers, and physicians are some of the professionals, which may be interested in referencing the proposed framework and experimenting with their own versions of patient decision aids. The framework is expected to improve standardization of future patient decision aids by offering abstract modular components, which satisfy various medical conditions, patient populations, technological platforms, and clinical workflows. The framework will further our understanding of technology-facilitated medical decision making, patient engagement, individual information needs, and patient-centered clinical workflows.

Chapter Summary

This chapter is used to make an introduction to the state of the United States health care system, patient-centered medicine, shared clinical decision making, patient decision aids and their anticipated impacts on the practice of modern medicine. Shortcomings of patient decision aids are described, which can be summarized as the lack of personalization of shared decision making and information needs, lack of emotional support, and lack of tangible provider utility. The chapter argues the need for creation of a patient decision aid framework and outlines contributions of this dissertation research project.

CHAPTER 2

LITERATURE REVIEW

Objectives of this chapter are to provide an overview of existing theory and research in the areas of patient decision aids, decision theory, involvement preferences, information needs, clinical practice, technology, and instruments meant to elicit patient characteristics and evaluate decision making quality. The chapter begins by introducing International Patient Decision Aids Standards (IPDAS) as a quality checklist framework. IPDAS definition, brief history, description, purpose, and current standing are presented. The chapter continues by describing four kinds of decision strategies known to literature. Then, individual preferences for shared decision making are explained as they relate to particular types of patient decision makers. These strategies and preferences form four types of patient-physician relationships and serve as the basis for the framework formulas. Eight models of human decision making are listed and summarized. The inclusion of human emotions in the listed decision making models is carefully followed. The review of various decision making models is meant to highlight the modular nature of the developed patient decision aid framework. The review of decision making models is followed by the discussion of the impact of information and information needs on clinical decision making. Two previously validated instruments are discussed in this chapter. Control Preferences Scale is a tool used to measure patients' individual desires for decision making autonomy. Decision Conflict Scale is the instrument designed to measure the effectiveness of a decision making process by revealing the levels of the ensuing decisional conflict. Some of the desirable forms of clinical integration of patient decision aids are then discussed as they are described in the supporting literature. Current state of IT-enabled patient decision aids follows, which helps to explain the role of technology in patient decision aid development. The technology section and the chapter are concluded by a tabulated summary of the revealed research gaps.

International Patient Decision Aids Standards

Prior to the development of the International Patient Decision Aids (IPDAS) criteria, researchers voiced their concerns about the inability to know if an instrument is a reliable source of health information (Elwyn et al., 2006). IPDAS criteria were established via a collaborative effort of participants from such areas as decision making sciences, behavioral fields, health care providers, policy makes, and patients (Bekker, 2010; Glyn Elwyn, et al., 2009). The purpose of the IPDAS criteria were to create a reliable evaluation method of the quality of patient decision aids (Glyn Elwyn, et al., 2009). IPDAS documentation was assembled as a joint venture of 122 individuals from 14 countries who participated in a rating process of over 80 measures and 12 quality dimensions (Elwyn, et al., 2006; Glyn Elwyn, et al., 2009). The IPDAS collaboration group delivered a 63-item checklist, which could be used by both application developers and users (Collaboration, 2005; Elwyn, et al., 2006). The checklist consisted of three main sections devoted to content, development process, and application effectiveness. Since its establishment, IPDAS criteria have become a recognized framework for the assessment of patient decision aid quality (Williams, Jones, Elwyn, & Edwards, 2008). Critics of the framework say that its desire to be a single resource for all of the patients' needs reduces its value and effectiveness. Bekker (Bekker, 2010) calls for the exploration on why certain IPDAS-approved decision aids may actually hinder instead of facilitate the decision making process (Bekker, 2010). Appendix B lists the checklist items developed and used by the IPDAS.

Decision Strategies: Four Kinds

Decision strategy, context, and information management are stated to be some of the fundamental components of decision support systems (Zhuang, Wilkin, & Ceglowski, 2012). Four main strategies assist users in reaching the vast majority of decisions: 1) recommend for, 2) recommend against, 3) factual information, and 4) how-to recommendation (Dalal & Bonaccio, 2010; Zhuang, et al., 2012). One of the oldest advice-giving decision strategies focuses on recommending the best and most fitting alternative (Harvey & Fischer, 1997). Highlighting of the best alternative is also known as the "recommend for" or the inclusion decision strategy (Heller, Levin, & Goransson, 2002). "Recommend for" decision strategy suits those seeking to delegate their decision making autonomy, since it is the most direct

approach to quickly orient towards a suitable alternative. The next advice-giving decision strategy focuses on recommending against a particular course of action and, thus, is called a “recommend against” or exclusion decision strategy (Dalal & Bonaccio, 2010). “Recommend against” decision strategy is a better fit for those seeking to share their decision making autonomy, since it does not prescribe any one specific alternative, but simply reveals the least fitting option (Zhuang, et al., 2012). The third decision strategy is the provision of factual information, which refrains from any explicit recommendations. Factual information decision strategy suits those who value their autonomies and prefer an independent decision making process (Dalal & Bonaccio, 2010). The fourth strategy is “how-to” decision support, which also does not make any specific recommendations but instead facilitates the process through structure and presentation (Zhuang, et al., 2012). The IPDAS criteria are an attempt to systematize the “how-to” strategy for future patient decision aids.

Decision Making Preferences: Four Patient Types

There is an agreement in literature that four main patient types establish four patient-physician relationships and four individual decision making preferences (Emanuel & Emanuel, 1992; Green, 1988; Scott & Lenert, 2000). The patient types (and relationship models) are Paternalistic, Informative (or Informed), Collaborative, and Deliberative. Correlation between the desired and actual decision making preferences has the ability to predict patient regimen adherence (Hirsch, Keller, Krones, & Donner-Banzhoff, 2011). Sharing of the decision-making process should be driven by the individual patient desires. Otherwise, it may cause undue anxiety and fail to achieve the desired health care improvements (Elwyn, Edwards, & Kinnersley, 1999). Matching decision making strategies with individual participation preferences is now recommended as a more rational approach to decision aids rather than advocating an increased control for everyone regardless of their individual desires (Kasper, Kopke, Muhlhauser, Nubling, & Heesen, 2008).

The vast majority of the existing decision aids assume that patients wish to be primary decision makers; however evidence reveals that only a minority of patients seek such autonomy (Deber, Kraetschmer, & Irvine, 1996; Scott & Lenert, 2000). In today’s practice, patients’ engagement preferences are generally matched in fewer than 50 percent of the cases (Degner, Sloan, & Venkatesh, 1997; Kasper, et al., 2008). Simultaneously, patients, whose treatment selections have been matched with their goals and values, are more confident and

less conflicting about the resulting decisions (K. R. Sepucha et al., 2011). Decision aids, which are robust enough to reflect true decision making preferences are expected to increase the value of clinical care and achieve larger patient audiences (Lenert & Cher, 1999; Scott & Lenert, 2000).

Paternalistic Patient

Traditional medicine rests on the physician ability to combine technical competence with moral sensitivity (Green, 1988). Paternalistic model of patient-physician relationship assumes that doctors and their patients share common goals and personal values (Emanuel & Emanuel, 1992). Paternalistic model vests physicians with performing professional problem-solving as well as personal decision making tasks, and patients are expected to be grateful for the decisions made on their behalves (Emanuel & Emanuel, 1992; Scott & Lenert, 2000). Emanuel and Emanuel (Emanuel & Emanuel, 1992) state that Paternalistic model can be fully justified in cases of medical emergencies when losing time may cause irreversible patient harm. Even though the population preferring this completely passive role is not large, it is still be as high as 8 percent of all patients. Paternalistic model is stated to be the most prevalent type of consultation style (Elwyn, et al., 1999). Paternalistic patients may be more numerous in select populations, since the vast majority of patients exhibit a diminishing desire for decision making involvement as the severity of illness increases. Approximately half of all end-stage renal disease patients are psychologically compromised by a sudden diagnosis and, thus, may be comforted knowing that difficult decisions can be delegated (Kaprowy, 1991). Older, male, and poorly educated patients are the more frequent seekers of the traditional Paternalistic relationships (Benbassat, Pilpel, & Tidhar, 1998; Scott & Lenert, 2000). This patient type wishes to relinquish the process of treatment selection and prefers a “recommend for” decision strategy.

Informed Patient

Informed model presumes a clear separation of medical facts and individual patient values. Patients preferring this type of a relationship fully recognize their belief systems and are capable of exercising independent decision making (Scott & Lenert, 2000). Physicians of this relationship model act as technical domain experts who provide patients with facts necessary to decide autonomously (Emanuel & Emanuel, 1992). Problem solving and

decision making processes are separated and assigned to tasks performed by each of the parties. Physicians are relieved of such duties as clarifying personal values, and patients are prepared to make personally fitting treatment choices. The majority of patients do not seek complete decision making autonomy but neither do they want entirely passive Paternalistic roles (Benbassat, et al., 1998). Informed patient type prefers provisioning of factual information as the decision making strategy.

Collaborative Patient

Collaborative model clearly separates medical facts from patient values while tasking physicians with assisting patients in elucidating and articulating their personal belief systems (Emanuel & Emanuel, 1992). Doctors of this relationship model are not only technical domain experts but also personal counselors and advisers. Collaborative patients rely on their physicians for clarification of values. Green (Green, 1988) recommends that Collaborative model replace informed consent, which currently serves a legal rather than clinical purpose. Scott and Lenert (Scott & Lenert, 2000) state that physicians of Collaborative patients should not dictate or judge personal values but help with eliciting beliefs and aligning them with the available treatment options. It is stated that 50-60 percent of all patients are of Collaborative type. Collaborative patient prefers to share the decision making autonomy and compare the output of “recommendation for” and “recommendation against” decision strategies.

Deliberative Patient

Physicians of Deliberative patients influence their clients’ beliefs by suggesting the best personal values for particular clinical situations (Emanuel & Emanuel, 1992). Doctors rely on their domain knowledge together with prior experiences to explicate why some values are more admirable and worth of pursuing than others. Deliberative relationships urge physicians to abandon objectivity and act as friends who attempt to correct their patients’ mistaken views for their own best interests (Scott & Lenert, 2000). In the end, both patients and their doctors need to believe that the chosen path is the best available alternative. It is stated that 10-20 percent of all patients are of Deliberative type. This group often includes female and highly educated individuals (Emanuel & Emanuel, 1992; Scott & Lenert, 2000). As with the Collaborative patient type, Deliberative patients prefer to share their decision making autonomy and compare the output of the “recommend for” and “recommend against”

decision strategies.

Decision Making Models

Elwyn (Elwyn, Stiel, Durand, & Boivin, 2011) highlights the importance of explicit theory use to guide the future development of decision support aids. One of his publications summarizes eight influential decision theories, which may be implemented in future patient decision aids. Further discussion of these theories indicates a general shift towards the need to consider human emotions as an integral part of clinical treatment selection. It is suggested that the role of emotions in medical decision making should be acknowledged and the resulting biases should be minimized. It is also mentioned that incorporation of an existing decision making theory may simplify instrument comparisons while allowing for their continuous systematic improvement. This section summarizes the following eight theories and their respective views of human decision making: 1) Expected Utility theory, 2) Conflict theory, 3) Prospect theory, 4) Fuzzy Trace theory, 5) Differentiation and Consolidation theory, 6) Ecological Rationality theory, 7) Rational-emotional Decision Avoidance theory, 8) and Affective Forecasting theory.

Expected Utility Theory

Expected Utility is one of the oldest, most predominant, and well-studied decision making theories. Its logic assigns scores to possible outcomes together with their numerical probabilities (G. Elwyn, et al., 2011). Evidence suggests that this is not the best model for clinical decision making because patients and providers rarely think in terms of expected utility when seeking treatment elections (Holmes-Rovner, 2007). Expected Utility theory assumes that decisions are completely rational and emotionless. The theory also presumes that information about outcomes and their probabilities of occurrence is complete.

Conflict Theory

Conflict theory does not consider human decision making emotionless (Elwyn et al., 2011). It recognizes worrying, anxiety, and stress as typical context of the decision making process. Conflict theory explains cognitive dissonance stemming from the desire to expedite the deliberation process and fear that premature selection may lead to subsequent regret. Outcomes are scored by patients, and the most personally desirable outcomes are expected to

yield the least amount of the resulting cognitive dissonance. Conflict theory has led to the development of the Decisional Conflict Scale, which is now the most commonly used instrument for the assessment of patient decision aid effectiveness (D. Stacey, et al., 2011). Conflict theory lacks the capacity to de-bias hypothetical answers of healthy non-patients, which may be useful for research experiments.

Prospect Theory

Prospect theory states that people arrive at decisions by comparing potential gains and losses (G. Elwyn, et al., 2011). Humans are considered risk-averse, and individual life experiences shape personal heuristics used in the decision making processes (Zhou & Jiao, 2013). Differences in life experience serve as anchor points and lead to differences in outcome desirability. Prospect theory demonstrates how these anchor points can affect present emotional states and cause human decision makers to act differently in order to avoid risk. Prospect theory lacks a clear deliberation component, which could be used to identify and reduce potential biases for decision makers in clinical settings (G. Elwyn, et al., 2011).

Fuzzy Trace Theory

Fuzzy Trace theory proves that human decision making is not precise and relies on fuzzy mental representations (Reyna, 2008). According to this theory, providing patients with detailed information may be less effective in facilitating the decision making process than simple summaries or visual representations. Fuzzy Trace theory considers the deliberation process implicit, and no suggestions are offered to improve the decision making quality.

Differentiation and Consolidation Theory

Differentiation and Consolidation theory outlines three aspects influencing human decision making process, which are values, impression, and information. Iterative evaluation of the three aspects helps to arrive at the most fitting alternative (Svenson, 1992). The theory assumes that if none of the alternatives emerge as superior, status quo can be safely maintained. The aspect of values plays a role when comparing options according to their proximity to individual desires. Impression aspect is concerned with the personal judgments of significant others. Some options may not be in concordance with the belief systems of those close to decision makers. Information aspect of the theory is based on the presumption

that all decision makers want to review as much information as possible and that such information is complete (G. Elwyn, et al., 2011).

Ecological Rationality Theory

Ecological Rationality theory postulates that human decision making happens under the constraints of limited time, knowledge, and computational ability (Gigerenzer & Gaissmaier, 2011). The pressure from the three constraints forces decision makers to apply such shortcuts as recognition heuristics rather than use a deliberate effort of rational analysis. Clinical decision making may be novel for many patients, which lowers the potential accuracy of heuristics (G. Elwyn, et al., 2011). Ecological Rationality theory admits that human emotions lead to bias, but it does not provide any prescription on how to correct it in order to optimize the process of decision making.

Rational-emotional Decision Avoidance Theory

Rational-emotional Decision Avoidance theory states that humans have an inherent need to regulate negative emotions, which subsequently causes decision avoidance (Anderson, 2003). Wide range of negative emotions may produce inaction as subjects hope that a more favorable solution will eventually surface. Possibility of an incorrect decision is associated with psychological distress, and its avoidance justifies inaction. To remedy inaction in time-sensitive clinical decisions, it is recommended to highlight the negative outcomes of a missed opportunity (G. Elwyn, et al., 2011). The theory says that clear options with positive attributes facilitate the decision making process and reduce the amount of time to selection.

Affective Forecasting Theory

The theory of Affective Forecasting postulates that human decision making is emotional and influenced by the anticipated reactions to possible future events (Gilbert, Driver-Linn, & Wilson, 2002). According to the theory, human decision making is affected by the overestimation of the duration and intensity of an anticipated future emotional state (Buehler & McFarland, 2001). Affective Forecasting introduces and defines the notions of focalism and adaptation neglect in an attempt to explain this decision making bias (G. Elwyn, et al., 2011). Focalism is the type of forecasting bias, which causes decision makers to

underestimate the impact of competing future events on their thoughts and feelings (Wilson & Gilbert, 2005). As a result, forecasters misrepresent their predictions of both the intensity and duration of emotional reactions to possible future events. Existing literature reveals that healthy individuals tend to predict that being on dialysis treatment would create an unpleasant mood the vast majority of the time, while actual dialysis patients commonly report positive mood states (Ubel, Loewenstein, & Jepson, 2005). Misrepresentation of future mood expectations may not be attributed to focalism alone. Another possible explanation is adaptation neglect. Adaptation neglect is a type of forecasting bias, which causes decision makers to ignore the influence of psychological adaptation to a particular stimulus (Gilbert, et al., 2002; Wilson, Wheatley, Meyers, Gilbert, & Axson, 2000). Human memories are known to contain accurate summaries of past emotional states (Buehler & McFarland, 2001). Comparing future events to past experiences may reduce the intensity of forecasting bias by helping decision makers recognize that emotional responses fade over time (Buehler & McFarland, 2001; Ubel, et al., 2005; Wilson, et al., 2000). One study suggests that even a greater reduction of forecasting bias is possible when participants are asked to identify and list various coping mechanisms meant to minimize the emotional impact of a challenging future event (Ubel, et al., 2005). Affective Forecasting theory has the capacity to de-bias answers of healthy non-patients participating in study experiments.

Decision making theories are meant to guide humans through a selection process. Studying information about existing alternatives is still a necessary step of human decision making.

Information and Information Need

It is important to understand that information is capable of both increasing uncertainty as well as reducing it (Dervin & Nilan, 1986). Cognitive psychology research shows that unrestricted information flows and material complexity may quickly overwhelm decision makers leading to systematic errors (Carrigan, Gardner, Conner, & Maule, 2004). It has been shown that patients become anxious when they are presented with an abundance of information too soon (Kaprowy, 1991). Information needs tend to vary considerably from one patient to the next. Some patients may use information gathering as a coping mechanism and a form of a stress reduction. Others may be so overwhelmed that they admit hearing and comprehending only 25 to 50 percent of the relayed information (Kaprowy, 1991). In one

study, Ameling (Ameling et al., 2012) found that patients are openly critical of the large amount of presented information even when decision aids are designed according to the widely accepted international standards. Ameling (Ameling, et al., 2012) had to design a complementary minimalist version of the material to address the stated concerns. The amount and type of information provided by patient decision aids should be preceded by an explicit elucidation of personal needs (Feldman-Stewart, O'Brien, et al., 2012). Sharing of clinical decision-making processes often fails because it is not preceded by information sharing (Elwyn, et al., 1999). Information need happens upon recognition of general inadequacy to meet a particular goal (Case, 2002). Information need is a construct uncorrelated with individual engagement preferences. Patients yearning for the maximum amount of information may simultaneously seek to delegate their decision making autonomy (Degner, et al., 1997). Patient desires for information are often described to be stronger than those for sharing the decision making responsibility (Elwyn, et al., 1999). Process of active information seeking has been shown to be one of key components for living a long life on dialysis (Ormandy, 2008). Patients show that they seek different kinds of information at different points of their disease trajectories. Varying degrees of psychological states and autonomy preferences have been shown to affect information needs (Ankem, 2006; Cassileth, Zupkis, Sutton-Smith, & March, 1980). In a psychologically compromised state, patients may develop a conflict between information need and fear of encountering bad news (Parker et al., 2007). Physicians state that patients should be provided with the exact amount of information they desire, and research resonates that patients themselves are capable of identifying the amount of information they need (Kaprowy, 1991). Information Styles Questionnaire is an instrument, which can be used in a clinical setting to elicit the desired level of informational detail (Cassileth, et al., 1980). The instrument asks patients to select one of the three statements to describe their current information needs:

I want only the information needed to care for myself properly.

I want additional information only if it is good news.

I want as much information as possible good and bad.

Control Preferences Scale

Demographic and situational patient characteristics tend to explain only up to 20 percent of variability in decision making preferences while the remaining 80 percent remains

unexplained (Benbassat, et al., 1998; Degner, et al., 1997). Since prediction of decision making preferences based on individual characteristics is problematic, explicit enquiry is recommended (Benbassat, et al., 1998; Scott & Lenert, 1998). One kind of explicit enquiry is elucidation of patient preferences with a specifically designed forced-choice (FC) instrument. The instrument emerges from grounded theory, offers a set of alternative statements, and ask patients to indicate their preferences (Benbassat, et al., 1998; Degner, et al., 1997).

Control Preferences Scale (CPS) is an existing instrument used to elucidate individual decision making preferences. It is stated to be one of the best known ways to reveal personal engagement desires in a clinical setting. The scale uses five statements, which contain varying degrees of decision making autonomy. The statements are directly correlated with the existing four patient types. Originally, the five statements were presented to patients in the form of separate cards. Two cards at a time were given, and the patients were tasked to sort them in the order of preference. Now, it is recommended to display all five of them on a single page in order to improve patient comprehension of the measured dimension. The statements are as follows:

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

The page with the five statements listed above is accompanied by drawings (see Figure 1) and one question: "In terms of making decisions about your health care with your doctor, which one of the following best describes how you would like to make decisions?"

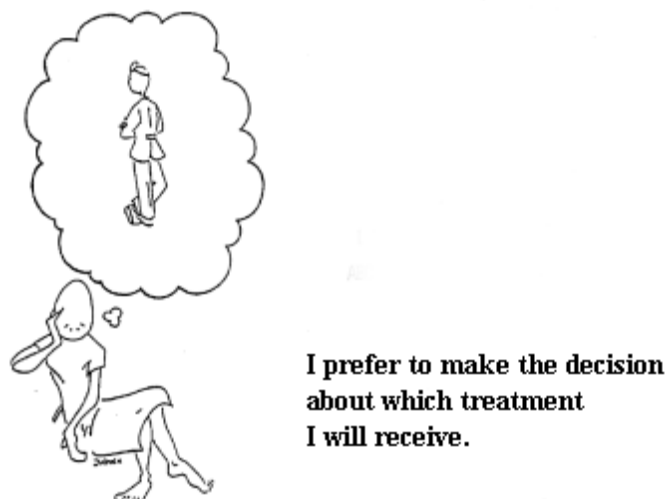


Figure 1. Control Preferences Scale. Informed Patient Type

Cards A reflects patient's desire for autonomy and is aligned with the Informed patient type. Cards D and E represent Paternalistic patient type preferring to delegate the decision making autonomy. Cards B and C are aligned with Collaborative and Deliberative patient types, where joined decision making is desired.

Decisional Conflict Scale

Decisional Conflict Scale (DCS) is an instrument designed to measure perceptions of personal uncertainty when selecting a medical treatment (R. G. Thomson et al., 2007). Decisional Conflict Scale assesses subjective perceptions of the decision making effectiveness with questionnaires on conflict, satisfaction, and regret (Bekker, 2010; OHRI, 2012). Decisional Conflict Scale stems from Conflict theory of decision making. Some debate about the scale is ongoing, which disputes its accuracy and the assumption that high levels of conflict negatively affect the decision making process. Other critique is concerned with the scale's focus on measuring the decision making process instead of outcome. Critics say that the result may often times be more important than the journey of getting there (Bekker, 2010). Nonetheless, one recent review discloses that DCS is still the most commonly applied instrument in measuring the usefulness of patient decision aids (D. Stacey, et al., 2011).

Clinical Integration

One of the main purposes of decision aids is to improve the quality of presented information and facilitate decision sharing both of which have been shown to be less than

optimal during regular clinical encounters (Holmes-Rovner, 2007). Researchers note that decision aids should be designed to address the simultaneous needs of patients and physicians involved in the process of clinical decision making (J. G. Dolan & Frisina, 2002; Levine, et al., 1992; D. Stacey, et al., 2011). Even though all elements of a successful adoption of patient decision aids in clinical practice remain unknown, levels of physician involvement are stated to be one of the defining factors (Dominick L. Frosch, Singer, & Timmermans, 2011).

Technology acceptance is an individual's voluntary adoption of an information system (Dünnebeil, Sunyaev, Blohm, Leimeister, & Krcmar, 2012). Technology Acceptance Model (TAM) introduces perceived usefulness and perceived ease of use as the two main variables influencing users' technology acceptance rates (Chang, Hwang, Hung, & Li, 2007; Pynoo et al., 2012; Yi, Jackson, Park, & Probst, 2006). Perceived usefulness is the main predictor of physician acceptance of a clinical information system (Chau & Hu, 2002; Dünnebeil, et al., 2012). Physicians recognize technology as useful when it has the ability to enhance their job performance (Pynoo, et al., 2012). Research shows that physicians exhibit positive attitudes towards decision aid systems when they assist them in their tasks daily tasks (Glasspool et al., 2007). Doctors are often forced to participate in routine data entry tasks, which they view as inefficient and time-consuming (Hertzum, 2011; Lun, 1995; Zheng, Padman, Johnson, & Diamond, 2005). It is recommended that developers of future patient decision aids remain cognizant of the varied caseloads of practicing physicians and move away from the one-size-fits-all approach (Harrison, et al., 2009). Doctors agree that educating and involving patients in the decision making processes is important. However, lack of time is stated as the main barrier for improving the two areas (Elwyn, et al., 1999). Physicians are more willing to adopt a new technology when they recognize its potential to positively affect patient-physician relationships, facilitate communication, and advance the quality of provided care (Chen & Hsiao, 2012). Professional autonomy can be defined as the ability to make decisions unaided by others and according to the profession's body of knowledge (WebMD, 2006). Physicians are placed at the top of the healthcare hierarchy, and 68 percent of them agree that clinical freedom is essential to successful medical practice (Walter & Lopez, 2008). Doctors are the determining factor of patient-physician communication styles, since patients rarely insist on sharing the decision-making processes (Elwyn, et al., 1999). Walter and Lopez (Walter & Lopez, 2008) state that physicians are more likely to support technology which fosters their

autonomy and resist any element that threatens it. It is suggested that researchers and system designers assess clinical technology in the light of the provided tasks and services (Chau & Hu, 2002). If doctors perceive that the technology is compatible with their current workflows, they are more likely to adopt and utilize it (Melas, Zampetakis, Dimopoulou, & Moustakis, 2011). Awareness of personal needs serves as a useful element for matching patients with specific healthcare professionals and treatment programs (Kaprowy, 1991). Future patient-physician relationships should be based on the accommodation of personal needs rather than a prescription of preordained policies. Modern medical care often lacks an effective method for patient-physician information transfer (Levine, et al., 1992). Individualized output of decision aids can be used to guide informed conversations during clinical consultations (Lenert & Cher, 1999). Patient decision aids can be used to communicate probabilistic information of treatment outcomes because it is still uncertain if physicians can be assigned this particular task (Benbassat, et al., 1998). Lack of knowledge during the initial stage of diagnosis is stated to be the determining factor in losing physician trust (Kaprowy, 1991). It is recommended to identify information seekers and attempt to satisfy their information needs prior to meeting with their physicians. Patients say that they often seek to satisfy their information needs from such health care professionals as nurses, social workers, dietitians, pharmacists, and laboratory technicians. Nurses are mentioned as the immediate link and often the best source of medical information (Kaprowy, 1991). In addition to health care professionals, patients name books, magazines, television, and newsletters as the secondary sources of information. Assessments of patient information needs and decision making preferences should be repeated with regular intervals because their desires are expected to vary throughout the disease trajectory. Clinically-integrated patient decision aids must be situationally relevant (Zhuang, et al., 2012). Decision aids may be of limited usefulness if they are unavailable to patients and their physicians at the immediate point of care (Lenert & Cher, 1999).

IT-enabled Patient Decision Aids

Review of IT-enabled patient decision aids in this chapter is done as an independent literature review process. The search is performed through the Web of Science search engine. The first iteration of search is the phrase “patient decision aid” of the publications ranging from 2005 to present time. The year 2005 carries the significance as the development year for the International Patient Decision Aids Standards (IPDAS) criteria checklist. The first search

iteration yields 110 results, which are examined following the following inclusion parameters: 1) intervention media format must not be described as being a) booklet, b) video, or c) paper-based, 2) intervention media format must be identified either in abstract or full-text of the article, 3) only one most recent article per patient decision aid is included, since some studies resulted in multiple publications. Application of this inclusion rule produces the results of 19 relevant articles. The second search iteration is the phrase “patient decision support,” which follows application of the same inclusion rule and yields 44 initial results with 6 remaining relevant articles. The third search iteration is “decision support interventions,” which yielded 74 results but contains only 4 relevant publications. The fourth and fifth search iterations are the phrases “patient decision aid technologies” and “decision support technologies,” which are not limited by a range of dates because of the highly specific long-tailed formats. The result of the last two search iterations is 26 publications but only 3 original relevant articles. The entire five-iteration search process yields 32 pertinent publications. The articles are analyzed for common information systems themes, which are presented in the following sections.

Provisioning of Healthcare Information

Health information search and personal information need are the two variables frequently connected with patient decision making. German application developers, which are primarily employed by the leading insurance companies, have identified information search as one of key activity areas of their patient populations (Härter et al., 2011). The Internet has many known pitfalls when it comes to health information. Patients report feeling overwhelmed by the amount, frustrated by the inability to discover the right kind, and confused and even frightened by their findings (K. Sepucha & Mulley, 2009). Computerized decision aids can improve patient desires to accept health-related information and even positively affect short-term drug adherence rates (Weymiller et al., 2007).

IT-enabled interventions show that self-directed information search has the ability to better satisfy individual information needs and can serve as an effective method for procurement of relevant medical knowledge (Li et al., 2014). Computerized interventions can use self-directed information search to educate while simultaneously promoting patient empowerment. Although some publications reveal strong effects of health information on patient empowerment, they ultimately fail to offer recommendation guidelines for what can be

considered the minimum amount of information necessary for medical treatment selections (Alden, 2014). Internet delivery of patient decision aids has the ability to supply rapidly updated health information in a personally-tailored fashion and do so at the desired time of the decision making process (Hoffman et al., 2013). Information needs can be satisfied individually by either sharing knowledge in manageable pieces or letting users control information flows (Glyn Elwyn, et al., 2011; Ng, Lee, Lee, & Abdullah, 2013).

Cultural and background individualization is a desirable feature of computerized decision aids because previous studies underline limited relevancy for culturally unaware interventions (Jibaja-Weiss et al., 2011). IT-enabled decision aids can support a multitude of learning styles and display content accommodated for individual literacy levels (Safran, 2003). Satisfying information needs for low-literacy populations is an important task if decision making interventions are to become mainstream. Information technology can be used as a foundation for interventions serving mixed-literacy audience. Entertainment decision aids can be helpful in educating low-literacy populations about their treatment options.

Applications can use such features as animated characters, which communicate treatment options and guide patients through the decision making process in order while managing the amount of cognitive load (Li, et al., 2014). When an intervention is designed to serve a low-literacy group, it can effectively inform and motivate both high and low-literacy patients during the process of medical treatment selection (R. J. Volk et al., 2008). However, the outstanding challenge is that low-literacy patients may also lack most basic computer skills, and software designers often presume availability of the Internet. Policy makers, researchers, and healthcare providers now show concern that growing popularity of IT-enabled patient decision aids may cause to marginalize less IT-savvy users (Ng, et al., 2013).

One of the reasons for the ongoing migration of patient decision aids to the Internet is the ability of such interventions to include interactive multimedia (Elwyn, Frosch, Volandes, Edwards, & Montori, 2010). In 1999, the majority of decision aids were in the form of booklets, audio or videotapes, but 80 percent of them became Internet-based by 2005 (K. Sepucha & Mulley, 2009). Multimedia components, such as video clips with physician recommendations, have been successfully used to increase treatment uptake rates by improving patients' decision readiness regardless of literacy levels (Miller Jr et al., 2011). Such software elements as videotaped physician recommendations should be used with

caution in order to prevent inadvertent infusion of subjective bias.

Narratives of real patients can have powerful effects on medical decision making, and inclusion of patient stories in Web-based patient decision aids has been a widely debated topic. Patients may rely on such stories more readily during their deliberations rather than on weighed statistical information. Some evidence suggests that applications with properly constructed narratives can assist patients in mitigating anxiety and forming accurate forecasting predictions (Elwyn, et al., 2010). Even changing the presentation format of such narratives has the ability to influence the ensuing information need. One study shows that video narratives tend to increase the following information search by more than 4 minutes while text transcripts of the same narratives shorten it by more than 5 minutes (Shaffer, Owens, & Zikmund-Fisher, 2013). Thus, not only the inclusion of patient narratives but even their format can influence individual desire for healthcare information.

Another study corroborates the effects of presentation format on patient decision making. When computerized decision aids are compared to their print-based counterparts, researchers find that the populations preferring online or paper formats differ in several important ways: 1) Web users are more likely to use value-clarification instruments, 2) Web users spend more time with the instrument, 3) Web users report that decision aid length is too great even when it is identical to the printed material, and 4) Web users prefer to review decision aids prior to their primary care appointments (Tomko et al.). Some researchers believe that patients, healthcare providers, and practice managers should be given the right combination of online and offline patient decision aids for the most optimal treatment selection process (Hoffman, et al., 2013).

Side-by-side advantages versus disadvantages comparison has been one of the most recommended ways to present treatment alternatives and construct application interface design (Abhyankar, Summers, Velikova, & Bekker, 2014; Fátima Izquierdo, Javier Gracia, Mercedes Guerra, Juan Antonio Blasco, & Elena Andradas, 2011). Computerization of decision making interventions adds a new component of immediate visual feedback via interface interactivity (Glasspool, et al., 2007). Interactivity and immediate feedback allow for exploring potential consequences of chosen actions and ameliorating some of the cognitive load associated with the complex nature of value-influenced medical selections. Digital dashboards have been successfully used in patient decision aids for immediate feedback and

option comparison without causing information overload (James G Dolan, Veazie, & Russ, 2013).

Clarification of Personal Values

Clarification of personal values and their alignment with the available treatment alternatives is one of the most effective functions of computerized patient decision aids (Ruffin Iv, Fetters, & Jimbo, 2007). Veterans Affairs Medical Center (VAMC) has demonstrated the effectiveness of value-based interventions on their patient populations (Schapira et al., 2007). The United Kingdom's National Health Service (NHS) has also shown that computerized interventions with value clarification exercises can lower healthcare costs by reducing the number of electable medically-invasive procedures (Hollinghurst et al., 2010). Another group of the UK researchers resonate that interactive value clarifying applications can be used to reduce decisional conflict and succeed involving patients in clinical decision making (Protheroe, Bower, Chew-Graham, Peters, & Fahey, 2007).

Web-based patient decision aids find it difficult to retain their value-clarification features, and it is reported that fewer than 10 percent of analyzed treatment selections meet the IPDAS criteria for informed decision making (K. Sepucha & Mulley, 2009). Reviews of the available interventions state that many of them are a mere digitalization of formerly printed healthcare information, which does not qualify for decision supporting interventions (Dawn Stacey et al., 2014). One study, which assesses the effectiveness of publicly available educational materials, finds that many existing Internet sources are of suboptimal content (Iacovetto et al., 2014). Healthcare Web sites often present biased information, frequently omit the associated treatment risks, and overlook the existence of treatment alternatives. Patient decision aids are meant to de-bias, balance informational presentation, and align treatments with personal values in order to promote higher decision making quality.

Researchers note the prevalence of merely informational health care materials and argue that finding online patient decision aids may constitute a real challenge. It is stated that three popular search engines (Google, Yahoo, and MSN) produce only 16 percent of first page results in the form of decision making interventions (Morris, Drake, Saarimaki, Bennett, & O'Connor, 2008). Researchers also conclude that patients are less likely to consult plain informational Web sites than patient decision aids and that knowledge scores are significantly lower in the groups of patients not exposed to patient decision aids (D. L. Frosch, Bhatnagar,

Tally, Hamori, & Kaplan, 2008).

One multicenter randomized control trial has explicitly compared the effects of two computerized patient decision aids (Feldman-Stewart, Tong, et al., 2012). The first intervention has provisioned treatment information without attempting to align the existing alternatives with personal values. The second intervention has included a specific values clarification exercise. The study concludes that patients benefit when computerized patient decision aids help to align personal values with the available treatment options. Users of such interventions are better prepared for decision making and exhibit a reduction in decisional conflict.

Personal values and treatment selection summaries can be recorded behind the scenes and shared with health care providers to facilitate the following office visit discussions. One study shows that such approach leads to a 27 percent reduction of the resulting decisional conflict, which signifies a notable improvement of the decision making quality (Li, et al., 2014). Another study protocol recommends that patients with multiple chronic conditions use computerized interventions with such features as support for shared decision making, prioritization of patient-suggested personal goals, and physician-supported clinical integration (Yu et al., 2014).

Support for Clinical Integration

Physician involvement is one of the defining factors for the real-world adoption rates of computerized decision aids (Clouston et al., 2014). Traditional dissemination methods of posting applications online free of charge has been shown somewhat ineffective and with lackluster support from practicing physicians (Evans, Edwards, Coulter, & Elwyn, 2007). One suggestion is to enhance online availability through the establishment of a universal clearinghouse for patient decision aids where users can search and interact with approved deliberation instruments instead of general health care Web sites (Morris, et al., 2008). However, several such clearinghouses of online patient decision aids already exist. The challenge is that intervention registrations remain voluntary and, thus, dependent on the will of their creators (Ng, et al., 2013). Thus, interested stakeholders ranging from researchers to world's governments have begun to recognized the fact that physician involvement is also necessary (James G Dolan, et al., 2013). Massachusetts General Hospital has a notable Electronic Health Records implementation, which enables physicians to prescribe patient

decision aids through individual medical records (K. Sepucha & Mulley, 2009). Information technology can take interventions even further by proactively identifying eligible candidates and automatically distributing the corresponding instruments to qualified patients prior to their clinical visits (Brackett, Kearing, Cochran, Tosteson, & Blair Brooks, 2010).

Patient decision aids need to support physicians explicitly rather than implicitly. If no explicit physician support is supplied, physicians' preconceived notions of healthcare technology intruding on professional authority may also negatively affect their views of such interventions. Computerization of decision aids can offer advanced presentation and deliberation mechanisms with the help of artificial intelligence. Artificial intelligence can structure output or draw inferences upon many patient characteristics and context variables such as desires for shared decision making, gender, prior treatment experience, technology skepticism, self-efficacy, attitudes towards physicians, preference for laymen or technical terms, and some others (Simon et al., 2012). Although potentially effective, it has been shown that interventions with artificial intelligence algorithms meet physician resistance who fear that such software will produce conflicting recommendations and interfere with the essence of their medical consultations (Durand, Wegwarth, Boivin, & Elwyn, 2012). Other researchers resonate stating that if a patient decision aid is not explicitly developed to be used as an adjunct to clinical consultations, it may attempt to substitute actual clinical encounters (Elwyn, et al., 2010).

Physicians have only limited understanding of the way patient decision aids can assist their clinical practice. Competing organizational goals combined with preexisting attitudes yield a diminished desire to advocate decision aids and integrate them in their workflows regardless of usefulness to patients and online availability (Rhodri Evans, Adrian Edwards, et al., 2007). Successful real-life adoption of patient decision aids frequently depends on many of the same factors as implementation of other information technology systems in organizational settings. Physicians may resist the inclusion of such technology stating that their normal 15-minute encounter does not allocate enough time for a meaningful preference-based collaboration session, but integration into organizational processes and supportive leadership help to mitigate the initial resistance (K. Sepucha & Mulley, 2009). The original skepticism towards patient decision aids changes after physicians are presented with valuable features and can witness medical practice outcomes (Glasspool, et al., 2007).

One study of patient decision aids reviews their integration through the lens of Normalization Process Model (Elwyn, Légaré, van der Weijden, Edwards, & May, 2008). This lens attempts to reveal some of the specific factors, which act as promoters or inhibitors of patient decision aids in clinical practice. Instead of focusing on technology dissemination, Normalization Process Model highlights the benefit of having a common goal such as shared-decision making, which reveals that patient decision aids depend on the support of multiple stakeholders including patients, physicians, and office staff. Extant decision making interventions do not necessarily assist in clinical interaction and, thus, provide limited usefulness to the involved stakeholders. The NPM lens reveals that organizational norms motivate physicians to maximize efficiency while the supporting staff is preoccupied with performance metrics frequently tied to their operational capacity (Elwyn, et al., 2008). Healthcare providers and their office staff frequently operate in the context of many competing duties and responsibilities where new technology should not require attention and initiative, but should, ideally, strive to lighten the existing load of strenuous clinical schedules (Brackett, et al., 2010). Patient decision aids need to devote more attention to organizational processes and performance metrics while educating and guiding patients through the steps of treatment selection.

Although computerized interventions increase patient readiness to arrive at suitable decisions, failure to translate this readiness into improved treatment uptake rates is often attributed to inadequate patient involvement and poor patient-physician relationships (Miller Jr, et al., 2011). Patients' decision making quality seems to improve with better knowledge scores, but it does not necessarily lead to a simultaneous improvement of patient involvement and patient-physician relationships (Li, et al., 2014).

Facilitation of Shared Decision Making

Treatment selection frequently involves other people besides patients such as healthcare providers, spouses, and other family members (Fátima Izquierdo, et al., 2011). Patient decision aids can act as catalysts for patient-physician communication, shared decision making, and patient empowerment (Alden, 2014). The United States Affordable Care Act makes a special provision for patient decision aids as a way to inform and promote shared decision making (Dominick L Frosch et al., 2011; Trenaman, Bryan, & Bansback, 2014). Germany's Federal Ministry of Education and Research has also been sponsoring the

development of patient decision aids for physicians wishing to improve clinical relationships and involve patients (Härter, et al., 2011).

There are some conflicting views on whether active patient involvement and empowerment is equally beneficial for the entirety of patient populations. Physicians feel that not all patients want to participate in treatment selection and will resist shared decision making opportunities. Physicians quote their patients saying that they would prefer to concede decision making autonomy in favor of their healthcare providers (Rhodri Evans, Adrian Edwards, et al., 2007). There are also conflicting views on when it is best to expose patients to computerized decision making interventions. There seems to be the notion that dissemination of computerized decision aids is most effective when paired with office visits (Miller, Brenner, Griffith, Pignone, & Lewis, 2012). However, one study notes that if patients are paired with such instruments after clinical consultations, their readiness to make selections increases but knowledge scores remain unaffected (Sivell et al., 2012). Another study claims that high-risk and high-uncertainty decisions (such as evaluations of potential liver transplant options) are characterized by the inability of current intervention technology to improve decision making confidence even while increasing patient knowledge scores (M. L. Volk, Roney, & Fagerlin, 2014). In addition, complex decisions characterized by simultaneous high-risk and high-uncertainty tend to affect patients' knowledge scores even after clinical encounters.

Interaction with a computerized intervention can be recorded behind the scenes and used in promoting shared decision making of the subsequent clinical consultations (Ng, et al., 2013). Special precautions should be taken in order to protect any patient identifying data and use it only for the intended purposes.

Emotional Adaptation Support

Some of the original IPDAS creators argue that the process of decision aid development needs to be furthered by careful consideration of the necessary design features, instrument goals, and context applicability (Elwyn, et al., 2010). One of such goals should be accurate forecasting of future feelings, preferences as well as mental adaptation to potentially undesirable circumstances. An incorrect projection of future physical and emotional states has been correlated with bad decision making (K. Sepucha & Mulley, 2009). The role of emotions in clinical decision making is evident, and patient emotional states should be considered as

one of the influencing factors (Fátima Izquierdo, et al., 2011).

Emotional adaptation can take several forms. Affective Forecasting theory is named as a possibly fitting candidate for emotional support modules of computerized interventions. Decision aids can include an adaptation exercise, which presents parallel lists of treatment attributes and asks patients to compare them to some of their past experiences (Abhyankar, et al., 2014). Another form of technology-assisted emotional adaptation can be online communication with social peers categorized by similar conditions (Elwyn, et al., 2010; Hoffman, et al., 2013).

Computerized interventions can strive for less emotional treatment selections by guiding patients through the process of rational decision making. However, designing such software poses significant obstacles of translating rational mental maps into the corresponding application interfaces. Users find such applications helpful, but even the existing successful interventions fall short of proposing an information systems framework for future application developers (Durand, et al., 2012).

Framework Need

Although many patient decision aids have already been computerized, few scientific studies focus on aggregating proven software attributes into solution frameworks ready for application developers. The United States Department of Health and Human Services includes patient decision aids into a broader definition of "interactive health communication applications", which are meant to combine information with at least one of the following: decision support, social support, or behavior change support (K. Sepucha & Mulley, 2009).

One of the most comprehensive yearly reviews of patient decision aids, compiled by Cochrane Library, does not specifically separate computerized interventions from their technology-free counterparts (Dawn Stacey, et al., 2014). At the same time, intervention medium format does seem to matter to patients, and preference for a particular medium type seems to correlate with the actual desire to consult such tools for treatment selection purposes (Tomko, et al.). One recommendation is to follow individualization path and offer more than one type of medium (computerized, paper, etc.) based on the revealed preferences. However, online interventions are easier to keep current when compared to their video or booklet counterparts, and their dissemination method can potentially encompass larger audiences.

Optimization of computerized decision making interventions is expected to evolve

from the multidisciplinary knowledge of such domains as health informatics, user experience design, human-computer interaction, psychology, education, and implementation sciences. There is a call for development of multiple patient decision aid frameworks, which stem from various disciplines, are designed for specific purposes, and can incorporate adoption recommendations (Elwyn, et al., 2010; Hoffman, et al., 2013). As an example, some interventions may focus on personalization and deliberation approaches while others may be used to improve emotional adaptation and clinical communication. One upcoming study protocol suggests that complex patients with multiple chronic illnesses may also have different needs. Computerization of decision aids for such complex patients will require development of a separate framework because their needs lie beyond the scope of a single value-based treatment selection (Yu, et al., 2014). Another argument for the creation of multiple frameworks is based on the tendency to over-engineer applications, which can be content-rich and interactive, but simultaneously useless for a context-dependent implementation (Glyn Elwyn, et al., 2011).

Some publications have begun the development of abstract process maps, which contain suggestion lists together with outstanding challenges and still unanswered questions. One publication argues that all Web-based patient decision aids should have the means to achieve three fundamental tasks: a) present information, b) achieve accurate affective forecasting, and c) construct personal preferences (Glyn Elwyn, et al., 2011). Another high-level recommendation is to view patient decision aids as tools for "healthcare consumers", which should contain attributes assisting in 1) using health information, 2) clarifying personal values, 3) communicating with providers, 4) negotiating decision making roles, and 5) arriving at treatment selections (Li, et al., 2014).

Table 1 contains attribute comparison of the existing patient decision aids, their general recommendations, and conceptual frameworks discussed in this section. The compared attributes represent basic themes revealed by the literature review, which are clarification of personal values, provisioning of healthcare information, sharing of decision making processes, addressing patient emotional states, and assisting in clinical integration. Table 1 helps to clarify the current state of technology-enabled patient decision aid development where many successful attributes have already been individually recognized. However, both research and application development domains still lack a reusable clearly

prescriptive framework that can be applied to construct effective and standard-driven interventions for a diverse number of conditions.

Table 1. Attribute Comparisons of the Existing IT-enabled Patient Decision Aids

Description	Values Clarification	Provisioning of Healthcare Information	Patient Involvement in Treatment Selection	Emotional Support	Clinical Integration Component
Goal-setting toolkit for patients with chronic disease (Yu, et al., 2014)	Patient-identified goals	None shared	Shared decision making focused on personal goals	None shared	Acknowledged but not addressed
Evaluating quality of potential liver transplant (M. L. Volk, et al., 2014)	Personal risk tolerance	Comparison of risks and benefits	Assumes involvement with improved knowledge	Acknowledges bias but does not correct it	None shared
Medication selection for rheumatoid arthritis patients (Li, et al., 2014)	Values are aligned with treatment options	Animated videos used as teaching materials. Self-directed personalization of information search.	Assumes involvement with improved knowledge	None shared	None shared
Evaluating the need for colorectal cancer screening (Clouston, et al., 2014)	Values are not considered. Goal of decision aid is to increase screening rates	Multiple formats are offered both online and offline	None shared	None shared	Physician importance in patient decision aid success rate is highlighted, but no clinical integration solution is offered
Electing the modality of treatment of basal cell carcinoma (Alden, 2014)	Values are aligned with treatment options	None shared	Assumes equal involvement achieved through alignment of values with treatments	None shared	None shared
Breast cancer treatment selection decision aid (Abhyankar, et al., 2014)	None shared	Option-attribute format of balanced and comprehensive information. All options are	None shared	Emotional adaptation exercise is used to reduce bias of healthy study participants not as an explicit	None shared

		explicit and presented in parallel		design recommendation	
Brest cancer treatment selection with online video narratives (Shaffer, et al., 2013)	Not shared	Self-directed information search is stimulated via patient video narratives	Not shared	Not shared	Not shared
General recommendations for IT-based patient decision aids (Ng, et al., 2013)	Values must be aligned with treatment options	Information must be conveyed interactively	Equal involvement is assumed	Not shared	Decision aids must assist clinicians
Selection of non-opioid pain medication for osteoarthritis pain (James G Dolan, et al., 2013)	Personal values are aligned with treatment options	Electronic dashboards reduce cognitive load. Self-directed information search facilitates informed decision making	None shared	None shared	None shared
Treatment selection aid for prostate cancer patients (Feldman-Stewart, Tong, et al., 2012)	Clarification of values yields less decision making preparedness and diminished regret	Attribute comparison presentation to support rational decision making	Equal participation is assumed, but scale is used to assess individual readiness for decision making	Rational decision making is assumed, so no emotional support is provided	None shared
General recommendations based on analyses of knee osteoarthritis and breast cancer treatment selections (Elwyn, Rix, Holt, & Jones, 2012)	None shared	Information procurement should be interactive and engaging	Acknowledgement that shared decision making is important, that patients vary in involvement desires, and that organizational barriers exist	None shared	Clinical utility is not apparent to doctors. Physicians may be reluctant to recommend tools to patients due to existing skepticism
Amniocentesis testing heuristic-based decision	Values are clarified,	Electronic dashboards,	None shared	Normative emotionless	Physicians fear that

aid (Durand, et al., 2012)	sorted in the order of importance, and aligned with treatment options	attribute comparisons in two columns, and interactive drag and drop interface		decision making is assumed	advanced deliberation tools can interfere with consultations
Colorectal screening evaluation instrument (Miller Jr, et al., 2011)	None shared	Designed to serve low-literacy audience (under 8 th grade reading level). Interactive multimedia material with touch screen interface	Readiness for decision making is measured	None shared	None shared
Entertainment instrument for breast cancer surgery decisions (Jibaja-Weiss, et al., 2011)	Digital jewelry box holds personal concerns and assists in aligning values with treatments	Soap opera episodes are paired with interactive learning modules to serve low-literacy populations	Not shared	Not shared	Not shared
Spanish breast cancer patient decision aid (Fátima Izquierdo, et al., 2011)	Values are aligned with treatment options according to IPDAS	Interactive modules and self-directed access to detailed information. Probability-weighted benefits/risks	Patient empowerment is sought through education. Paternalistic relationship is assumed	None shared	None shared
Process map for web-based decision aids (Glyn Elwyn, et al., 2011)	Preference construction must be supported to align values with treatments	Information navigation can be mandatory or self-directed. Interactive deliberation tools may include multimedia	Equal participation desires assumed	Accurate affective forecasting must be achieved, but no specific recommendations are given	None shared
Vasectomy evaluation patient decision aid	No value alignment is	Inclusion of probabilities	None shared	None shared	None shared

(Labrecque, Paunescu, Plesu, Stacey, & Légaré, 2010)	equally effective to aligning of values with treatments	with graphs is equally effective as procurement of simple side-by-side descriptions(Elwyn, et al., 2010)			
General recommendations for designing patient decision aids for difficult health decisions (Elwyn, et al., 2010)	Value clarifications and alignment with treatment options are needed	Interactive multimedia technologies to reduce cognitive load and assist in deliberation. Probability-based listing of attributes and information procurement in sufficient detail	None shared	Consideration of emotional states is mandatory. Adaptive Forecasting exercise is one of the available options	If used during clinical encounters, must be sensitive to existing workflows. Summaries of upcoming treatment selections may assist in clinical encounters
Conceptual decision aid framework for joined patient-physician treatment selections (K. Sepucha & Mulley, 2009)	Preference construction and aligning of values with treatment options are needed	Tailored information enhances experience, since informational inadequacy frustrates, confuses, and frightens users Evidence-based stories are used to convey information by animated character. Interactive interface for low literacy population	Acknowledges that majority of patients do not participate at desired levels. Short office visits inhibit collaboration	Acknowledges emotions and that forecasting bias is associated with poor quality decisions. Technology can diminish bias through social support	Support of organizational processes, such as prescribing decision aids through medical records
Animated, self-serve, and web-based decision aid for selecting rheumatoid arthritis medication (Li et al., 2009)	Personal priorities are clarified by highlighting treatment concerns		Assumes equal involvement facilitated by knowledge	None shared	None shared
Online patient decision aid for prostate cancer treatment selection (D. L. Frosch, et al., 2008)	Aligning of personal values with treatment options is effective	Online self-paced module is recommended	None shared	None shared	None shared

Framework to assist in embedding patient decision aid technology in clinical practice (Elwyn, et al., 2008)	None shared	None shared	Must focus on shared decision making rather than provisioning of information. Must support all stakeholders	Not shared	Organizational norms favor work efficiency. Decision aids must be redesigned to support clinical work. Instruments should focus on facilitating patient-physician relationships and assist in provider-lead tasks.
Design recommendations to reduce cognitive load of patient decision aids through visual feedback (Glasspool, et al., 2007)	Not shared	Graphical chart feedback ameliorates working memory load. Arguments for and against treatments	In-clinic screen sharing with patient-specific information improves involvement levels	Not shared	Instruments should focus on facilitating patient-physician relationships and assist in provider-lead tasks.
Design of a prostate cancer screening decision aid (Rhodri Evans et al., 2007)	Alignment of values with treatment options	Information flows go beyond providers' offices and instruments must support provisioning both before and after consultations	Active patient engagement is promoted. Equal beneficial levels are assumed	Anxiety and regret are present. No clear recommendation is offered	Clinicians need to actively involve patients in shared decision making
Comparison of web-based and paper-based prostate cancer screening decision aids (Tomko, et al.)	Alignment of values with treatment options	Information is best provisioned by preferred format means. Mixed formats should be supported	None shared	None shared	Patients may have media format preferences (paper or online), which should be recognized and supported
Web-based breast cancer screening patient decision aid (M. D. Thomson & Hoffman-Goetz, 2007)	Culturally sensitive values must be explored and aligned with treatment options	Multimedia and plain language are recommended to better serve low literacy and culturally diverse populations	Successful education initiative assumes universally active patient engagement	None shared	None shared
General recommendations	None shared	Individually	Online	Online social	None shared

for online patient decision aids made in conjunction with existing instruments (Schwitzer, 2002)		tailored outcomes probabilities should be presented	accessibility is meant to engage patients. Equal participation levels are assumed. Assumes equal involvement.	networks and videotaped interviews are recommended for emotional support	
Comprehensive yearly review of patient decision aids with evidence-based recommendations (Dawn Stacey, et al., 2014)	High evidence that patient decision aids help clarify personal values	High evidence that patient decision aids improve knowledge scores	Improvement in knowledge scores and decisional conflict presumes more active involvement	High evidence that patient decision aids reduce decisional conflict	None shared
Instruments for considering left ventricular assist device to treat heart failure (Iacovetto, et al., 2014)	Decision aids must consult IPDAS criteria	Information presentation must be complete, unbiased, and suit patients' reading levels. Experiential information shared by other patients is a frequently requested feature. Individual information tailoring is suggested	None shared	None shared	None shared
Recommendations for Internet disseminated patient decision aids (Hoffman, et al., 2013)	Information technology is an effective way to access patients' values-based preferences		Variability of patient activation is acknowledged, but without offering prescriptive solutions	None shared	Best integration principles are unknown and need to be evaluated
Early diagnosis breast cancer patient decision aid (Sivell, et al., 2012)	Decision making treatment selection must be consistent with patient values	Self-directed information search. Online format	Equal participation is assumed. Improved readiness to decide is expected to engage	Theory of Planned Behavior and Common Sense Model are used to include human emotional states	None shared
Shared decision making the United States in its relation to patient decision aids (Dominick L Frosch, et	Decisions must be patient-centered and	Presented information must be evidence-based,	Equal participation is assumed. Successful	None shared	Primary care clinics must become more patient

al., 2011)	aligned with values according to such existing standards as IPDAS	and designed together with patients and physicians	instruments are anticipated to improve engagement	centered to utilize patient decision aids. Online dissemination methods must include promotion by third parties
------------	---	--	---	---

Table 1 highlights the need for a prescriptive patient decision aid framework, which would combine documented attributes in order to maximize potential benefits and standardize future application development.

Potential Benefits of IT-based Patient Decision Aids and Framework-based Software Development

Computerized patient decision aids have several advantages over their more traditional paper counterparts. Computerization of patient decision aids can enable the beneficial aspects of self-directed information search, stimulate patient-physician relationships via shared decision making, prepare for emotionally-charged treatment selections, educate, and empower patients. IT-enabled interventions have several proven ways for improving knowledge scores and decision making quality through interface design. Electronic dashboards offer quick comparisons of treatment attributes, are preferred by patients, and known to reduce cognitive load. Information technology has an ability to mix presentation formats and interactive multimedia to suit preferences of wider patient populations. IT-enabled frameworks can be expanded to include online social support, video narratives, and patient stories, which are highly debated but powerful features. Information technology is a cheaper and faster way to effectively disseminate current medical information than booklet and other more traditional formats. IT-enabled decision making interventions can achieve many of these goals while respecting physician professional authority.

Several studies show their understanding of the importance of developing patient decision aid frameworks (Elwyn, et al., 2010; Hoffman, et al., 2013). They highlight the fact that many successful attributes and features of computerized patient interventions have already been discovered, and it is now necessary to group these features into applicable and readily reusable blueprints (Yu, et al., 2014). Some researchers call to design multiple

information systems frameworks, since creation of an all-encompassing framework for every type of context poses a real challenge (Glyn Elwyn, et al., 2011). Initial intervention blueprints can serve as stepping stones to further refinement of higher specificity solutions. Patients vary in a multitude of dimensions. Development of an information systems framework may be essential for understanding when to apply decision interventions. Literature exemplifies successful implementations of patient decision aids both before and after clinical encounters but falls short of making a definite recommendation (Sivell, et al., 2012; Tomko, et al.; M. L. Volk, et al., 2014). Applications developed around an information systems framework will allow keeping intervention attributes constant while testing the effects of the surrounding context.

Some of the reviewed studies share portions of their design features but none make an explicit effort to group them into an information systems blueprint of proven attributes ready for intervention developers (K. Sepucha & Mulley, 2009). None of the reviewed studies combine all of the previously successful attributes of emotional adaptation, patient involvement, physician utility, and provisioning of health care information.

Research Gaps Summary

Literature review of the existing patient decision aids has revealed several research gaps, which can be summarized as 1) lack of standards ensuring uniform application of successful strategies for presenting healthcare information, 2) lack of common strategies for successful involvement of patients in treatment selection processes, 3) lack of consideration of the role of human emotions in medical decision making, and 4) lack of solutions facilitating integration of such instruments in live clinical practice.

Chapter Summary

Chapter 2 is devoted to an in-depth literature review of the material first introduced in Chapter 1. The chapter begins with a brief history of the International Patient Decision Aids Standards (IPDAS) criteria, their usefulness, and limitations. Then, four patient types are described in their relation to individual decision making preferences, decision strategies, and patient-physician relationships. The chapter continues with the role of information and information needs in clinical decision making. Two instruments are explained in detail: Control Preferences Scale and Decision Conflict Scale. The chapter concludes with the

physicians' view of technology, attributes of a successful clinical application, and an overview of the existing IT-enabled patient decision aids.

CHAPTER 3

RESEARCH APPROACH

This chapter identifies the selected methodology, lists its advantages and disadvantages, and enumerates the steps needed to complete a full research cycle. Design Science research is named as the chosen methodology. The chapter discusses research problem and motivation, solution objectives, framework design, demonstration, and evaluation as dictated by the selected Design Science research methodology. First section of the text is devoted to familiarizing readers with Design Science research. The section presents methodology definition, purpose, strengths and weaknesses, steps, and reason for selection. The following section discusses identification and motivation of the problem this research is meant to address. The problem is subdivided and represented via the enumeration of constructs and variables as instructed by the Design Science research methodology. The problem representation is succeeded by the descriptions of the solution objectives of the proposed framework. Solution objectives are designed with the help of four framework components 1) Emotional Adaptation Gateway, 2) Decision Strategy Gateway, 3) Information Need Gateway, and 4) Workflow Recommendation Gateway. The four Gateway components are intended to meet the stated objectives and address the identified problem. Gateway components are the core of the developed patient decision aid framework. In order to demonstrate framework effectiveness, the dissertation project uses live instantiation of a disease-specific patient decision aid and shares the results of its quantitative evaluation as well as qualitative physician feedback. Experiment data are collected from student volunteers, and US-licensed family practice physicians are enlisted for the subsequent qualitative evaluation. Data analysis is performed with the Independent Samples T-test approach and qualitative physician responses are shared as original quotations.

Design Science

Design Science research is an applied problem-solving methodology, which uses specific previously established steps to identify a problem, propose a solution, demonstrate utility, evaluate effectiveness, and communicate findings. In information systems, Design Science research can be defined as a paradigm aiming at the expansion of human and organizational capabilities through innovation of technological artifacts (Hevner, et al., 2004). Another way to see Design Science research is as a solution-focused methodology for specific problems of wide-range professional domains (Van Aken, 2005). This research methodology typically performs several iterations of the initially outlined steps starting with identifying an existing problem and ending with evaluating a proposed solution. It is noted that Design Science should be contrasted to its non-scientific predecessor of design discipline (Cross, 2001). Unlike Design Science, design discipline is a frivolous approach to artifact development and improvement. Design Science is a theory-based and methodologically rigorous research process, which expands scientific knowledge while proposing applicable solutions. Some of the stated past weaknesses of Design Science are the inability to find theoretical support for otherwise successful innovations and somewhat poor integration with such research tasks as theory building, experimentation, and observation (Iivari, 2007). These weaknesses can be partially addressed by demonstrating consistent predictability and staying cognizant of a needed scientific contribution. This dissertation work selects Design Science research methodology because of the stated objective to advance the fields of health care and information systems via a solution-oriented innovation of patient decision aids. One of the most commonly listed outputs of Design Science research takes the form of a technological prescription. In this paper, the prescription is a patient decision aid framework developed for a particular set of objectives. Framework design and evaluation are then related to both scientific and professional audiences. Figure 2 summarizes the steps undertaken by this research, which consults Design Science research methodology as the formal guide.

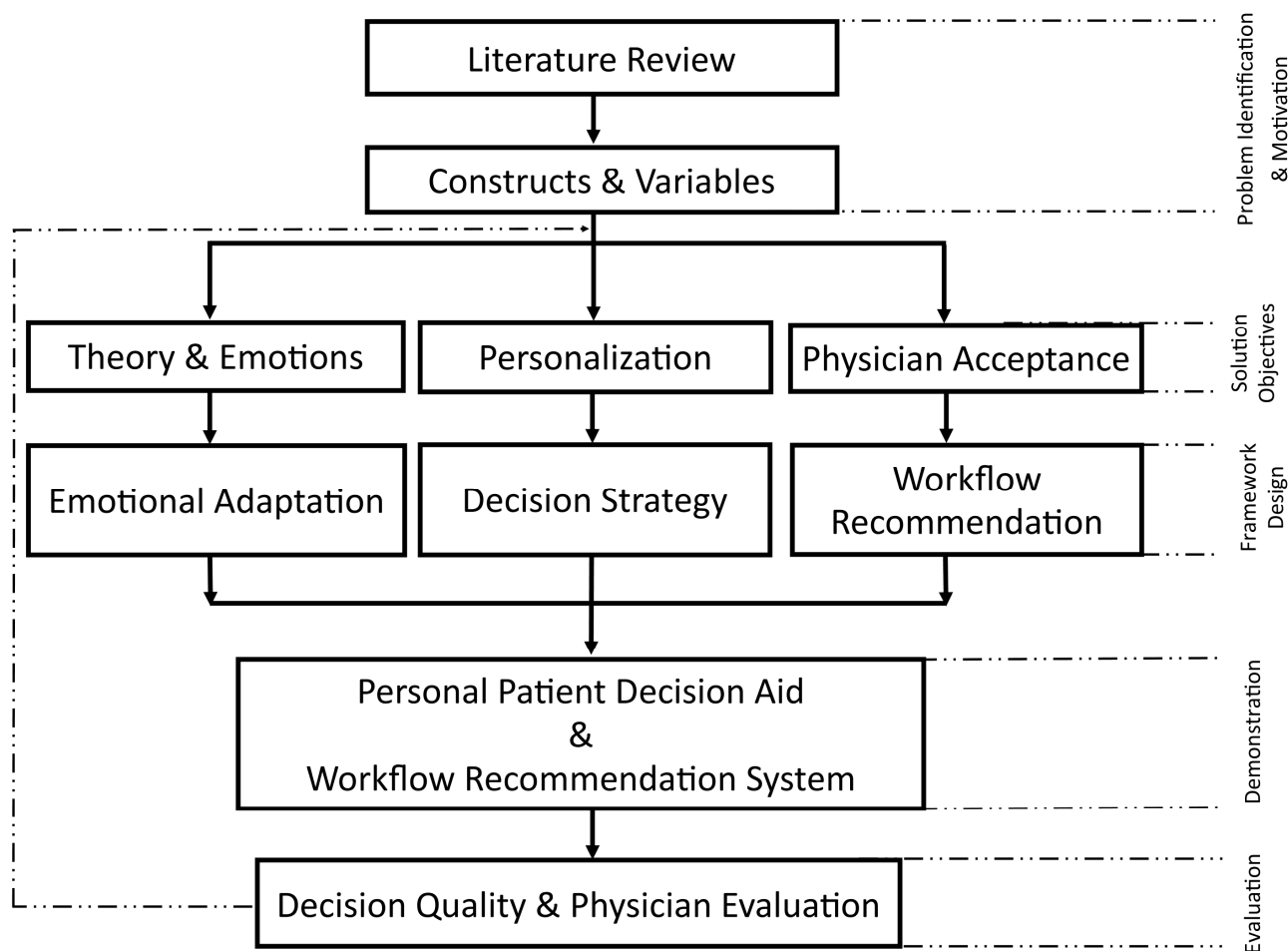


Figure 2. Dissertation Steps. Design Science Research Methodology

Steps of Design Science research are iterative and can be seen on the right side of Figure 2 in their relation to the proposed framework. As seen in Figure 2, framework development process is iterative and begins with the review of literature, identification of current shortcomings, and documentation of constructs and variables directly associated with the revealed research gaps. The constructs and variables are also used for later evaluation of the framework and the effectiveness of the first artifact instantiation. The second stage of the framework development process consists of producing solution objectives, which are interconnected with the constructs and variables. At this stage, the solution objectives are descriptive, and their goal is to depict the fundamental logic of the framework. The third development stage contains prescriptive solutions for each of the specified objectives. Low-level prescriptions are meant to serve future application developers and researchers who wish to either create framework-based decision making interventions or expand the original blueprint. The fourth stage of the framework development process is used to produce a live

instantiation of the proposed prescriptions. Demonstration of the artifact is necessary for the fifth stage of the iterative design circle devoted to validation and evaluation. Evaluation of the framework establishes a loopback connection between the results and the initial objectives. Evaluation of the framework may reveal that the shortcomings identified during the literature review stage are not sufficiently addressed by the solution objectives. In this case, another iteration of the entire research process may be necessary. Each of these individual iterative stages are described in the following sections in their relation to the proposed information systems framework.

Problem Identification and Motivation

Literature Review chapter has focused on identifying the gaps of the existing patient decision aids and outlining constructs, which are used to shape the solution. Current state of patient decision aids is problematic. Their relative maturity and expected usefulness coincide with the lack of actual use and low clinical adoption rates. Literature Review chapter has uncovered three main shortcomings (constructs) listed in Figure 2. Future patient decision aids need to: 1) make explicit use of decision making theory, which accounts for the role of human emotions, 2) satisfy personal decision making preferences and information needs, and 3) improve clinical utility and physician acceptance. Each of the constructs can be further disassembled into the constituting variables. This research identifies the following variables for each of the described constructs as follows:

- Emotional support of human decision making: modern decision making theory, which attempts to moderate the effects of emotional bias (G. Elwyn, et al., 2011).
- Decision making preferences: autonomous decision making, dependent decision making, and collaborative decision making (Emanuel & Emanuel, 1992; Kasper, Heesen, Kopke, Fulcher, & Geiger, 2011; Scott & Lenert, 2000). Recommendation for decision strategy, recommendation against decision strategy, and provision of factual information (Dalal & Bonaccio, 2010; Zhuang, et al., 2012).
- Information needs: minimum amount of information, maximum amount of information, and sufficient amount of information to arrive at a treatment

selection (Degner, et al., 1997; Feldman-Stewart, O'Brien, et al., 2012; Kasper, et al., 2011). Self-directed information search (Li, et al., 2014).

- Physician acceptance: streamlining of clinical workflow for patient centeredness, personalization of provided service, and understanding of responsibility allocation (J. G. Dolan & Frisina, 2002; Dominick L. Frosch, et al., 2011; Green, 1988; Levine, et al., 1992). Preserving physician autonomy and existing administrative load (Hertzum, 2011; Lun, 1995; Zheng, et al., 2005).

Solution Objectives

As seen in Figure 2, first solution objective focuses on providing better emotional support for human decision makers. Second objective focuses on personalization of satisfying individual information needs and desires for decision making autonomy. Third and final objective is designed to improve the levels of physician acceptance and clinical utilization rates.

Framework Design

Once the solution objectives are described, formal patient decision aid framework is developed, which is validated by the mathematical binary operation rules. The framework standardizes the process of patient decision aid design by closing the gaps identified in the Literature Review chapter. The framework offers four core components: 1) Emotional Adaptation Gateway, 2) Decision Strategy Gateway, 3) Information Need Gateway, and 4) Workflow Recommendation Gateway. Emotional Adaptation Gateway is the component aimed at achieving emotional adaptation with the help of a chosen decision making theory. The selected theory must encompass emotions and attempt to correct biases caused by the highly-emotional states of medical decision making. Decision Strategy Gateway is the personalization component consisting of reusable binary matrices and formulas, which personalize the treatment selection process by satisfying the individual desires for decision making autonomy. Information Need Gateway is the component, which applies a separate set of binary matrices and formulas to personalize the treatment selection process by addressing individual information needs. Workflow Recommendation Gateway is the component with a third set of binary matrices and formulas aimed at the objective of improving physician

acceptance via providing clinical utility. Patient decision aids created according to this framework are expected to yield higher quality decisions and integrate better into existing clinical processes.

Demonstration

Emotional Adaptation Gateway, Decision Strategy Gateway, and Information Need Gateway components of the framework are presented with an instantiation of a patient decision aid prototype for dialysis treatment selection, which is a form of treatment for patients with kidney failure (Carmack, 2011). The purpose of the first prototype instantiation is to strengthen the framework's summative validity by demonstrating that the new patient decision aid has the capacity to alleviate emotional bias, personalize the decision making process, and decrease the resulting decisional conflict. The application is then assessed through an experiment, which compares the functionality of a traditional patient decision aid to the one based on the developed framework.

Workflow Recommendation Gateway component of the framework is presented with a hypothetical scenario analysis of a clinical encounter, which increases patient centeredness by applying the developed formulas and matrices to individualize patients' medical experiences. The assessment involves soliciting physician input on the component's usefulness and the levels of implementation desirability.

Data Collection

Students from Dakota State University are asked to perform a set of role-playing tasks identical to those of future kidney failure patients. More specifically, students of Dakota State University's Information Systems program are asked to volunteer their time evaluating the first patient decision aid prototype. The participants are solicited in class and via university email. They are supplied with Universal Resource Locator (URL) to a JavaScript function randomly assigning them to experiment or control groups. The patient decision aid is published online, and data are collected anonymously and confidentially. Both groups are tasked to review the available options and perform individual treatment selections. Immediately post-selection, the participants are exposed to the questions of the Decisional Conflict Scale. DCS answers are later used to assess the ability of the new patient decision aid

and the underlying framework to meet the initial design objectives of Decision Strategy Gateway, Information Need Gateway, and Emotional Adaptation Gateway.

US-licensed family practice physicians are solicited for qualitative feedback regarding their views on the usefulness and implementation desirability of the framework workflow recommendation component. The physicians are presented with a detailed scenario analysis of a hypothetical clinical encounter, which applies the framework formulas and matrices to optimize clinical encounters for patient centeredness.

Evaluation

Prototype evaluation demonstrates the ability of the framework to close the gaps identified in the Literature Review chapter and meet the specified objectives. Decisional Conflict Scale (DCS) is the instrument used for quantitative data collection. Uncertainty Subscore of the scale represents the decision maker's level of certainty after arriving at a treatment selection. Other subscores used in evaluation are Informed and Effective Decision Subscore. Informed Subscore reveals the subjective feeling of being adequately informed while Effective Decision Subscore highlights the perception of decision making effectiveness. Decisional Conflict Scale marks a better decision making process with lower values of Total Score and each of the corresponding subscores.

A known statistical technique (Independent Samples T-test analysis) is used to compare the decision making quality of the prototype built on the framework against a pre-existing application without the proposed Gateway components. Independent Samples T-test analysis is used to evaluate Emotional Adaptation Gateway, Decisional Strategy Gateway, and Information Need Gateway by comparing the corresponding mean scores of the experiment and control groups.

Evaluation of Workflow Recommender Gateway is qualitative. Several US-licensed and board certified family practice physicians are solicited for their input regarding a hypothetical scenario analysis. Physicians are asked to evaluate both potential usefulness of the aid in a clinical setting and their willingness to implement and use such an instrument in their daily routines.

Chapter Summary

Research Methodology chapter describes the chosen Design Science research

methodology by providing the definition, listing its pros and cons, and explaining the reasons for its selection. The chapter continues by explaining the research steps of this dissertation project as specified by the elected Design Science approach. As shown in Figure 2 and elaborated in the chapter's sections, this research follows an iterative process of identifying problem and motivation, listing solution objectives, developing framework, staging artifact demonstration, performing data collection, and completing scientific evaluation.

CHAPTER 4

DESIGN OF A PATIENT-CENTERED AND CLINICALLY INTEGRATED PATIENT DECISION AID

This chapter is used to expound upon the design of the proposed framework. The text begins by forming an explicit connection between the identified shortcomings of the existing patient decision aids and the specified objectives, requirements, and application features intended to close the stated deficiencies. The chapter is continued with high-level figures and diagrams before moving onto the low-level vector formulas and binary matrices. Formative validity and Summative validity are presented, and pre-validated instruments used for data elucidation and analysis are explained.

The chapter begins with a table of the framework objectives aligned with the identified shortcomings and proposed application features. The text is continued with drawings of the framework's high level figures and diagrams. The figures and diagrams contain specific components, application layers, and end user interaction examples. Then, each of the four Gateway components is elaborated. Emotional Adaptation Gateway is the component developed to alleviate the bias stemming from the high level of human emotions consistent with medical treatment selections.

Decision Strategy Gateway is the component developed to personalize the process of treatment selection based on individual desires for shared decision making. Coefficient x is part of Decision Strategy Gateway used to record the output of the revealed individual desires for shared decision making in the Patient Type matrix. Patient Type Matrix is also part of Decision Strategy Gateway, which is a developed binary matrix used to hold the revealed individual desires for shared decision making. Strategy Type Matrix is the second binary matrix of Decision Strategy Gateway, which uses theory to align individual desires for shared decision making with the corresponding decision strategies. Strategy Output Vector is the

binary vector of Decision Strategy Gateway used to reveal the individual decision making strategy for a particular decision maker. Strategy Output Vector is one of the framework's key personalization components.

Information Need Gateway is the next component used to personalize the process of treatment selection. It is based on an individual's needs for decision supporting information. Coefficient y is part of Information Need Gateway used to record the output of the revealed individual information needs in the Information Selection matrix. Information Need Gateway also contains Information Selection Matrix, which is a binary matrix meant to hold the revealed individual information needs. The second binary matrix of Information Need Gateway is Amount of Information Matrix, which aligns individual information needs with the application attributes. Information Output Vector is the framework's second binary personalization vector. Information Output Vector reveals the exact amount of information suitable for a particular decision maker.

The final framework's gateway component described in this chapter is Workflow Recommendation Gateway. This component is designed to improve patient centeredness of live the clinical consultations by supporting physician workflows. Workflow Recommendation Matrix is the matrix used to align individual desires for shared decision making with the corresponding clinical workflow modules. Workflow Output Vector is the last framework's binary vector developed to reveal a recommended patient centric clinical workflow for a particular decision maker type.

After presenting the framework's gateways and components, the text explains the two types of validity employed by this dissertation research. Formative validity is supported with mathematical rigor and extant relevant literature while Summative validity is achieved through artifact instantiation, physician surveys, and statistical analysis of the collected experiment data.

The chapter is concluded by explaining how the Decisional Conflict Scale scores and subscores are computed, which serve as later inputs for the Independent Samples T-test analysis. The scale's calculations of Total Score and three separate subscores are explained.

Framework Objectives

Table 2 aligns the existing patient decision aid shortcomings with the proposed framework objectives and corresponding application features. As seen in Table 2, the

framework closes the gap of information need personalization by satisfying information needs with an individually-tailored output. The information needs objective is aligned with the application feature appropriately named Information Need Gateway. Similarly, lack of individualization based on the decision making preferences is the deficiency addressed by the framework's strategy personalization. Decision Strategy Gateway is the application component, which must be applied to close the stated deficiency. The framework is created with an awareness of human bias by including an objective to account for emotions with the help of a carefully selected decision making theory. Thus, an application based on the framework must also contain Emotional Adaptation Gateway, which reduces the effects of bias of highly-emotional mind states. Clinical integration is achieved via improving physician acceptance of patient decision aids. Workflow Recommendation Gateway is tasked to advance patient centeredness and operating efficiency of live clinical consultations without an increase in administrative task load or encroaching upon doctors' professional autonomy.

Table 2. Shortcomings, Objectives, and Features

Existing Shortcomings	Framework Objectives	Application Features
Lack of individualization based on patient information needs.	Personalization: information needs are tailored individually.	Information Need Gateway
Lack of individualization based on patient decision making preferences.	Personalization: decision making preferences are tailored individually.	Decision Strategy Gateway
Lack of design based on decision making theory, which includes the role of human emotions.	Explicit use of decision making theory, which accounts for human emotions.	Emotional Adaptation Gateway
Lack of clinical integration and utility.	Clinical integration and physician acceptance.	Workflow Recommendation Gateway

Framework Diagrams

Figure 3 displays a high level activity diagram of the proposed framework. The framework begins by elucidating individual desires for shared decision making. The elicited desires are then used as input for strategy personalization (Decision Strategy Gateway) and workflow recommendation (Workflow Recommendation Gateway) features of the application.

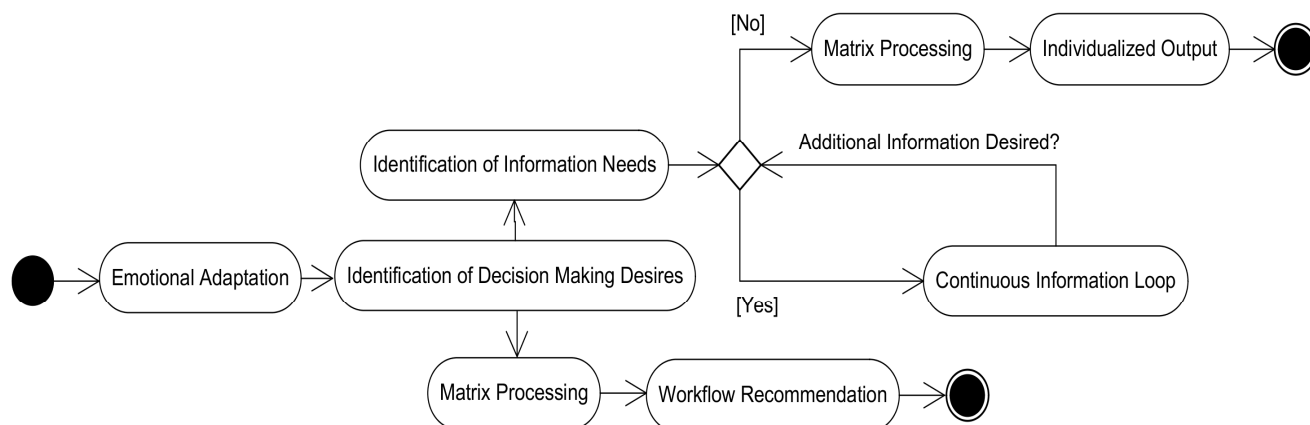


Figure 3. Framework Activity Diagram

Tailoring of individual information needs relies on the continuous identification of desire to review additional information. The developed binary Gateway matrices, which are discussed in a greater detail in the following sections, process the elucidated preferences for the purpose of shaping personalized output and clinical workflow recommendations.

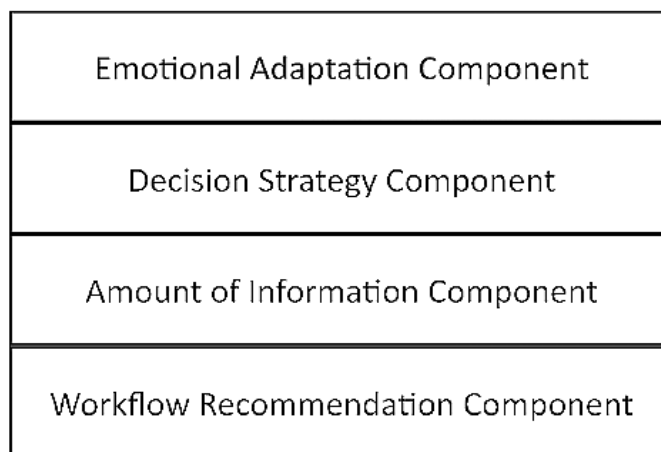


Figure 4. The Framework with a Layered View

Figure 4 is a layered view of the framework. It begins with the top layer of Emotional Adaptation Component, which applies a chosen emotion-aware decision making theory and attempts to de-bias the fragile emotional state of medical treatment selection. Emotional Adaptation Component does not contain any formulas or binary matrices. Its only requirement is to follow an existing decision making theory and incorporate a form of an emotional

adaptation exercise. The next layer is Decision Strategy Component. It contains Decision Strategy Gateway described in a greater detail in the following sections of the chapter. This layer is responsible for eliciting patients' decision making preferences and individualizing output with the help of the developed formulas and binary matrices. The next layer is Amount of Information Component, which contains the formulas and binary matrices used to individualize the amount of presented information. The last layer is Workflow Recommendation Component. It also contains a set of binary formulas and matrices, and its aim is to improve the rates of clinical utilization through physician acceptance and workflow redesign.

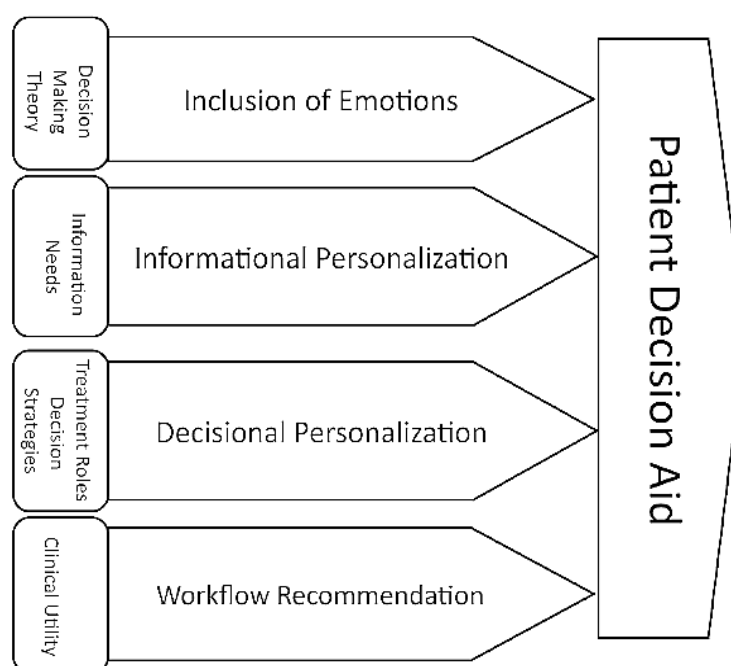


Figure 5. Theoretical and Technical Building Blocks of the Framework

Figure 5 is the view of the framework's theoretical and technical building blocks. As seen in Figure 5, selection of a decision making theory helps with the inclusion of emotions. Variability of personal information needs, which cannot be predicted by demographic or other contextual data, drives the development of the framework's personalization of information output. Variability of individual desires for shared decision making shape the development of Decision Strategy Gateway. Need to provide clinical utility assists in developing the workflow recommendation component.

Emotional Adaptation Gateway

Until recently, decision making theories ignored the effects of stress and emotions typically present during important health-related decisions. The lack of recognition of the role of emotions in human decision making processes may be attributed to the traditional view of medicine and treatment selection where patients are silent recipients of the provided health care services. For instance, Expected Utility theory is difficult to apply to real-world clinical decision making because of its inherent reliance on the quantitative desirability estimates and the corresponding probabilities of each of the potential medical outcomes. Actual process of clinical treatment selection is not as definitive as is demanded by the Expected Utility theory, since many medical outcomes cannot be easily assigned probability and desirability scores.

Affective Forecasting theory is one theory, which seems particularly suitable in the framework context because of its inclusion of human emotions, existing successful healthcare applications, and its inherent ability to de-bias hypothetical responses of healthy non-patients. The framework developed by this dissertation incorporates an adaptation exercise, which has been successfully applied by Ubel and colleagues (Ubel, et al., 2005) to prepare decision makers by reducing the undesirable effects of human forecasting bias. The exercise is not difficult to modify to serve a wide range of treatment selections. The exact version of the adaptation exercise used in this dissertation can be found in Appendix A.

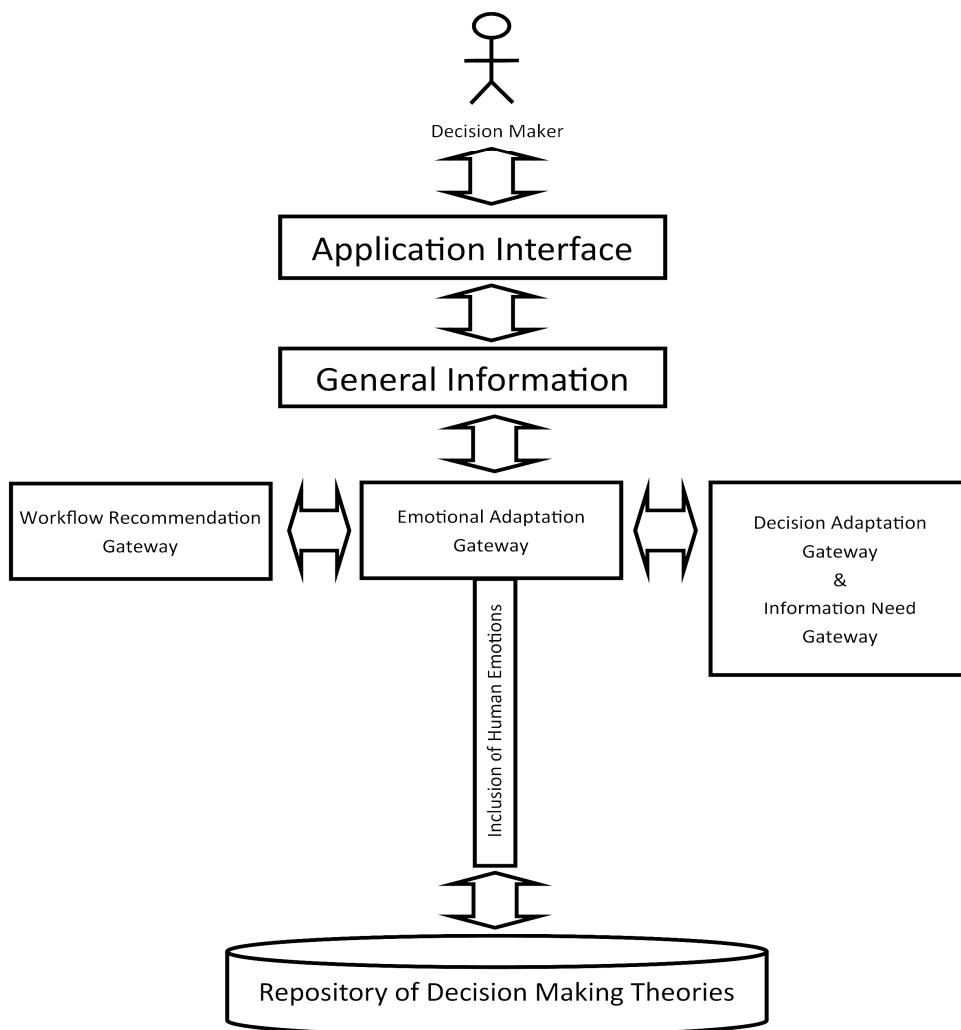


Figure 6. Use Case Diagram of Emotional Adaptation Gateway

Figure 6 is a graphical use case diagram of Emotional Adaptation Gateway put forward by the developed framework. Patient decision maker is interfaced with the Gateway after being exposed to the general description of his/her healthcare condition and available treatment options. The dynamic nature of this Gateway is not patient-specific but rather depends upon the presence of alternative decision making theories, which acknowledge and attempt to correct the biases caused by emotional clinical treatment selections. Although the framework implements the adaptation exercise stemming from the Affective Forecasting theory, other decision making theories may also prove to be similarly useful.

Decision Strategy Gateway

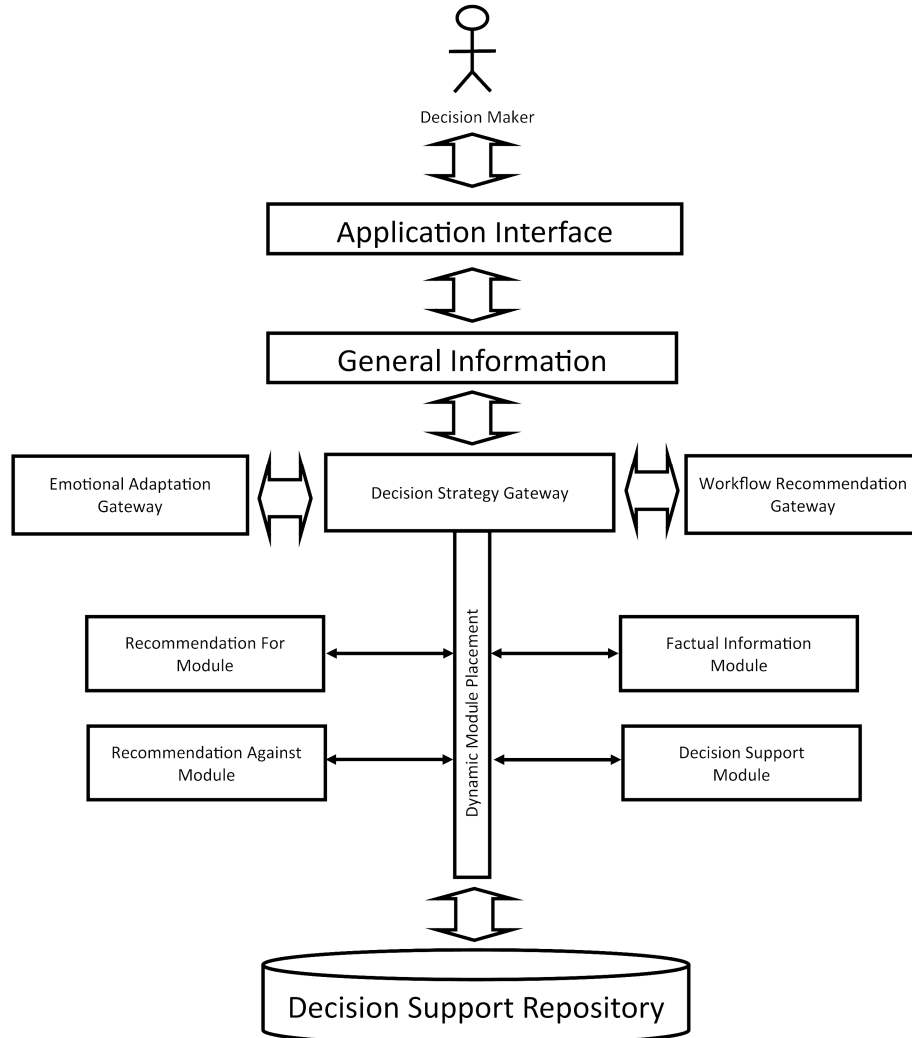


Figure 7. Use Case Diagram of Decision Strategy Gateway

Figure 7 is a use case diagram of Decision Strategy Gateway. As depicted in the diagram, decision makers are paired with the application interface, which precedes Decision Strategy Gateway with general disease information, available treatment options, and Emotional Adaptation Gateway. Decision Strategy Gateway uses a previously validated instrument (the Control Preferences Scale) to reveal personal desires for shared decision making. The developed binary matrices are then applied to match the elucidated preferences for shared decision making with the corresponding decision making strategy modules residing within the repository.

Coefficient x – Recording Preferences for Shared Decision Making

The Control Preferences Scale is the instrument for revealing individual desires for shared decision making used by the Decision Strategy Gateway as well as Workflow Recommendation Gateway framework components. Coefficient x assists in recording the results of the Control Preferences Scale in the Patient Type matrix. Coefficient x is the direct binary output of the Control Preferences Scale which is used to record individual preferences for shared decision making in the Patient Type (PT) matrix (see Table 3). Coefficient x can accept values in the following range: $\{x \in \mathbb{R} | 1 \leq x \leq n\}$, where n is the total number of decision maker types as measured by the CPS instrument. Lower coefficient values signify desires for reduced decision making autonomy while larger coefficient values highlight the desires for more autonomous decision making styles. For example, Coefficient x = 1 represents a passive (Paternalistic) decision maker while x = n is the decision maker with the highest degree of desired autonomy (Informative patient).

Patient Type (PT) Matrix

PT matrix is a binary 1 x n matrix for n decision maker types identified by the Control Preferences Scale. The matrix contains the following four variances of decision making autonomy: PT1 = Paternalistic decision maker, PT2 = Collaborative decision maker, PT3 = Deliberative decision maker, and PT4 = Informative decision maker.

Table 3. Manipulation of Patient Type (PT) Matrix

Each component of Patient Type Matrix (PT) is set by
$PT_x = \begin{cases} 1 & \text{if patient has a preference for decision making style } x \\ 0 & \text{otherwise} \end{cases}$

Table 3 contains the logic of the binary manipulation of PT matrix with Coefficient x. Individual preferences for shared decision making are recorded within the matrix by assigning the binary value 1 (one) in the component marked by Coefficient x.

Table 4. Binary Representation of Patient Type (PT) Matrix

	Paternalistic	Collaborative	Deliberative	Informative
Decision Maker	1	0	0	0

Table 4 is a low-level representation of the binary format of PT matrix. Decision maker types are set with 1 (one) to mark the corresponding individual preference for shared decision making. The remaining matrix components are set to the default value of 0 (zero).

Strategy Type (ST) Matrix

Strategy Type (ST) matrix represents the decision making strategies available within the system. As seen in Table 5, ST matrix uses the binary value 1 (one) to align the decision maker types with the corresponding decision making strategies.

Table 5. Values of Strategy Type (ST) Matrix

Each component of Strategy Type (ST) matrix is set by

$$ST_{ikx} = \begin{cases} 1 & \text{if strategy module } x \text{ is relevant for decision making preference } k \\ 0 & \text{otherwise} \end{cases}$$

Each decision maker type is aligned with a single strategy by setting the binary value 1 (one) to the corresponding component of the Strategy Type matrix.

Table 6. Binary Representation of Strategy Type (ST) Matrix

Decision Strategy Decision Maker	Recommend For	Recommend For and Recommend Against	Factual Information
	Paternalistic	1	0
Collaborative	0	1	0
Deliberative	0	1	0
Informative	0	0	1

Table 6 is a low-level representation of Strategy Type matrix where binary value 1 (one) aligns known decision maker types with the corresponding decision strategies. As seen in Table 6, Paternalistic (passive) decision maker is paired with the Recommend For decision strategy module, and ST matrix sets the corresponding component with the binary value 1 (one). Collaborative and Deliberative decision makers are paired with the Recommend For and Recommend Against decision strategy module, and ST matrix records binary value 1

(one) in the corresponding matrix component. Finally, Informative decision maker type is paired with the Factual Information module, and ST matrix sets the corresponding component of Factual Information decision strategy module to binary value 1 (one). Each decision maker type is aligned with a single module of decision making strategy.

Strategy Output (SO) Vector

The framework puts forward Strategy Output (SO) vector, which is achieved via binary multiplication of the PT and ST matrices:

$$SO = PT * ST$$

Binary multiplication is used for output processing and works as a filter between the framework's static logic described in the ST matrix and dynamic individual preferences recorded in the PT matrix. SO vector produces a 1 x n matrix of binary information meant to reveal a personalized decision making strategy.

Table 7. Values of Strategy Output (SO) Vector

Each component of Strategy Output (SO) vector is set by
$SO_x = \begin{cases} 1 & \text{for recommended decision making strategy } x \\ 0 & \text{otherwise} \end{cases}$

Table 7 shows how SO vector marks a specific decision strategy resulting from the binary multiplication operation.

Table 8. Binary Representation of Strategy Output (SO) Vector

	Recommend For	Recommend For and Recommend Against	Factual Information
Decision Maker	1	0	0

Table 8 is a low-level representation of Strategy Output vector where binary value 1 (one) marks a specific instance of an individual decision strategy module for a particular decision maker type. The remaining components of the matrix keep their default values of 0 (zero).

Information Need Gateway

Figure 8 depicts use case diagram of Information Need Gateway and the modules used for its dynamic assembly. The application begins by presenting decision makers with general information about the disease, treatment options, and Emotional Adaptation Gateway. Then, Decision Strategy Gateway applies the Control Preferences Scale instrument to reveal personal desires for shared decision making. After forming the individual decision strategy by calculating Strategy Output vector, the application proceeds to satisfy personal information needs with Information Need Gateway.

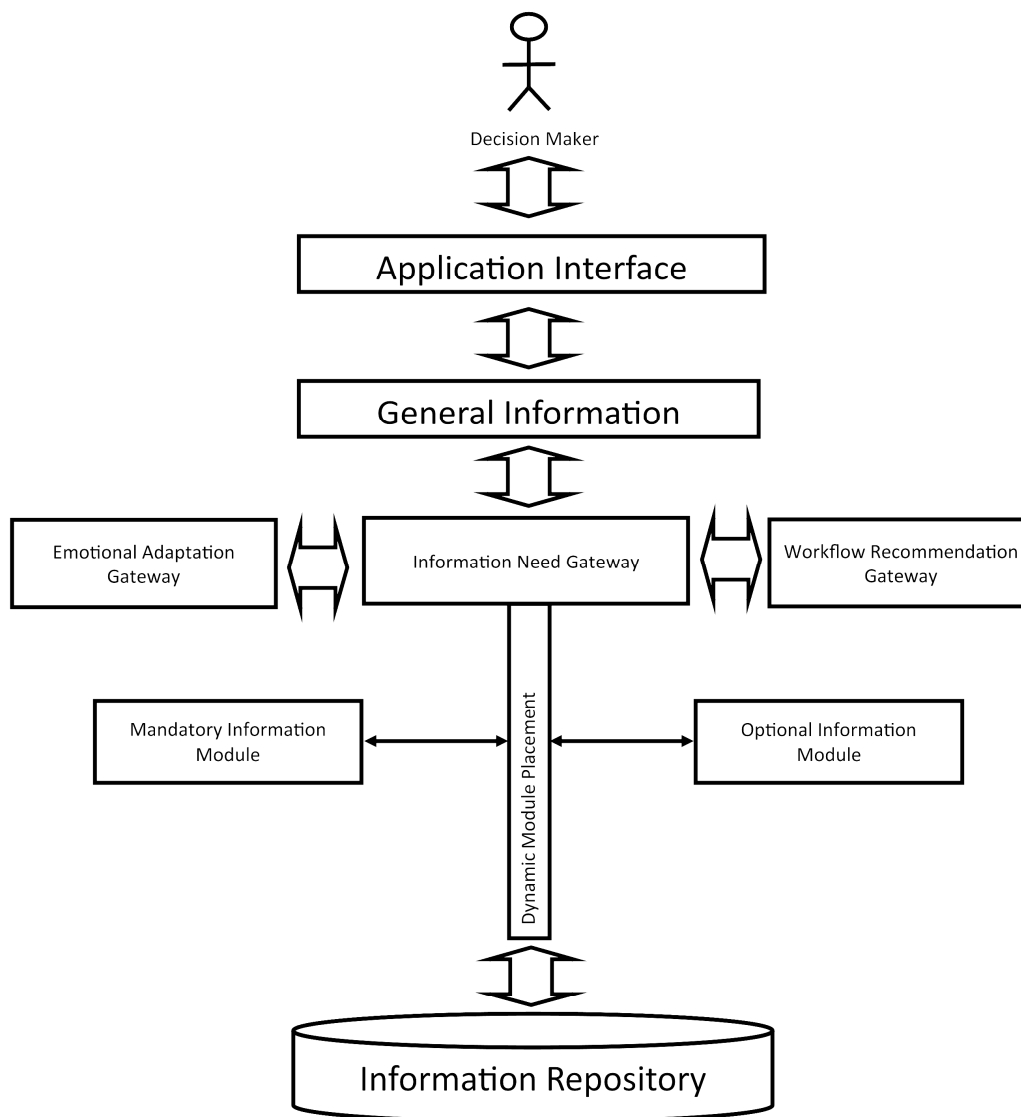


Figure 8. Use Case Diagram of Information Need Gateway

Coefficient y - Recording Information Need Preferences

Coefficient y is used to record the number of information modules decision makers elect to review. Coefficient y accepts the following values: $\{y \in R | 1 \leq y \leq n\}$, and it is incremented by 1 (one) with every additional information module a decision maker wishes to examine. First information module is mandatory, which means that the lowest value of Coefficient y is 1 (one). It is recommended to follow the Content guidelines of the IPDAS Criteria document (see Appendix C) for the structure of the mandatory information module. Content section of the IPDAS Criteria document is considered the minimum amount of information necessary for a clinical treatment selection.

Information Selection (IS) Matrix

Coefficient y is used to record individual information need preferences in the Information Selection (IS) matrix. The first component of the matrix reflects the minimum baseline deemed necessary to arrive at a treatment selection (Content section of the IPDAS Criteria document). The remaining information modules follow and increment the value of Coefficient y by 1 (one) until $y = n$ is reached where n represents the last component of the IS matrix.

Table 9. Manipulation of Information (IS) Selection Matrix

Each component of Information Selection Matrix (IS_y) is set by

$$IS_y = \begin{cases} 1 & \text{if patient has a preference for information module } y \\ 0 & \text{otherwise} \end{cases}$$

Table 9 shows the logic of binary manipulation of the IS matrix with Coefficient y . Information need is satisfied individually by allowing decision makers to elect additional information modules via direct manipulation of the Coefficient y values. Information need preferences are recorded in the IS matrix by assigning the binary value 1 (one) to the corresponding matrix component.

Table 10. Binary Representation of IS Matrix

	Minimum Information	Balanced Information	Maximum Information
Decision Maker	1	0	0

Table 10 is a low-level representation of the Information Selection matrix where Coefficient y marks an individual information need with a binary value 1 (one) in a corresponding matrix component. The remaining values keep their default values of 0 (zero).

Amount of Information (AI) Matrix

Amount of Information (AI) matrix represents information modules available within the system. Information modules of the matrix are typically based on the extant literature where patients reveal their concerns about the type of information missing from their usual clinical consultations (Kaprowy, 1991). The AI matrix aligns the available information modules with the corresponding personal information needs.

Table 11. Values of Amount of Information (AI) Matrix

Each component of Amount of Information (AI) matrix is set by
$AI_{yn} = \begin{cases} 1 & \text{if information module } n \text{ is relevant for information preference } y \\ 0 & \text{otherwise} \end{cases}$

As seen in Table 11, binary value 1 (one) marks information modules relevant for a particular information need while the value of 0 (zero) highlights the modules not applicable to the corresponding level of information need.

Table 12. Binary Representation of Amount of Information (AI) Matrix

	IPDAS Criteria Content Section	Additional Module n-1	Information Module n
Minimum Information	1	0	0
Balanced Information	1	1	0
Maximum Information	1	1	1

Table 12 is a low-level representation of the Amount of Information matrix where binary value 1 (one) marks relevant information modules for a possible range of personal information needs. The remaining components of AI matrix are set to their default binary values of 0 (zero).

Information Output (IO) Vector

Information Output (IO) vector is achieved with binary multiplication of Information Selection (IS) matrix and Amount of Information (AI) matrix:

$$IO = IS * AI$$

Binary multiplication of the two matrices acts as a filter, which combines the logic of the AI matrix and the individual preferences recorded in the IS matrix to produce personalized application output capable of satisfying individual information needs.

Table 13. Values of Information Output (IO) Vector

Each component of Information Output (IO) vector is set by

$$IO_y = \begin{cases} 1 & \text{for recommended information need attribute } y \\ 0 & \text{otherwise} \end{cases}$$

Information Output vector reveals the result via a single row of binary information. Table 13 shows how Information Output vector marks the specific information need modules paired with an individual decision maker.

Table 14. Binary Representation of Information Output (IO) Vector

	IPDAS Criteria Content Section	Additional Module n-1	Information Module n
Decision Maker	1	0	0

Table 14 depicts a low-level representation of the Information Output vector where binary value one (1) marks recommended information module(s) for an individual decision

maker. The remaining vector components keep their default binary values of zero (0).

Workflow Recommendation Gateway

Figure 9 is a use case diagram of Workflow Recommendation Gateway. This framework component improves physician acceptance rates of patient decision aids by increasing patient centeredness and operating efficiency of clinical encounters. Individual desires for shared decision making, which are previously recorded in the Patient Type matrix, are reused as one of the Workflow Recommendation Gateway inputs.

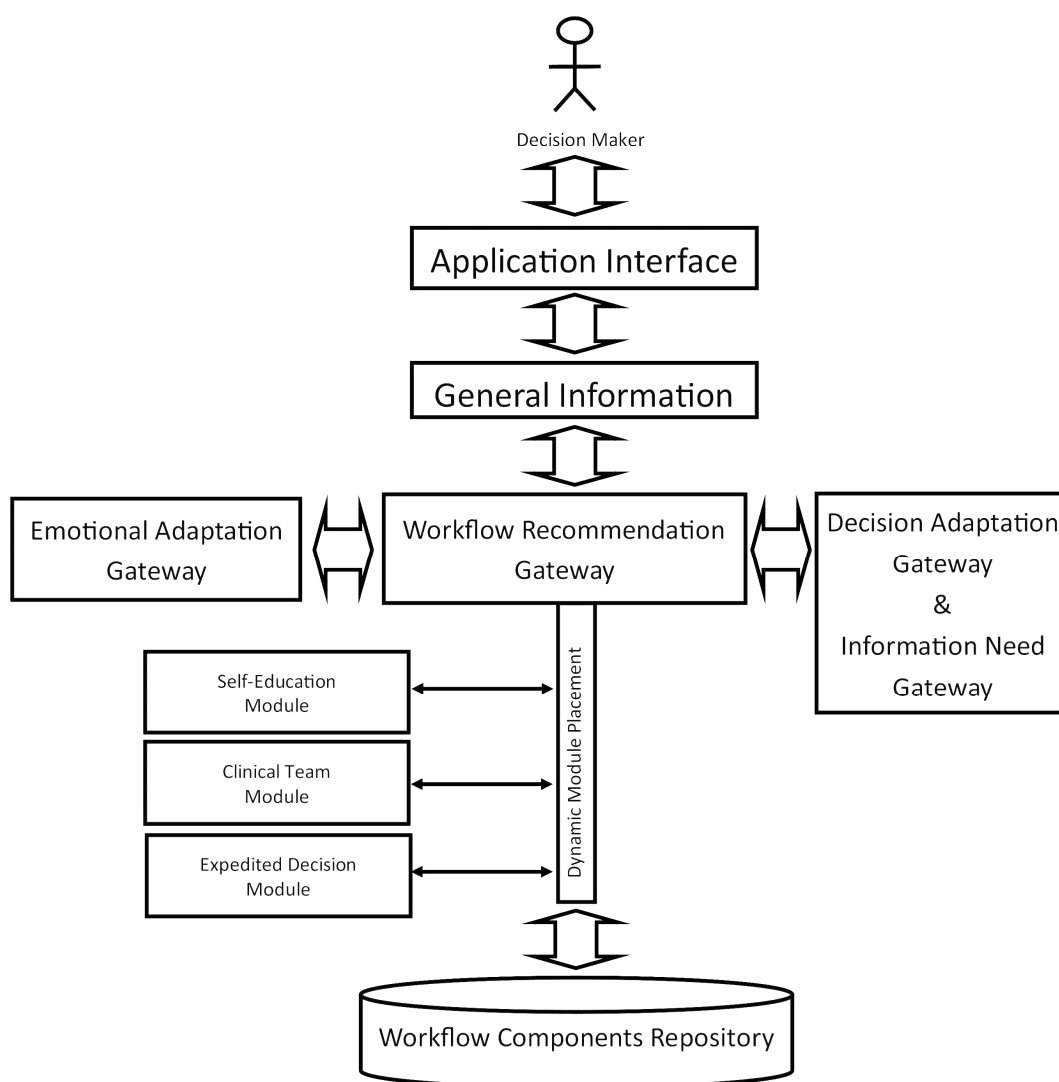


Figure 9. Use Case Diagram of Workflow Recommendation Gateway

Personalized workflow recommendations are made by matching the available clinical

modules with individual desires for shared decision making. Self-Education module, Clinical Team module, and Expedited Decision module are some of the examples of the workflows, which can be used to improve efficiency and patient centeredness without compromising physician professional autonomy or burdening physicians with unnecessary administrative tasks. Specific attributes of these workflow modules are described in a greater detail in Chapter 5.

Workflow Recommendation (WR) Matrix

Workflow Recommendation (WR) matrix consists of clinical workflow modules available within the system. As seen in Table 15, the WR matrix uses binary value 1 (one) to match personal desires for shared decision making with the corresponding clinical modules.

Table 15. Values of Workflow Recommendation (WR) Matrix

Each component of Workflow Recommendation (WR) matrix is set by
$WR_{kx} = \begin{cases} 1 & \text{if clinical workflow module } x \text{ is relevant for decision making preference } k \\ 0 & \text{otherwise} \end{cases}$

Each decision maker type is aligned with a single module by setting the binary value 1 (one) to the corresponding component of the Workflow Recommendation matrix.

Table 16. Binary Representation of Workflow Recommendation Matrix

Clinical Module Decision Maker	Expedited Decision Module	Clinical Team Module	Self-Education Module
Paternalistic	1	0	0
Collaborative/Deliberative	0	1	0
Informative	0	0	1

Table 16 is a low-level representation of the Workflow Recommendation matrix where binary value 1 (one) marks relevant clinical workflow modules for individual types of decision makers. The remaining matrix components keep their default binary values of 0 (zero).

The framework addresses the challenges of technology acceptance described in the Literature Review chapter by providing utility while not burdening physicians with administrative data entry tasks. The framework increases physician's perceived usefulness of patient decision aids by improving patient centeredness and enhancing operating efficiency of the existing care delivery methods. The framework does not encroach upon physician professional autonomy by supporting rather than replacing the format of their extant clinical consultations. The framework adopts a flexible modular approach of optimizing patient centeredness and operating efficiency without forcing physicians to abide by rigid technology-driven standards.

Since Paternalistic decision makers desire minimal involvement in the decision making process, they are paired with the Expedited Decision module. Expedited Decision module resembles a traditional office visit where doctors act as patient guardians who share personal values and goals and select the most fitting treatment option on behalf of their clients. Patients' personal information needs can be satisfied after treatment selection is made, since lack of pertinent information does not prevent Paternalistic patients from reaching the desired level of shared decision making. As a contrast, Informative patients are the most autonomous decision maker types. They know their values and are looking for factual information to facilitate the desired independent process of treatment selection. Workflow Recommendation Gateway aligns such patients with the Self-Education module prior to the actual physician session. Self-education material may include watching videos, comparing treatment risks and benefits, and using interactive teaching applications. Finally, Collaborative and Deliberative patient types prefer to have joined discussions with a clinical worker before arriving at a treatment selection. Clinical Team module may include sessions with such professionals as nurses, physician assistants, and even psychologists, which will help decision makers satisfy their individual treatment selection needs.

Workflow Output (WO) Vector

Output of the Control Preferences Scale recorded in the PT matrix is reused by

Workflow Recommendation Gateway. Workflow Recommendation Gateway applies the formula of Workflow Output (WO) vector in order to suggest the most patient centered clinical workflow for a particular decision maker type. Workflow Output vector formula multiplies Patient Type matrix by Workflow Recommendation matrix:

$$WO = PT * WR$$

Table 17. Values of Workflow Output (WO) Vector

Each component of Workflow Output (WO) vector is set by
$WO_x = \begin{cases} 1 & \text{for recommended clinical workflow module } x \\ 0 & \text{otherwise} \end{cases}$

Table 17 depicts how WO vector makes an individualized workflow recommendation of a clinical treatment selection process.

Table 18. Binary Representation of Workflow Output (WO) Vector

	Expedited Decision Module	Clinical Team Module	Self-Education Module
Decision Maker	1	0	0

Table 18 is a low-level representation of the Workflow Output vector, where binary value 1 (one) marks a specific instance of a clinical workflow recommendation. The remaining vector components keep their default values of 0 (zero).

Validity

The proposed framework is supported by two types of validity. Formative validity is dedicated to correctness of the framework's assumptions. Summative validity continues the formal assessment, which connects the framework's stated objectives with the demonstrated results. Table 19 contains a summary list of research objectives and their corresponding Formative and Summative evaluations.

Table 19. Evaluation Methods

Objective	Formative Validity	Summative Validity
Explicit use of decision making theory	Use of formal decision making theory, which includes human emotions as recommended by Elwyn Glyn (G. Elwyn, et al., 2011).	
Personalization: information needs are tailored individually	Information baseline is defined by the IPDAS Criteria Content section (O'Connor, et al., 2007). Explicit enquiry drives informational personalization (Benbassat, et al., 1998). The Control Preferences Scale is used to reveal the desired level of decision making autonomy. Decision strategies are aligned with the desired levels of decision making autonomy.	Collected data analyzed with the Independent Samples T-test of the Decisional Conflict's mean scores of 1) Total Score, 2) Uncertainty Subscore, 2) Informed Subscore, 3) Effective Decision Subscore.
Personalization: decision making preferences are satisfied individually	Levels of physician involvement are one of the defining factors for clinical practice adoption (Dominick L. Frosch, et al., 2011). Physicians value their professional autonomy.	Verification through survey of licensed physicians. Hypothetical scenario is presented, and qualitative data are collected.
Clinical integration and physician acceptance	Mathematical verification of accuracy.	Prototype implementation
Framework reliability		

Formative Validity

Formative validity of the proposed framework proves its correctness. Formal specification of the framework and the described components depends on the validity of the underlying assumptions. The assumptions of patient types, decision strategies, and individual information needs are verified with the help of the supporting literature and evidence listed in Table 20.

Table 20. Validity of Assumptions

Assumptions/Concept	Supporting Literature	Evidence
Patient Types	(Emanuel et al. 1992)	Comparing/contrasting attributes of the four patient types. Literature synthesis.
Patient Types	(Green 1988)	Framework for defining clinical decision-making expectations.
Patient Types	(Scott et al. 2000)	NIH (National Institutes of Health) grant-supported work with a recommendation to individualize based on the four patient types.
Patient Types and Desires for Information	(Benbassat et al. 1998)	Patient desires for information and decision-making are classified. Variability is largely (80%) unexplained. Review of published surveys.
Patient Types and Desires for Information	(Degner et al. 1997)	Development of the Control Preferences Scale (CPS), which is “clinically relevant, easily administered, valid, and reliable” (Degner et al. 1997). Desires for information are a separate construct.
Patient Types and Desires for Information	(Deber et al. 1996)	Patients may wish to be fully informed but not involved in the decision-making processes. Original investigation. Survey of 300 patients.
Patient Types and Desires for Information	(Sutherland et al. 1989)	Survey of 52 outpatient cancer patients. Decision-making desires and information needs seeking should be evaluated and independently satisfied.
Information Tailoring and Decision Strategies	(Thomson et al. 2007)	Need to tailor information to increase comprehension and need to individualize decision strategies to improve cultural sensitivity of decision aids. Systematic review of Web-based cancer decision aids.
Information Tailoring	(Feldman-Stewart et al. 2012)	Presented information should reflect varying degrees of individual patient needs. Review and analysis of 50 randomized control trials.
Information Tailoring	(Stacey et al. 2011)	Need to explore the effects of informational detail on the quality of decision making. Systematic review of 55 randomized control trials.
Decision Strategies	(Dalal et al. 2010)	Two original studies meant to reveal provisioning of information with various decision making strategies.
Decision Strategies	(Zhuang et al. 2012)	Development of a framework for clinical decision making, which includes individual decision strategies. Online survey of 20 hypothetical clinical cases.
Values in Decision-	(Elwyn et al.	Construction of personal values is an important

Making	2009)	step in the decision making process. Literature-based debate.
Values in Decision-Making	(Adam et al. 2008)	Patient decision aids should be designed to consider individual values. National survey of orthopedic surgeons in the United Kingdom.
Decision Strategies	(Man-Son-Hing et al. 1999)	Positive effects of the decision-strategy listing of advantages versus disadvantages on understanding risks and benefits associated with treatment options. Randomized control trial involving 287 patients.
Values in Decision-Making and Information Tailoring	(O'Connor et al. 2007)	Minimum data set of IPDAS evaluation measures should be set as a baseline. Degree of informational detail for positive effects should be explored. Systematic review of randomized control studies.
Values in Decision-Making	(Legare et al. 2007)	Patient decision aid designed according to the IPDAS is considered meaningful and easy to understand in a qualitative study with six focus groups.
Patient Types and Decision Strategies	(Holmes-Rovner et al. 2007)	As many as 25% of patients may not wish to be involved in clinical decision making. Alternatives must be easily compared, understood, and acted upon. IPDAS symposium.
Patient Decision Aids to Provide Clinical Utility	(Levine, Gafni et al., 1992; Dolan and Frisina, 2002; Stacey, Bennett et al., 2011)	Future patient decision aids should provide simultaneous utility to both patients and their physicians.
Physician Impact on Patient Decision Aid Adoption	(Frosch, Singer et al., 2011)	Levels of physician involvement are pivotal to adoption of patient decision aids in everyday practice.
Physician Technology Acceptance	(Chen and Hsiao, 2012)	Physicians positively view technology, which has a potential to improve patient-physician relationships.
Physician Technology Acceptance	(Chau and Hu, 2002; Dünnebeil, Sunyaev et al., 2012)	Perceived usefulness is the main predictor of physician acceptance of new technology.

If these assumptions hold true, then the system will always produce personalized output and patient-centered clinical workflow recommendations. In this section, Formative validation of the artifact is presented through identification of supporting literature and empirical studies that indicate that an approach based on these assumptions should be

successful in meeting all of the framework's stated objectives. Binary matrix operations are a proven, consistent, and predictable method of data manipulation, which guarantees predictable reliability. The developed binary vector formulas of Strategy Output, Information Output, and Workflow Output are based on the previously validated mathematically proven binary matrix operations.

Summative Validity

The framework's Summative validity is the verification of system properties and ability to achieve the stated objectives through a live demonstration, statistical analysis of experiment data, and qualitative feedback of the US-licensed physicians. Qualitative feedback is gained in response to a hypothetical scenario demonstrating the artifact's ability to meet the objective of improving patient centeredness and clinical workflow improvement. Statistical analysis compares mean values of the Decisional Conflict Scale's Total Score and corresponding subscores for the experiment and control groups.

Decisional Conflict Scale

Decisional Conflict Scale calculates one Total Score and several Subscores used to quantify the quality of the decision making process. Each of the sixteen Decisional Conflict Score questions is assigned a score in the range of zero through four. The value of Total Score is calculated as follows:

$$Total\ Score = \left(\frac{\sum_{q=1}^{q=16} 0 \leq q \leq 4}{16} \right) \times 25$$

Question assignments are summed, divided by the total number of questions (sixteen), and multiplied by twenty-five. The resulting Total Score is a numerical representation of personal decisional conflict. Low Total Score values depict high quality decision making process (low levels of internal conflict), and high values indicate a potential problem.

Uncertainty Subscore quantifies the degree of certainty a decision maker has after making a particular treatment selection. Low scores (good) mean that a decision maker is certain about the choice while high scores (bad) depict uncertainty. Uncertainty Subscore of the Decisional Conflict Scale is calculated as follows:

$$\textit{Uncertainty Subscore} = \left(\frac{\sum_{q10}^{q12} 0 \leq q \leq 4}{3} \right) \times 25$$

To achieve Uncertainty Subscore, answers to questions 10 through 12 are summed, divided by three, and multiplied by twenty-five. As with Total Score, each question can be assigned a numerical value ranging from zero to four.

Informed Subscore reveals the feeling of being adequately informed. Low scores reveal informational sufficiency while high scores mean that the subject feels generally uninformed. Informed Subscore is calculated by summing the answers to questions 1 through 3, dividing by three, and multiplying the result by twenty-five:

$$\textit{Informed Subscore} = \left(\frac{\sum_{q1}^{q3} 0 \leq q \leq 4}{3} \right) \times 25$$

Effective Decision Subscore is, yet, another subset of the Decisional Conflict Scale. It represents effectiveness of the decision making process. Answers to questions 13 through 16 are summed, divided by four, and multiplied by twenty-five:

$$\textit{Effective Decision Subscore} = \left(\frac{\sum_{q13}^{q16} 0 \leq q \leq 4}{3} \right) \times 25$$

Low values of Effective Decision Subscore mark decision making effectiveness while high scores signify a generally ineffective process. The 16-question version of the Decisional Conflict Scale previously recommended by the Foundation for Informed Medical Decision Making can be found in Appendix B.

Chapter Summary

This chapter has presented the developed framework for future decision aids. The framework's objectives can be summarized as follows: 1) provide theory-supported means for emotional adaptation, 2) identify and satisfy individual preferences for shared decision making, 3) identify and satisfy personal information needs, and 3) improve physician acceptance rates through clinical workflow optimization. Four corresponding Gateways have been developed to address the stated objectives. Emotional Adaptation Gateway prepares patients for the highly-emotional process of clinical decision making. Decision Strategy

Gateway individualizes decision making strategy based on the revealed desires for shared decision making. Information Need Gateway provides the means to record and satisfy individual information needs. Workflow Recommendation Gateway is the framework's component with the objective to improve physician acceptance rate by improving patient centeredness and workflow efficiency without adding to physician workload or diminishing professional autonomy. The chapter is used to explain the four Gateways in terms of high-level diagrams as well as low-level binary formulas and matrices. The text expands on the two types of validity recruited to ensure the framework's scientific rigor. The chapter is concluded with an explanation of the Decisional Conflict Scale's calculations, which serve for the statistical evaluation of the first artifact instantiation.

CHAPTER 5

IMPLEMENTATION OF A PATIENT DECISION AID FOR DIALYSIS TREATMENT SELECTION

In this chapter implementation of the first framework-based and disease-specific patient decision aid is described. The chapter is devoted to sharing the first development cycle of selecting a condition, comparing existing instruments, designing experiment study, aligning hypotheses with artifact features and experiment measurements, building the application, conducting the study, and evaluating application effectiveness.

Condition Selection

End-stage renal disease (ESRD) is becoming a major health problem as the number of patients entering chronic renal programs continues to increase (Kaprowy, 1991). In the United States alone, chronic kidney disease (CKD) affects as many as 20 million adults (Keith, Nichols, Gullion, Brown, & Smith, 2004). Many of them live to become end-stage renal disease patients. End-stage renal disease is the last stage of chronic kidney disease when renal replacement therapy becomes a necessary life-supporting treatment. There are several forms of renal replacement therapy two of which are considered medically equivalent: hemodialysis and peritoneal dialysis. Selecting a dialysis treatment can be characterized as a process of aligning personal value judgments, which should reflect patients' individual desires and lifestyles, with the most fitting option (Wang & Chen, 2012). Literature reveals that ESRD patients have been experiencing difficulties in electing treatments because of their inability to participate in the decision making process and satisfy unmet information needs (Christensen & Ehlers, 2002). Unfitting treatment types have been shown to worsen patients' mental states, regimen adherence rates, quality of life, and subsequent medical outcomes (Feroze, Martin, Reina-Patton, Kalantar-Zadeh, & Kopple, 2010; Rahimi, Ahmadi, & Gholyaf, 2008). Existing

patient decision aids for dialysis treatment selection lack the capacity for emotional adaptation, personalization of information needs and decision making responsibilities, and integration with clinical workflows.

Existing Instruments

There are four existing online instruments, which attempt to facilitate the decision making process of dialysis treatment selection. Table 21 lists some of the instrument features in their relation to the developed framework.

Table 21. Existing Dialysis Treatment Selectors

	IPDAS Standards	Emotional Adaptation	Personalization of Decision Strategy	Personalization of Information Needs	Clinical Utility
Dialysis - NHS Choices Chronic Kidney Disease Option Grid	No	Yes	No	No	No
Kidney Failure: What Type of Dialysis Should I Have?	Yes	No	No	No	No
Dialysis Treatment Evaluator - DaVita	No	No	No	No	No

More detailed comparison of the existing dialysis treatment selectors can be found in Appendix D. In this text, the existing dialysis instruments are called treatment selectors because of the lack of published design principles and standards make it difficult to characterize all of them as patient decision aids.

Hypotheses

In Table 22, study hypotheses are aligned with the corresponding artifact features and objective measurements used to evaluate the first decision aid instantiation. The section below Table 22 is used to describe each research inquiry as an equivalent set of Null and Alternative hypotheses. Null hypothesis rejection cut-off value is set to $p=0.1$.

Table 22. Hypotheses, Artifact Features, and Measurement

Hypothesis	Artifact Feature	Measurement
H1. Decision aids based on the proposed framework are better.	Emotional Adaptation Gateway, Information Need Gateway and Decision Strategy Gateway. Emotional adaptation with a chosen decision making theory. Personalization of decision making process with Strategy Output vector and Information Output vector.	Independent Samples T-test analysis for Total Score of Decisional Conflict Scale of experiment and control groups.
H2. Decision aids based on the framework better satisfy information needs.	Information Need Gateway. Personalization of information need with Information Output vector.	Independent Samples T-test analysis for Informed Subscore of Decisional Conflict Scale of experiment and control groups.
H3. Decision aids based on the framework improve decision effectiveness.	Personalization of information need with Information Output vector and personalization of decision strategy with Strategy Output vector.	Independent Samples T-test analysis for Effective Decision Subscore of Decisional Conflict Scale of experiment and control groups.
H4. Decision aids based on the framework reduce decisional uncertainty.	Personalization of information need with Information Output vector and personalization of decision strategy with Strategy Output vector.	Independent Samples T-test analysis for Uncertainty Subscore of Decisional Conflict Scale of experiment and control groups.
H5. Decision aids based on the proposed framework support more individual patient types.	Personalization of the decision making process with Strategy Output Vector and Information Output Vector.	Comparison of Total Score mean difference between experiment and control groups for individual decision maker types.

H1. Decision aids based on the proposed framework are better.

Null Hypothesis: Total Score of Decisional Conflict Scale remains unchanged for the experiment and control groups.

Alternative Hypothesis: Mean Total Score value of Decisional Conflict Scale is lower in the experiment than control group.

H2. Decision aids based on the framework better satisfy information needs.

Null Hypothesis: Informed Subscore of Decisional Conflict Scale remains unchanged for the experiment and control groups.

Alternative Hypothesis: Mean Informed Subscore of Decisional Conflict Scale is lower in the experiment than control group.

H3. Decision aids based on the framework improve decision effectiveness.

Null Hypothesis: Effective Decision Subscore of Decisional Conflict Scale remains unchanged for the experiment and control groups.

Alternative Hypothesis: Mean Effective Decision Subscore of Decisional Conflict Scale is lower in the experiment than control group.

H4. Decision aids based on the framework reduce decisional uncertainty.

Null Hypothesis: Uncertainty Subscore of Decisional Conflict Scale remains unchanged for the experiment and control groups.

Alternative Hypothesis: Mean Uncertainty Subscore of Decisional Conflict Scale is lower in the experiment than control group.

H5. Decision aids based on the proposed framework support more individual patient types.

Null Hypothesis: Total Score of Decisional Conflict Scale for individual decision maker types does not produce bigger mean differences than for all decision maker types.

Alternative Hypothesis: Total Score of Decisional Conflict Scale for individual decision makers produces bigger mean differences than for all decision maker types.

Server-side and Client-side Programming

Online presentation of the application has several explicit benefits. The first benefit is increased availability. Online patient decision aids can be accessed by users at different times and regardless of geographic location. The second benefit is that online patient decision aids have an important fundamental capacity to support patients during different points of their disease trajectories. Research shows that some patients may exhibit changes in personal preferences and individual values during different points of their disease trajectories (Jenkins, Fallowfield, & Saul, 2001). The increased availability of online patient decision aids improves the ability of the software to support treatment selection processes whenever such need arises.

Online patient decision aids should contain both server-side and client-side programming. Server-side programming allows for the framework's dynamic output transformations, which can be hosted online and presented uniformly to a variety of client platforms. Server-side programming assists application developers with integrating the framework's binary vector logic into own instantiations, which then render dynamic output based on the data collected from user's client software.

In order to create interactive online applications, it is recommended to join server-side

technology with that of a client-side (Smyth, 2010). Client-side programming is an important interactivity aspect because it executes code on user clients as opposed to a hosting server. The combination of server and client-side programming creates the right environment for instantiating online patient decision aids capable of interacting with users, collecting data, processing matrix logic, and generating output instances in a uniform and consistent manner. Server-side portion of the application is used to execute the formulas of the developed framework while client-side scripting supports interactivity and presentation.

Instance Programming Selections

The first instantiation of the patient decision aid is implemented in the form of a web-based application programmed and scripted using a mix of PHP, JavaScript, and HTML technologies. PHP is one of the most popular web-development programming languages (Shafik & Ramsey, 2007). PHP is considered server-side technology because language processing takes place on the server, and the client is presented with browser-friendly outputs. JavaScript is a client-side scripting language, which is often used to extend the limited capabilities of HTML tags. With this structure, client installation of the software is unnecessary, and the patient decision aid can be instantly accessed via any network-connected computer, tablet, or smart phone device. Study participants are solicited to evaluate the decision aid effectiveness at their convenience by supplying them with the study dates and the application's URL (Uniform Resource Locator) link.

Session Control

Online environment is generally stateless meaning that Web servers do not usually track and maintain states of user previous visit(s) to a given site. However, server-side software has the ability to maintain state of user sessions and collect user interaction data. PHP `$_SESSION` array is used in this patient decision aid implementation to store the elucidated individual preferences on the server's file system. Each user is assigned an anonymous session id with a call of PHP `session_start()` function. Individual user selections are continuously appended to their anonymous session file, which is later used for matrix processing, output personalization, and statistical data analysis.

File Access

User selections are captured with a <form> HTML element and transmitted to PHP server via POST method, which stores data in an associative \$_POST array. The array is then used to write user selections to the server's file system for a later retrieval. This artifact instantiation applies file_put_contents() function of PHP language to write the session-specific contents of the \$_POST associative array to a file on the server's file system.

Randomization Function

The study implements JavaScript's Math.random() function, which randomly assigns study participants to one of the two Uniform Resource Locators (URLs). The first URL is the link to a patient decision aid designed according to the developed framework. Participants assigned to this link comprise the experiment group. The second URL is a patient decision aid implemented according to the IPDAS criteria checklist and is based on one of the existing dialysis treatment selectors.

Conducting the Study

The study is held on-line. After the random group assignment, all participants are asked to agree to a digital consent form and introduced to the basics of role playing. Hypothetical scenario is explained, objectives are outlined, and the participants are informed that the study will take 35-40 minutes of their time. Experiment group participants continue by completing the emotional adaptation exercise (Appendix A) and interacting with the Control Preferences Scale used to reveal their individual desires for shared decision making. They later proceed to the personalized output of the decision aid while members of the control group skip to the non-personalized alternative immediately after signing the digital informed consent form. As the last step, both groups are exposed to the Decisional Conflict Scale, which saves the anonymous and confidential answers on the Web hosting server.

Objectives

One of the main objectives of the experiment is to strengthen the proposed framework with Summative validity. A group of fifty-seven students from Dakota State University is asked to perform the tasks identical to those meant for future end-stage renal disease patients. Study data are collected, and the artifact's effectiveness is measured by comparing the

resulting scores of the Decisional Conflict Scale. Study design and process are further described in the following sections.

Participant Recruitment

Potential participants are solicited via university email. More specifically, students studying Information Systems at Dakota State University are asked to volunteer their time to assist in evaluating the first prototype. The participants are given a Universal Resource Locator (URL) link to the function randomly assigning them to either the experiment or control group.

Quantitative System Evaluation

Quantitative evaluation of the prototype's effectiveness of Emotional Adaptation Gateway, Decision Strategy Gateway, and Information Need Gateway is achieved with the statistical (Independent Samples T-test) comparison of the Decisional Conflict Scale means of the two participant groups. Decisional Conflict Scale values of Total Score, Uncertainty Subscore, Informed Subscore, and Effective Decision Subscore are used for the comparison. The study applies the 16-item version of the Decisional Conflict Scale, which is recommended by the Foundation for Informed Medical Decision Making. Appendix B contains the questions of the recommended version of the instrument. Next sections contain the actual invitation text used to solicit participation and some of the application screenshots.

An Invitation to Participate in a Study

You are being invited to participate in a scientific study aimed at improving the design of patient decision-support instruments. We hope that such instruments will assist patients in making better treatment selections while simultaneously reducing the enormous load of the emotionally-charged clinical decision making. We thank you for volunteering your time today. Your input is truly invaluable, and we believe that it will eventually help people throughout the world make better treatment selections.

LOCATION	DATE	TIME
http://experiment.primarycaredr.com	April 9-14, 2014	35-40 minutes

The study is by invitation only, so you will need to enter the following credentials:

Username: decision

Password: aid

If you are interested in sending additional questions or comments, you can always do so via email at sergey.motorny@vanderbilt.edu or phone at (615) 322-7063.

Role Playing

Role playing is a technique used to study human behavior patterns in particular settings. Role playing allows for creation of desired context without exposing study participants to the apparent risks of some real-life situations. Analysis of role playing data enables suggestions for new corrective actions prior to the actual human interaction.

Study Purpose

The purpose of this exercise is to learn about computer assisted clinical decision-making processes. Your participation in this study will help to improve future patient decision aids. We hope that such decision instruments will guide patients during complex treatment selection processes. Your participation in this study will serve an important purpose and is much appreciated!

Your Objective

Imagine that you are a patient with kidney failure. Your objective is to choose between two available treatment options. Both options are medically identical. However, one of them may be more fitting to you as an individual.

Begin Exercise

The entire exercise will be anywhere between 35 and 40 minutes in length at the end of which your opinions will be collected. Click on the button "Next" at the bottom of this page in order to begin.

- Dialysis is a process that does the work of healthy kidneys when you have kidney failure.
- Dialysis filters wastes, removes extra fluid, and restores the proper balance of chemicals in the blood.

- There are two basic types of dialysis: hemodialysis and peritoneal dialysis.
- Dialysis can help you feel better and live longer, but it is not a cure for kidney failure. After you start dialysis, you will need to keep doing it to stay as healthy as possible.

What is involved?

Hemodialysis

- Before hemodialysis treatments can begin, your doctor will need to create a site where blood can flow in and out of your body.
- Hemodialysis uses a man-made membrane called a dialyzer to clean your blood. You are connected to the dialyzer by tubes attached to your blood vessels.
- You will probably go to a hospital or dialysis center on a fairly set schedule. Hemodialysis usually is done 3 days a week and takes 3 to 5 hours a day.
- In some cases, hemodialysis can be done at home.

Peritoneal dialysis

- You will have a catheter placed in your belly (dialysis access) before you begin dialysis.
- Peritoneal dialysis uses the lining of your belly, which is called the peritoneal membrane, to filter your blood.
- The process of doing peritoneal dialysis is called an exchange. You will usually complete 4 to 6 exchanges every day.
- You will be taught how to do your treatment at home, on your own schedule.

Implementation Screenshots

The following application screenshots serve as an additional visual representation of the framework's first instantiation.

Information Need Gateway

Information Need Gateway supports personalization of information need. Figure 10 and Figure 11 show an example of personalization of information need as it applies different decision making strategies.

	What are the benefits?	What are the risks and side effects?
Hemodialysis	<ul style="list-style-type: none"> • It is most often done by trained health professionals who can watch for any problems. 	<ul style="list-style-type: none"> • It causes you to feel tired on the day of the treatments.
Peritoneal dialysis	<ul style="list-style-type: none"> • It gives you more freedom than hemodialysis. • It can be done at home or in any clean place. 	<ul style="list-style-type: none"> • The procedure may be hard for some people to do.

Would you like to continue reviewing information?

Yes No

Figure 10. Information Need Gateway. Risks and Benefits

The yes/no answers of the continuous information loop are recorded with Coefficient y in Information Selection matrix. Information Selection matrix is then multiplied by the available information modules of Amount of Information matrix to produce the dynamic individually tailored output suggested by the resulting Information Output vector.

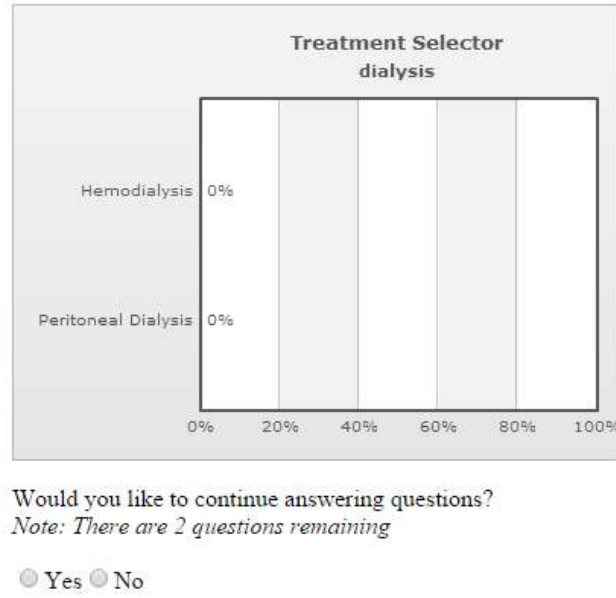


Figure 11. Information Need Gateway

Both Figure 10 and Figure 11 examples feature the question prompting users if they desire to continue the current process or are ready to review the application's next section. Users are capable of satisfying own individual information needs by direct manipulation of Coefficient y and, thus, dynamic output of the resulting Information Output vector formula:

$$IO = IS * AI$$

Amount of Information (AI) matrix contains the full range of information modules of the decision support system. It is recommended to use the Content section of the IPDAS Criteria checklist (see Appendix C) as a minimum information baseline in order to maintain a safe internationally accepted level of content quality. The upper limit of information presented to the user is only limited by the total number of modules contained in the Amount of Information matrix. The application relies on Information Output vector to enhance application experience by letting users satisfy own personal information needs.

Decision Strategy Gateway

The implementation of Decision Strategy Gateway consists of two parts. The first part elicits individual desires for shared decision making with the Control Preferences Scale. The second part applies the formula of Strategy Output vector

$$SO = PT * ST$$

The vector assists the application in personalizing output by forming an individual decision strategy, which matches the revealed decision maker type. Figure 12 depicts the implementation of the Control Preferences Scale as described by (Degner, et al., 1997). The scale identifies the decision maker type by asking users to choose the preferred treatment selection method.

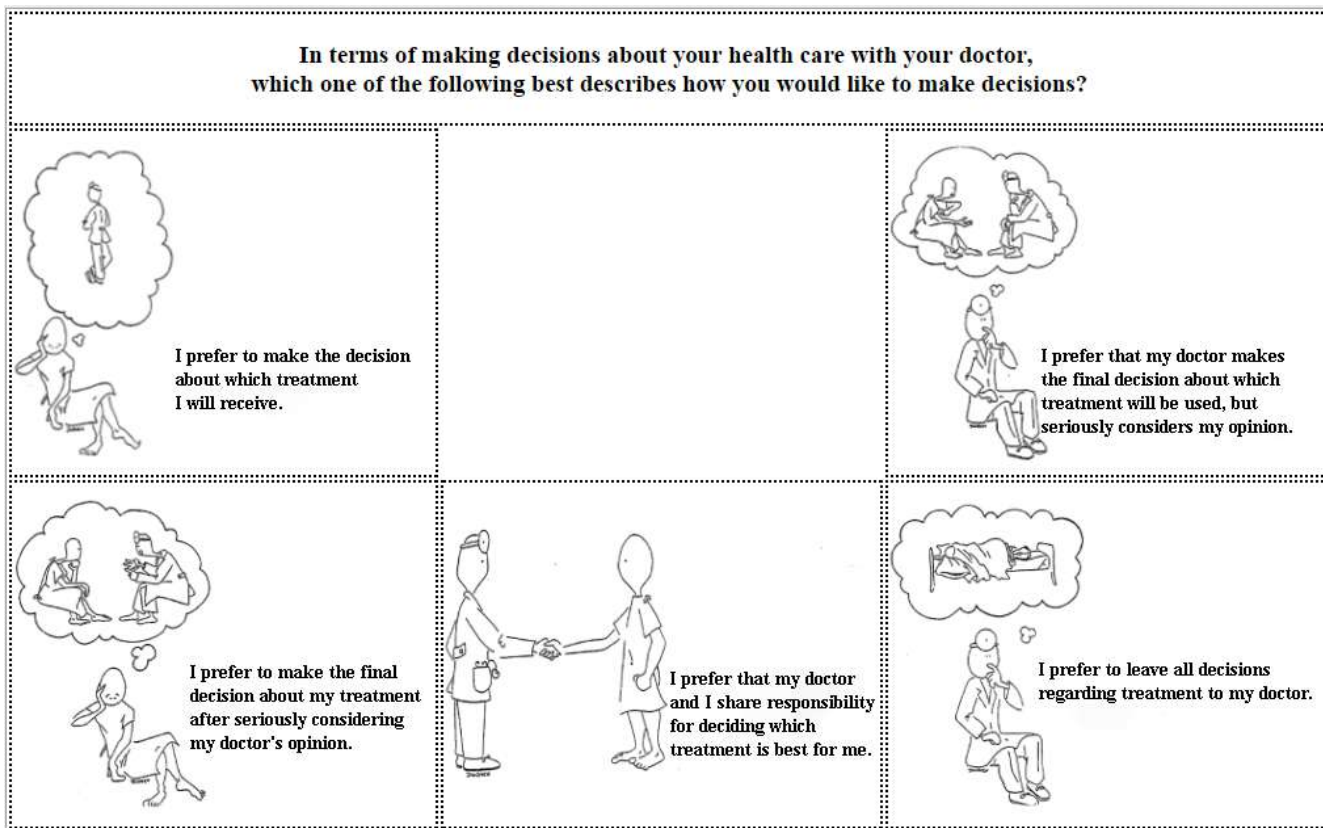


Figure 12. Implementation of Control Preferences Scale

Output of the Control Preferences Scale sets the value of Coefficient x , which is then applied to record the individual decision maker type in the corresponding component of Patient Type matrix. Strategy Output vector uses Patient Type matrix to generate dynamic individual strategy by multiplying it with Strategy Type matrix. Strategy Type matrix contains the range of the available decision making strategies for each decision maker type.

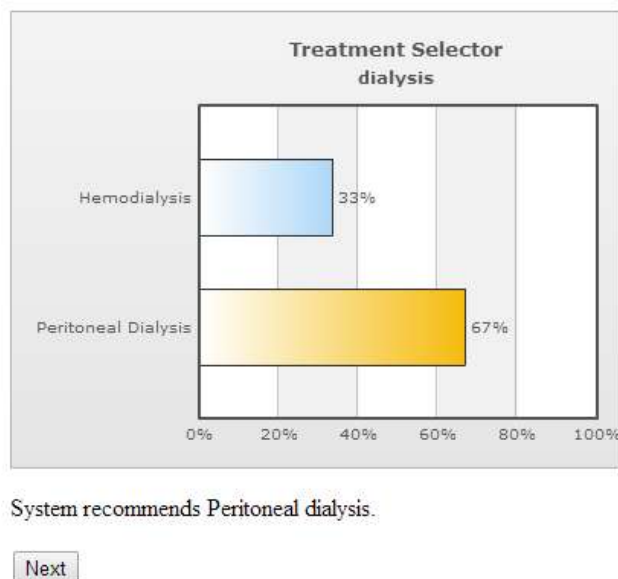


Figure 13. Implementation of Recommend For Decision Strategy

Figure 13 is a screenshot of Recommend For decision strategy displayed via Strategy Output vector in order to suggest a particular treatment option.

Workflow Recommendation Gateway

As previously shown Chapters 2 and 4, patient decision aids should help physicians improve patient centeredness of their clinical workflows. Patient decision aids can offer some of the latest developments in the domains of patient-centered medicine and patient-physician communication. The existing doctrine of patient-centered medicine suggests that medical appointments need to be responsive to patients' individual needs, preferences, and values (Little, et al., 2001). As previously stated by Green (Green, 1988), many health care litigations are caused by the misunderstandings of responsibility assignment rather than physicians' professional negligence. Informed consent has been shown to be largely inefficient in improving patient-physician communication and responsibility assignment (K. Sepucha et al., 2012). Table 23 lists the objectives of the implemented Workflow Recommendation Gateway.

Table 23. Objectives and Attributes

Objectives	Attributes
Increase physician acceptance by demonstrating improved patient centeredness.	Match shared decision making desires with patients' actual participation roles.
Increase physician acceptance by demonstrating improved clinical communication.	Provide live support for patients seeking joined decision making.
Increase physician acceptance by demonstrating support of clinical problem-solving tasks.	Relieve physicians of tasks aimed at clarifying personal values and long collaboration decision making sessions.
Increase physician acceptance by demonstrating protection of professional autonomy and status quo of administrative burden.	Physicians are not asked to do any additional data entry or ongoing clinical coordination. Medical treatment selections are finalized with physicians.

The task of workflow redesign may seem challenging to health care practitioners. Workflow Recommendation Gateway assists physicians in improving their clinical encounters for better patient centeredness and patient-physician communication. Workflow Recommendation Gateway respects physicians' professional autonomy by leaving the final treatment selection step for the patient-physician encounter.

Workflow Recommendation Modules

The United States Medical Licensing Examination (USMLE) pays special attention to the ability of future physicians to connect with their patients and hold patient-centered clinical sessions. According to the examination authorities, physicians should aim to connect with patients throughout clinical encounters and actively work on forming trusting patient-physician relationships, which respect patient feelings, values, and preferences (Le & Bhushan, 2006).

Appendix E contains OPTION Instrument, which was developed at Cardiff University to evaluate the level of physician success in involving patients during the process of clinical treatment selection. The instrument is a scale, which is used for the purpose of measuring and facilitating patient-centered interviews, fostering trusting patient-physician relationships, and arriving at treatment selections, which are true to patient values, preferences, and desires for shared decision making.

Both USMLE and OPTION instrument share common goals of fostering patient-centeredness and trusting patient-physician relationships, but both exhibit particular shortcomings. Even though USMLE highlights the importance of patient-centered sessions and trusting patient-physician relationships, the examination guide assumes that physicians will rely on their intuition and, thus, does not prescribe any actionable and consult-specific steps. As a contrast, OPTION instrument provides immediately actionable steps for conducting patient-centered interviews and establishing trusting patient-physician relationships, but it assumes unlimited physician time. USMLE states that both the interview and the relationship-building portions of a clinical consultation should not exceed 7-8 minutes (Le & Bhushan, 2006), which leaves physicians with no more than 40 seconds to address each bullet point of the OPTION instrument.

The solution implemented in this framework suggests spreading the responsibility of patient-centered care among patient-decision aids, clinical workers, and physicians. Decision making preferences and some of the individual needs are satisfied by patient decision aids and appointed clinical staff prior to the actual physician consultation. Physicians can then focus on building trusting relationships and arriving at personalized treatment selections while staying under the recommended limit of 7-8 minutes per patient.

Implementation of Workflow Recommendation Gateway enhances OPTION instrument by mapping individual patient characteristics with the corresponding scale measurements. Workflow Recommendation Gateway produces three clinical modules, which assist physicians in involving patients at the desired levels of engagement and, thus, improving the quality of their patient-centered care. Workflow Recommendation Gateway applies the output of the Control Preferences Scale to suggest either Self-Education (Informative patient) module, Clinical Team (Collaborative and Deliberative patient) module, or Expedited Decision (Paternalistic patient) module.

First, all patients are exposed to the following subroutine regardless of their individual characteristics. In the waiting room, the patient is paired with an electronic patient-decision aid, which begins the process of treatment selection in the following manner:

- The decision aid explains to the patient that treatment selection must be made.
- The decision aid states that several treatment alternatives are available.
- The decision aid lists the options, which also explain the choice of “no action”.

- The decision aid lists the pros and cons of the available options.
- The decision-aid program elicits the patient's preferred level of involvement (the Control Preferences Scale) in the decision making process.

Once individual patient type is identified, the patient continues with a personalized clinical workflow module designed to match the preferred decision making strategy. Workflow Recommendation matrix contains all of the following clinical workflow modules.

Self-Education (Informative) Module

Based on the identified preference for shared decision making, workflow recommendation software suggests the following clinical process for the Informative patient type:

1. Patient is paired with a clinical worker (nurse or physician assistant) for the assessment of information preferences:
 - Clinical worker assesses patient's preferred approach to receive additional information (printed material, videos, interactive application, etc.).
2. Patient is given a chance to review preferred additional information prior to seeing the doctor.
3. Patient sees the doctor for the final treatment selection step where:
 - Doctor checks that the patient has understood the information regarding the treatment.
 - Doctor offers to ask additional questions.
 - Doctor indicates the need to finalize treatment selection and review the decision.
 - Treatment selection is made by the **patient**.

Note: patient's personal values and fears do not need to be explored, since they are clear and known to the autonomous Informative patient type.

Clinical Team (Collaborative and Deliberative) Module

Based on the identified preference for shared decision making, workflow recommendation software suggests the following clinical process for the Collaborative and Deliberative patient types:

1. Patient is paired with a clinical worker (nurse or physician assistant) for the subsequent three-step assessment:

- Clinical worker assesses patient's preferred approach to receive additional information (printed material, videos, interactive application, etc.).
 - Clinical worker explores patient's personal values regarding the treatment and assists in aligning them with treatment options (desire to travel, stay active, work, etc.).
 - Clinical worker explores patient's personal fears regarding the treatment and attempts to address them (fear of needles, surgery, self-management, etc.).
2. Patient is given a chance to review preferred additional information prior to seeing the doctor.
 3. Patient sees the doctor for the final treatment selection step where:
 - Doctor checks that the patient has understood the information regarding the treatment.
 - Doctor offers to ask additional questions.
 - Doctor indicates the need to finalize treatment selection and review the decision.
 - Treatment selection is made **together** by the patient and the doctor.

Expedited Decision (Paternalistic) Module

Based on the elucidated preference for shared decision making, workflow recommendation software suggests the following clinical process for the Paternalistic patient type:

1. Patient sees the doctor for the treatment selection step where:
 - Doctor explores patient's personal values regarding the treatment (desire to travel, stay active, work, etc.).
 - Doctor explores patient's personal fears regarding the treatment and attempts to address them (fear of needles, surgery, self-management, etc.).
 - Doctor indicates the need to finalize treatment selection.
 - Treatment selection is made by the **physician**.
2. Patient is paired with a clinical worker (nurse or physician assistant) for the following post selection assessment:
 - Clinical worker assesses patient's preferred approach to receive additional information (printed material, videos, interactive application, etc.).

- Clinical worker checks that the patient has understood the information regarding the treatment.
- Clinical worker offers to ask additional questions.

3. Patient is given a chance to review preferred additional information.

Note: Aligning of personal values with the most fitting treatment is done by the doctor implicitly. Decision review is also not needed, since it is done by the physician on behalf of the patient.

Demonstration of Framework-Assisted Treatment Selection

In order to further illustrate the first instantiation, consider the following scenario where a Deliberative decision maker type uses the instrument to arrive at a treatment selection. The process begins with the emotional adaptation exercise, which prepares the decision maker for the upcoming treatment selection process. Emotional adaptation exercise (see Appendix A), which is based on the selected decision making theory, is followed by the identification of individual preferences for shared decision making. The Control Preferences Scale is then applied to elucidate individual desires for shared decision making, which are recorded with Coefficient x and stored in the binary Patient Type matrix. As previously discussed, Patient Type matrix contains four components, and Coefficient x accepts values from the following range: $\{x \in R | 1 \leq x \leq 4\}$.

Patient Type (PT) Matrix			
Paternalistic Patient Type	Collaborative Patient Type	Deliberative Patient Type	Informative Patient Type
0	0	1	0

Strategy Type (ST) Matrix			
	Recommend For Strategy	Recommend For and Recommend Against Strategy	Factual Information Strategy
Paternalistic Patient Type	1	0	0
Collaborative Patient Type	0	1	0
Deliberative Patient Type	0	1	0
Informative Patient Type	0	0	1

Strategy (SO) Output Vector			
	Recommend For Strategy	Recommend For and Recommend Against Strategy	Factual Information Strategy
	0	1	0

Figure 14. Demonstration of Decision Strategy Gateway

The hypothetical scenario involves the patient of Deliberative type ($x=3$). Therefore,

as shown in Figure 14, the corresponding third component of the Patient Type matrix is assigned the binary value 1 (one). As also depicted in Figure 14, Strategy Type matrix contains all known decision maker types and the corresponding decision making strategies. Strategy Output vector is then achieved by multiplying the Patient Type and Strategy Type matrices, which yields a personalized Recommend For and Recommend Against decision making strategy. Binary output of the Strategy Output vector is calculated as follows:

$$SO = [0 \ 0 \ 1 \ 0] * \begin{bmatrix} 1 & 0 & 0 \\ 0 & 1 & 0 \\ 0 & 1 & 0 \\ 0 & 0 & 1 \end{bmatrix} = [0 \ 1 \ 0]$$

The framework contains two output individualization vectors, and the second vector is that of Information Output. Information Selection matrix contains three components, representing the full range of personal information needs. Coefficient y accepts values from the following range $\{y \in R | 1 \leq y \leq 3\}$ and is used to mark the personally identified information need in the Information Selection matrix (see Figure 15).

Information Selection (IS) Matrix		
Minimum Information	Balanced Information	Maximum Information
0	0	1

Amount of Information (AI) Matrix			
	IPDAS Criteria Content Selection	Additional Module n-1	Information Module n
Minimum Information	1	0	0
Balanced Information	1	1	0
Maximum Information	1	1	1

Information Output (IO) Vector			
	IPDAS Criteria Content Selection	Additional Module n-1	Information Module n
	1	1	1

Figure 15. Demonstration of Information Need Gateway

The bottom value of Coefficient y range is the preference to review minimum amount of information. The top value of the range is the preference to review all of the available information. The middle value of Coefficient y highlights the desire to review more than the bare minimum but less than all available information on a particular treatment option. This scenario depicts the patient who elects to review all of the available information, which sets

the value of Coefficient y to $y = 3$. Coefficient y , in turn, marks the third component of the Information Selection matrix with binary value 1 (one). The Amount of Information matrix contains the corresponding information modules available for each level of personal information needs. Information Output vector is achieved by multiplying the Information Selection and Amount of Information matrices, and the result is translated into personalized output, which is all of the available information for this hypothetical scenario:

$$IO = [0 \ 0 \ 1] * \begin{bmatrix} 1 & 0 & 0 \\ 1 & 1 & 0 \\ 1 & 1 & 1 \end{bmatrix} = [1 \ 1 \ 1]$$

Combining the output of IO and SO vectors, the framework's recommendation is to expose the hypothetical Deliberative decision maker to the following course of action:

1. Expose the patient to all of the information modules of the system.
2. Expose the patient to Recommend For and Recommend Against decision strategy.

Demonstration of Framework-Assisted Workflow Recommendation

This section continues with a live demonstration of the first artifact instantiation by computing Workflow Output vector of Workflow Recommendation Gateway. Deliberative patient type has already been identified by the Control Preferences Scale and recorded with Coefficient x in the Patient Type matrix. As seen in Figure 16, Workflow Recommendation contains decision maker types and the corresponding clinical workflow modules. The modules are based on the OPTION instrument (see Appendix E) and individual patient type attributes. As demonstrated in the Literature Review chapter, Deliberative patients seek clinical collaboration in the form of treatment fact comparisons, clarification of personal values, and clarification of values.

Patient Type (PT) Matrix			
Paternalistic Patient Type	Collaborative Patient Type	Deliberative Patient Type	Informative Patient Type
0	0	1	0

Workflow Recommendation (WR) Matrix			
	Expedited Decision Module	Clinical Team Module	Self-Education Module
Paternalistic Patient Type	1	0	0
Collaborative Patient Type	0	1	0
Deliberative Patient Type	0	1	0
Informative Patient Type	0	0	1

Workflow Output (WO) Vector		
Expedited Decision Module	Clinical Team Module	Self-Education Module
0	1	0

Figure 16. Demonstration of Workflow Recommendation Gateway

Workflow Output vector is achieved via binary multiplication of the user-controlled Patient Type matrix and fixed, theory-driven Workflow Recommendation matrix. The calculation of the Workflow Recommendation matrix for the hypothetical Deliberative decision maker is as follows:

$$WO = [0 \ 0 \ 1 \ 0] * \begin{bmatrix} 1 & 0 & 0 \\ 0 & 1 & 0 \\ 0 & 1 & 0 \\ 0 & 0 & 1 \end{bmatrix} = [0 \ 1 \ 0]$$

Calculation of the Workflow Recommendation vector yields a single-row recommendation of Clinical Team module specifically designed for the Deliberative patient type.

Qualitative System Evaluation

“Conducting a patient-centered interview (PCI) is an essential component of successfully completing the encounter in the Step 2 CS. The main goal of the PCI are to establish a trusting doctor-patient relationship and to ensure that the encounter centers on the patient’s concerns and needs, not on the disease or the doctor.” –USMLE Step 2 CS, Fifth Edition

Workflow Recommendation Gateway was evaluated qualitatively by surveying subjective responses of three US-licensed and board certified family practice physicians in relation to the framework’s workflow recommendation component. The physicians were

given a hypothetical treatment selection scenario, which followed the typical USMLE format of displaying the patient's sex, age, brief previous medical history, and most recent diagnosis. The initial introduction was continued by asking the physicians to answer three questions meant to establish a baseline for a typical clinical workflow, patient-physician communication pattern, and motivation to rely on patient-centered care for the process of treatment selection.

Once the baseline was established, the physicians were tasked to evaluate potential usefulness of the framework's workflow personalization module. The first physician was asked to review the steps recommended for Collaborative and Paternalistic patient types. The second physician evaluated the modules for Informative and Paternalistic decision makers, and the survey of the third physician contained the individualization steps for Informative and Collaborative patients.

Once the hypothetical scenario modules were reviewed, the physicians were presented with a second set of open-ended questions. The questions were geared to evaluate the impact of the Workflow Recommendation Gateway component on patient centeredness, patient-physician communication, and overall process of clinical care delivery. The physicians were also asked to list possible advantages and disadvantages of the described workflow personalization component.

Hypothetical Scenario

54 yo M presents for follow-up of his recent End-Stage Renal Disease diagnosis due to chronic hypertension. He will need to start renal replacement therapy within the next several months and is looking for help with treatment selection (dialysis). The patient does not have previous history of heart problems, stroke, TIA, or diabetes. No depression, anxiety, or history of trauma.

Questions:

1. Given the hypothetical scenario above, can you describe a typical treatment selection process as it would take place at your clinical practice?
2. Given the hypothetical scenario above, can you describe typical patient-physician communication during the treatment selection encounter?
3. Given the hypothetical scenario above, can you describe how you would attempt to satisfy the patient's personal needs for shared decision making and value-based treatment

selection?

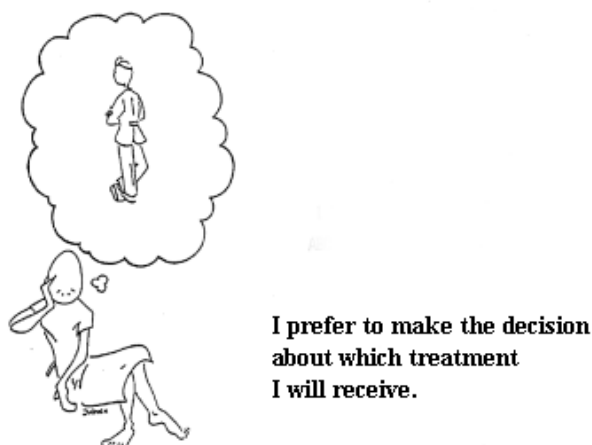
Workflow Recommendation Gateway

Please, review two hypothetical dialysis selection scenarios facilitated by workflow recommendation technology. The technology personalizes care delivery based on the individual patient profile. First, workflow recommendation technology identifies patient personal desires for participation in the decision making process. Then, the program suggests clinical workflow matching the patient's personal characteristics (see Figure 17).



Figure 17. Activity Diagram of Workflow Recommendation Gateway

Patient-Specific Clinical Steps for Informative Patient Type



Your patient has indicated to be of **Informative** type.

The patient's characteristics are as follows:

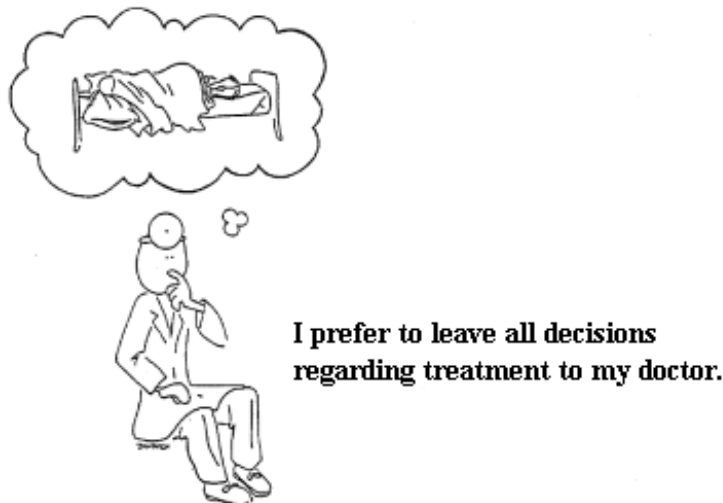
- Seeks objective factual information on his/her current state, available treatment options, and risks and benefits of each.
- Understands risk/benefit ratios and knows personal values.

Figure 18. Informative Patient Characteristics

Based on the identified Informative patient type (see Figure 18), workflow recommendation software suggests the following clinical process:

1. Patient is paired with a clinical worker (nurse or physician assistant) for the assessment of information preferences:
 - Clinical worker assesses patient's preferred approach to receive additional information (printed material, videos, interactive application, etc.).
2. Patient is given a chance to review the preferred additional information prior to seeing the doctor.
3. Patient sees the doctor for the final treatment selection step where:
 - Doctor checks that the patient has understood the information regarding the treatment.
 - Doctor offers to ask additional questions.
 - Doctor indicates the need to finalize treatment selection and review the decision.
 - Treatment selection is made by the **patient**.

Patient-Specific Clinical Steps for Passive/Paternalistic Patient Type



Your patient has indicated to be of **Passive/Paternalistic** type.

The patient's characteristics are as follows:

- Passive, agreeable, and accepting.
- Seeks to delegate the process of treatment selection.

Figure 19. Paternalistic/Passive Patient Characteristics

Based on the identified Paternalistic patient type (see Figure 19) workflow recommendation software suggests the following clinical process:

1. Patient sees the doctor for the treatment selection step where:
 - Doctor explores patient’s personal values regarding the treatment (desire to travel, stay active, work, etc.).
 - Doctor explores patient’s personal fears regarding the treatment and attempts to address them (fear of needles, surgery, self-management, etc.).
 - Doctor indicates the need to finalize treatment selection.
 - Treatment selection is made by the **physician**.
2. Patient is paired with a clinical worker (nurse or physician assistant) for the following post selection assessment:
 - Clinical worker assesses patient’s preferred approach to receive additional information (printed material, videos, interactive application, etc.).
 - Clinical worker checks that the patient has understood the information regarding the treatment.
 - Clinical worker offers to ask additional questions.
3. Patient is given a chance to review the preferred additional information.

Questions:

1. Given the presented scenario, can you describe the potential impact of workflow individualization technology on your clinical practice?
2. Given the presented scenario, can you describe how individualization of clinical workflows can affect patient centeredness?
3. Given the presented scenario, can you describe how individualization of clinical workflows can affect patient-physician communication?
4. Can you list any other potential benefits or drawbacks of the described workflow individualization technology?

Chapter Summary

This chapter is devoted to the first disease-specific instantiation of the framework-based patient decision aid. The aid is developed as an online instrument, which uses client-server technology and guides end-stage renal disease patients through a personalized decision

making process of dialysis treatment selection. For quantitative evaluation, research hypotheses are aligned with the corresponding artifact features and objective measures used in an experiment setting. For qualitative evaluation, the chapter contains the interview procedure used to assess the subjective physician perceptions towards the potential usefulness of the Workflow Recommendation Gateway component. In this chapter, some of the programming techniques and experiment evaluation protocols are highlighted. Text and application screenshots serve as further examples of the framework design principles. The chapter includes a demonstration of the instance-specific binary calculations and a hypothetical scenario featuring personalized clinical workflow recommendations.

CHAPTER 6

STUDY RESULTS

This chapter is devoted to the results of the two evaluation methods used to strengthen framework validity and gain insights about the first patient decision aid instantiation. The chapter begins with the results of the quantitative statistical analysis. Data assumptions, chosen statistical approach, and experiment findings are shared as they relate to each of the previously defined hypotheses. The text continues with the results of the qualitative evaluation of the Workflow Recommendation Gateway component achieved by personally interviewing three US-licensed family practice physicians.

Quantitative Experiment Results

The Independent Samples T-test analysis is the statistical method selected to compare the means of the experiment and control groups. The statistical technique is applied in order to reveal whether the Decisional Conflict Scale's Total Score, Effective Decision Subscore, Informed Subscore, and Uncertainty Subscore values are quantitatively different in control and experiment groups.

Prior to the analysis, the data have been checked to meet the following six underlying assumptions: 1) dependent variable is represented by continuous scale, 2) independent variable consists of two categorical, independent groups, 3) lack of relationships between the observations and groups, 4) no significant outliers, 5) dependent variable should be distributed normally, and 6) present homogeneity of variances.

Fifty-seven original results have been obtained via the solicitation email to Dakota State University students. Randomization function has diverted twenty-eight participants to be part of the control group while twenty-nine students were randomly assigned to the experiment group. Participant demographics summary is presented in Table 24, and the experiment results summary for all decision maker types can be seen in Table 25.

Table 24. Demographics Summary of Study Participants

Participants	Male	Female	Under 20	20-30	30-40	Over 40
57	46	11	5	41	7	4

Table 25. Summary of Results for All Decision Maker Types

		Number of Participants	Mean	P-value	Mean Difference
Total Score	Control	28	45.1	.000	22.9
	Experiment	29	22.3		
Effective Decision Subscore	Control	28	41.3	.002	20.0
	Experiment	29	21.3		
Informed Subscore	Control	28	40.8	.006	22.7
	Experiment	29	18.1		
Uncertainty Subscore	Control	28	56.3	.006	20.9
	Experiment	29	35.3		

Hypothesis H1: Decision aids based on the proposed framework are better

As seen in Table 25, Total Score means of the experiment and control groups are 22.3 and 45.1 respectively. Total Score of the Decisional Conflict Scale has been lowered for the experiment group by 22.9 percent, which can be seen in the table's Mean Difference column. Mean Difference indicates a significant improvement in the decision making quality for the experiment group. Independent Samples T-test analysis, further corroborates the finding with the P-value of 0.000, which highlights that indeed experiment and control groups are the samples of two separate populations. Based on the P-value's cut-off point of 0.1, Null Hypothesis is rejected, which states that Total Score of the experiment group is similar to than that of the control group. Alternative Hypothesis is supported, which states that Total Score is indeed statistically lower in the experiment group. The reached conclusion is that decision aids based on the proposed framework are better as indicated by the statistically significant improvement in the resulting overall decisional conflict measured by Total Score of the Decisional Conflict Scale.

Hypothesis H2: Decision aids based on the proposed framework better satisfy information needs

As seen in Table 25, Informed Subscore means of the experiment and control groups are 18.1 and 40.8 respectively. Informed Subscore of the Decisional Conflict Scale reveals that the experiment group is better informed than the control group by 22.7 percent, which can be seen in the Mean Difference column of Table 25. Independent Samples T-test analysis produces P-value of 0.006, which further confirms the findings by highlighting a clear separation of the two statistically different populations. Based on the P-value's cut-off point of 0.1, Null Hypothesis is rejected, which states that Informed Subscore of the experiment group is similar to that of the control group. Alternative Hypothesis is supported, which states that Informed Subscore of the experiment group is indeed lower than that of the control group. Rejection of Null Hypothesis in support of Alternative Hypothesis yields the conclusion that decision aids based on the proposed framework better satisfy individual information needs. This conclusion is clearly indicated by the statistically significant improvement in the feeling of being well-informed as measured by Informed Subscore of the Decisional Conflict Scale.

Hypothesis H3: Decision aids based on the proposed framework improve decision effectiveness

As seen in Table 25, Effective Decision Subscore means of the experiment and control groups are 21.3 and 41.3 respectively. Lower scores of the experiment group represent higher decision making efficiency. Participants of the experiment group exhibit higher decision effectiveness, which is presented quantitatively in the Mean Difference column of Table 25. Independent Samples T-test analysis produces P-value of 0.002, which signifies the statistical separation of the two populations. P-value's cut-off point of 0.1 yields the rejection of Null Hypothesis stating that decision effectiveness of the experiment and control groups is statistically identical. Alternative Hypothesis is supported, which states that Effective Decision Subscore is lower in the experiment than control group. The conclusion is reached that decision aids based on the proposed framework improve decision effectiveness as indicated by the statistically significant improvement of Decision Effectiveness Subscore of the Decisional Conflict Scale.

Hypothesis H4: Decision aids based on the proposed framework reduce decisional uncertainty

As seen in Table 25, Uncertainty Subscore means of the experiment and control groups are 35.3 and 56.3 respectively. Participants of the experiment group have a statistically significant reduction in their decisional uncertainty. The improvement of the experiment group is 20.9 percent as indicated in the Mean Difference column of Table 25. Independent Samples T-test analysis reveals P-value of 0.006, which confirms that the two means belong to two different populations. P-value's cut-off point of 0.1 yields the rejection of Null Hypothesis stating that decisional uncertainty is statistically identical for the two participant groups. Alternative Hypothesis is supported, which states that Decisional Uncertainty Subscore is lower in the experiment than control group. The resulting conclusion is that decision aids based on the proposed framework reduce decisional uncertainty as indicated by the statistically significant improvement of Uncertainty Subscore of the Decisional Conflict Scale.

Hypothesis H5: Decision aids based on the proposed framework support more individual patient types

As indicated by the literature review, current patient decision aids are designed to serve one decision maker type. Statistical summary of Table 26 reveals that this decision maker type is of Collaborative/Deliberative kind. Mean Total Score values of the Collaborative/Deliberative type are 24.9 and 25.8 for the respective experiment and control groups. P-value of 0.873 corroborates that the experiment and control groups do not represent two different population types. As seen in Table 26, the remaining decision maker types experience the opposite effect. They show statistically significant improvements of Total Score of the Decisional Conflict Scale, and the corresponding P-values confirm clear separation of the two participant populations.

Table 26. Summary of Results per Decision Maker Type

	Group	Total Score	P-Value
All Decision Maker Types	Control	45.1	.000
	Experiment	22.3	
Informative Decision Maker	Control	72.3	.000
	Experiment	15.6	

Collaborative/Deliberative Decision Maker	Control	25.8	.873
	Experiment	24.9	
Paternalistic Decision Maker	Control	76.6	.000
	Experiment	19.8	

Table 27 shows the summary of a separate Independent Samples T-test analysis after removing Collaborative/Deliberative decision makers from the results. The analysis maintains strong P-value, which differentiates unequivocally between the two populations. Participants of the experiment group exhibit a statistically significant improvement of the decision making quality as measured by Total Score of the Decisional Conflict Scale. In Table 27, Total Score values produce much stronger mean differences than the all-inclusive analysis shown in Table 25.

Table 27. Summary of Results for All but Collaborative Decision Maker Types

		Number of Participants	Mean	P-value	Mean Difference
Total Score	Control	11	75.0	.000	57.1
	Experiment	11	17.9		

If accounting for all decision maker types, Mean Difference of the two populations is 22.9 percent as seen in Table 25. However, as shown in Table 27, the removal of the Collaborative/Deliberative decision maker results in the much stronger improvement of 57.1 percent Mean Difference for the remaining types of decision makers. Null Hypothesis is rejected, which states that mean differences remain statistically unchanged. Alternative Hypothesis is supported, which concludes that decision aids based on the proposed framework support more individual types of decision makers.

Qualitative Physician Survey Results

The results of the physician survey reveal some of the subjective provider perceptions towards the existing processes of treatment selection and the potential clinical utility of the developed Workflow Recommendation Gateway component. Three US-licensed family practice physicians participated in the anonymous survey. The demographics profile consisted of one male and two female participants. Two of the physicians were in their thirties having

completed all of their professional credentialing requirements within the last five years. One physician was over fifty years of age and has been practicing healthcare for more than twenty years. Physician answers to the first question asking them to describe the existing process of treatment selection illustrate that much of the initial clinical consultation is dedicated to familiarizing patients with basic information about their diagnosis and recommended disease management steps:

“Explain the need to minimize radiocontrast. Explain the need for dialysis when the patients GFR is under 30. Encourage weight loss as well as alcohol and tobacco cessation if applicable.”

“We would discuss the current options, and I would do my best to talk about pros and cons of each.”

“I would make sure that the patient has understood the diagnosis given to him by the nephrologist.”

Workflow Recommendation Gateway follows the same logic. The designed framework component prepares patients for the initial part of clinical consultation by exposing them to some of the basic diagnosis and treatment information regardless of their personal desires for shared decision making.

The answers to the second baseline question meant to reveal typical patient-physician communication patterns highlight the fact that patient-physician communication often takes the form of a personalized teaching opportunity where physicians and their clients dedicate their time to review various disease-specific risks and treatment advantages and disadvantages:

“Review risks and complications associated with end stage renal disease and dialysis. Ask patient how I can help him make an informed decision. Ask patient if he needs more information regarding any of the treatment options.”

“In a perfect world, the patient would be presented with all the info needed to make an informed decision.”

“We would try to create an environment open to dialog. Would try to provide pertinent reading material and perhaps discussion with ancillary staff members that would help the patient gain more information to form better question.”

The last answer listed above is especially interesting because it signifies the fact that

the physician values the roles of staff members in facilitating patient-physician communication. Design principles of Workflow Recommendation Gateway support this part of a clinical consult by using the desires for shared decision making to form a personalized in-clinic learning experience. It also suggests relying on ancillary staff members as the process catalyst cognizant and respectful of the existing physician workload.

The final baseline question was structured to show how physicians would use their clinical encounter time to satisfy patients' desires for shared decision making and attempt to clarify personal values. Physician answers to the third baseline question demonstrate their awareness and understanding of the wide range of personal values and desires existing in the patient population:

“Ask patient if he has been able to rule out any of the options. What does he feel the pros and cons of each option are for him personally?”

“If asked, I would give my opinion based on patient's input as well as personal medical needs.”

“I would make sure that he knew that family members would be welcome to discuss any concerns or questions.”

The answers listed above show physician awareness of the fact that such patient characteristics as participation roles and individual values cannot be simply assumed. Physicians attempt to learn about these patient traits by inviting them to share their views through open-ended questions and waiting to make opinion-influenced recommendations. Design of Workflow Recommendation Gateway resonates the physician approach to reveal patient individuality. The Control Preferences Scale is used to gauge the desired level of clinical involvement. The gateway leaves it up to the care providers to decide on the most optimal way to present information and structure their open-ended questions.

After establishing the baseline of a typical clinical treatment selection process, physician survey proceeds to collecting subjective opinions on the perceived usefulness of the Workflow Recommendation Gateway. Physician answers to the first question pertaining the potential impact of such technology on clinical practice illustrate that one of their prime concerns is effective time management:

“Workflow individualization technology, could decrease the amount of time that the doctor and ancillary staff needs to spend with each patient by having a customized setting for

their needs.”

“It would help to decrease the amount of time the doctor and medical staff would need to spend researching patient information.”

“It would increase patient understanding of their disease and empower the patient in their decision. It would require more time spent in the clinic as well.”

The answers above indicate that physician time is of essence. The answers also highlight that Workflow Recommendation Gateway is perceived as useful in learning about patients, customizing clinical visits, informing, and empowering. First two answers show that technology can potentially serve as a time-saving instrument. However, the last answer states that it may actually have the opposite effect of increasing the total amount of time spent in the clinic.

The second physician question was directed at the impact of the framework’s component on patient centeredness. The answers seem to have a common theme that the proposed workflows facilitate the practice of patient-centered care:

“Patient centeredness would be more at the forefront of this type of care because of addressing each individual’s distinct preferences.”

“It sets the focus on the patient, giving them more control over their healthcare and forces the patient to become educated about the disease.”

“The care plan would be specifically based on each patient’s personal wants and needs. Therefore, treatment would revolve solely around each patient’s wants and needs as well.”

The third question was focused on evaluating the effects of Workflow Recommendation Gateway on patient-physician communication:

“It would allow the doctor-patient interaction to be more streamlined, efficient, and informative for both parties. Thereby, allowing for a more relaxed and productive meeting at each appointment.”

“Patient-physician communication would be more succinct and hopefully more satisfactory for each patient by neither under- or overestimating each patient’s desire for details into their treatment plan.”

“It would improve communication by forcing more education and involvement before making the final decision.”

The words streamlined, efficient, and succinct further support the accepting view of the framework for its potential usefulness as a time-saving instrument. The words relaxed, satisfactory, and improve show that the desirable time saving property is possible with a simultaneous enhancement of the quality of clinical communication.

The last question of the survey was meant to record physician perceptions of both potential benefits and drawbacks of the framework's workflow recommendation component:

“Drawbacks: Learning new software. Benefits: Happier patient and doctor and feeling that the right decision was made, not randomly, but rather in an organized, analytical, and caring fashion.”

“I think that the potential is obvious in the ability to precisely meet each patient's various desires for information. The main drawback that I see could be even less physician-patient interaction in a time when that seems always to be a concern. This could hopefully be compensated for by having more pertinent and satisfying interaction.”

“Time would be the biggest drawback. It is not always feasible to have the patient take so much time off work or away from family to attend all the appointments needed to complete the process.”

The listed benefits resonate with the previous answers of a better streamlined and more patient-centered decision making process matching patient's individuality. Learning new software is a commonly voiced concern of adopting new technology in a medical setting. High software learning curves have been impeding with the adoption of Electronic Health Record systems in clinics and hospitals for many years. It is a valid concern and should be addressed with the help of software usability experts who often invite end-users to participate in designing software interface. The other two shared drawbacks relate to the possible decrease of the amount of time spent on patient-physician communication and increase of time spent in clinic arriving at a suitable treatment option. These answers raise interesting points, which show that physicians are cognizant of the total amount of time spent on reaching a treatment selection, which includes their own investment as well as that of their supporting staff and patients. It is possible that physicians may be seeking to reduce the total amount of time needed to arrive at a suitable treatment decision.

Chapter Summary

This chapter is devoted to the evaluation methods used in assessing the effectiveness

of the first instantiation of the developed framework. Independent Samples T-test analysis is listed as the preferred approach of statistical inquiry. The chapter summarizes data assumptions and presents the findings as they relate to the each of the previously defined hypotheses. The experiment results indicate support for all five Alternative Hypotheses with the selected P-value cut-off point of 0.1. Physician perceptions are shared in the form of exact quotations to the questions discussed in the Implementation (Chapter 5) chapter. Physician survey results highlight the potential usefulness of the developed framework while revealing some of the intriguing physician views on patient centeredness, patient-physician communication, and the impact of such technology on the time-sensitive aspects of everyday clinical practice.

CHAPTER 7

RESULTS DISCUSSION

Discussion

The results of the experiment indicate support for the chosen design of the developed patient decision aid framework. The framework stresses the importance of providing emotional support and personalization based on such patient characteristics as individual information needs and desires for decision making involvement. These findings are of especial significance during the times when HIMSS keynote speaker refers to patient engagement in the digital age as the \$3 Trillion question (himss.org, 2014). The presented statistical analysis of the collected data indicates that patient engagement, when interfaced with digital decision aids, hinges on the ability of the software to distinguish among the known types of decision makers. Software output needs the ability to change decision strategies dynamically and according to the individual characteristics of patient decision makers. The assumption that all patients desire equal levels of decision making involvement and possess identical information needs is challenged. This work provides evidence that the process of treatment selection can be improved substantially with patients making their choices while feeling better informed and less uncertain. As previously shown, higher satisfaction with the treatment selection process and quality of information has many indirect consequences ranging from lower anxiety and higher regimen adherence rates to better quality of life and even an improvement of medical outcomes (Cukor et al., 2008; Graham et al., 2000; Rahimi, et al., 2008; R. G. Thomson, et al., 2007). The framework outlines four specific components, which directly impact the quality of medical treatment selections and perceived patient centeredness. Emotional Adaptation Gateway, Decision Strategy Gateway, and Information Needs Gateway improve emotional states, decision making effectiveness, and provisioning of health care information. Workflow Recommendation Gateway improves

patient-centeredness by providing physicians with a clinically relevant approach of workflow personalization. The results highlight that even though framework-based patient decision aids are better for the entire population of decision makers, the biggest difference is seen in satisfying the needs of the most and the least autonomous patient types. This finding is in line with the supporting literature, which reveals that current decision aids assume identical information needs and engagement preferences for the entirety of patient population.

The results of the qualitative survey of three US-licensed family practice physicians shed light on the perceived usefulness of the designed Workflow Recommendation Gateway as well as the existing patient-centered approaches. Overall design principles of Workflow Recommendation Gateway are corroborated with physician responses. One of the main objectives of Workflow Recommendation Gateways is to serve as a supplement and not replacement of live clinical consultations. The evaluation of Workflow Recommendation Gateway has shown that the component's design principles closely trail the existing clinical patterns while improving patient-centeredness of the provided care and respecting physician professional autonomy. Physician answers have revealed the unexpected result of the framework's potential to save time during a live clinical encounter. It should be noted that this benefit is juxtaposed by an opinion that the improvements in patient involvement and patient-physician communicating efficiency may inadvertently translate into an increase of the total decision making time for the patient. In fact, time seems to be the single most important theme affecting the framework's perceived usefulness. Physicians interpret potential time savings as direct benefits while classifying time losses as apparent shortcomings.

Contributions to Knowledge

The findings of this dissertation contribute to knowledge in two ways. First, the developed framework is reusable and can be implemented to serve a variety of medical conditions. It has been developed in a modular format, so that some of the components can be updated and replaced in line with our expanded understanding of patient decision aids and the roles they play in modern healthcare delivery systems. Patient Type matrix can be expanded to include additional decision maker types while Strategy Type matrix can include other decision making strategies. Emotional Adaptation Gateway can be replaced with an alternative emotional adaptation exercise, and the modules of Workflow Recommendation Gateway can be modified to include newer revisions of patient-centered consultations. The

template expands the knowledge of the patient decision aid domain by showing that the instruments should reflect the needs of individual stakeholders. Recognizing the role of emotions, personal desires for shared decision making, and individual information needs will facilitate positive experiences during treatment selections. The template also expands the knowledge of patient decision aids by highlighting some of the specific attributes that physicians perceive as clinically useful. Physician roles in success of patient decision aids should not be overlooked, since they are key stakeholders to their implementation.

Second, the evaluation of the instantiated artifact serves as a live example of the developed framework that strengthens its Summative validity. The proposed framework can be further validated and improved with additional disease-specific instantiations. However, the first artifact instantiation has been shown to successfully achieve the stated objectives. Framework-based instruments better satisfy personal information needs, improve decision making effectiveness, reduce decisional uncertainty, and support more individual decision maker types.

Contributions to Practice

The study contributes to two professional domains. The first domain is of software developers. Programs can use the framework to design and build future patient decision aids for a variety of conditions. Software developers can reference the framework for some of the general design principles of emotional adaptation, personalization or clinical utility. The second professional domain is that of healthcare delivery professionals. Providers can consult the framework for a better understanding of patient decision aids and the technology's capacity to optimize patient-centered workflows, assign treatment selection responsibilities, and improve patient satisfaction and regimen adherence rates.

Impact

This framework will allow creating better patient decision aids, which prepare patients emotionally and support a variety of information needs and decision making strategies. The framework will also lead to an increase of patient decision aid adoption rates in everyday clinical practice via offering a specific theory driven component for optimizing patient-centeredness. Higher adoption rates are expected to help to transform healthcare delivery systems by involving patients in treatment selection processes at the desired levels of shared

decision making. As literature shows, improved adoption rates of patient decision aids may also lead to such indirect outcomes as lower healthcare costs and higher regimen adherence rates. Development of additional framework-based patient decision aids will simplify future evaluations of their effectiveness for various diseases and disease trajectories. Known design principles of these instruments will allow for their faster comparisons even when applied in dissimilar context. Wider use of patient decision aids by healthcare providers will accelerate their acceptance and integration into existing electronic health records.

Future Improvement of Patient Engagement and Clinical Integration

Future research direction and potential improvement of the developed framework may focus on identifying the areas, which may better suit Collaborative/Deliberative decision maker types. As previously suggested by Elwyn Glyn (Glyn Elwyn, et al., 2011), close interaction with the users during the process of software development may give additional insights about individual patient preferences and discovery of new unmet needs. It has been noted by the extant literature that patient involvement in clinical decision making is correlated with an improvement of regimen adherence rates (Safran, 2003). Therefore, other potential framework development areas may focus on using patient decision aids as engagement instruments for the generally uninvolved Paternalistic patient types. Special care must be taken during such engagement attempts not to increase undue patient anxiety, which is common for unmet personal participation desires. Clinical utility of patient decision aids in everyday practice can be further increased by integrating the Workflow Recommendation Gateway component with the existing electronic health records (EHR). Successful EHR integration can facilitate such studies as the impact of decision aids on patient centeredness when individual participation desires and information needs are displayed together with patient history, vital signs, and most recent diagnosis.

Limitations

One of the limitations of this work is the selection of participant population and the other is generalization of results following a role playing evaluation. All of the study participants were students at Dakota State University. They were enrolled in either on-campus or on-line courses. It is possible that our solicitation of the student population has inadvertently introduced a bias, which is representative of this population type alone. There is

also a possibility that the two groups had an unknown relationship, which could have affected the results of the chosen statistical evaluation method. The second limitation pertains to the task of role playing and the subsequent generalization of the results to the intended population. Role playing can be a valuable tool in eliciting responses to hypothetical scenarios. However, some research reveals that human subjects do not always act in the manner consistent with their subjective opinions of how they think they will act in such situations (Freedman, 1969; Greenberg & Eskew, 1993). This experiment attempts to lessen the response-to-action inconsistency by minimizing the role of emotions in human forecasting bias. The affective forecasting adaptation exercise has been previously used to successfully approximate the responses of hypothetical non-patients to those of the actual patients (Ubel, et al., 2005).

Conclusion

The developed patient-centered and clinically integrated framework and the patient decision aid for dialysis treatment selection are the corresponding information systems template and its first successful instantiation. The template is prescriptive and supplies all of the necessary components for developing future electronic patient decision aids, which prepare patients emotionally, personalize output according to their individual information needs, form personalized decision making strategies, and improve physician acceptance through patient-centered workflow redesign. The first instantiation of the artifact serves as a live example and strengthens Summative validity of the framework. Experiment results reveal that the developed framework improves the quality of treatment selection processes marked by a statistically significant reduction of the resulting scores of the Decision Conflict Scale. Qualitative physician interviews support the design features of the workflow recommendation component by showing the mostly positive expectations of the instrument's potential usefulness.

REFERENCES

- Abhyankar, P., Summers, B. A., Velikova, G., & Bekker, H. L. (2014). Framing Options as Choice or Opportunity Does the Frame Influence Decisions? *Medical Decision Making*.
- Alden, D. L. (2014). Decision Aid Influences on Factors Associated with Patient Empowerment prior to Cancer Treatment Decision Making. *Medical Decision Making*.
- Ameling, J. M., Auguste, P., Ephraim, P. L., Lewis-Boyer, L., DePasquale, N., Greer, R. C., . . . Boulware, L. E. (2012). Development of a decision aid to inform patients' and families' renal replacement therapy selection decisions. *Bmc Medical Informatics and Decision Making*, 12(1), 140.
- Anderson, C. J. (2003). The psychology of doing nothing: forms of decision avoidance result from reason and emotion. *Psychological bulletin*, 129(1), 139.
- Ankem, K. (2006). Factors influencing information needs among cancer patients: A meta-analysis. *Library & information science research*, 28(1), 7-23.
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine*, 366(9), 780-781.
- Bekker, H. L. (2010). The loss of reason in patient decision aid research: Do checklists damage the quality of informed choice interventions? *Patient Education and Counseling*, 78(3), 357-364.
- Benbassat, J., Pilpel, D., & Tidhar, M. (1998). Patients' preferences for participation in clinical decision. [Article]. *Behavioral Medicine*, 24(2), 81.
- Boyd, C. M., Darer, J., Boulton, C., Fried, L. P., Boulton, L., & Wu, A. W. (2005). Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance. *JAMA*, 294(6), 716-724.
- Brackett, C., Kearing, S., Cochran, N., Tosteson, A. N. A., & Blair Brooks, W. (2010). Strategies for distributing cancer screening decision aids in primary care. *Patient Education and Counseling*, 78(2), 166-168.

- Buehler, R., & McFarland, C. (2001). Intensity Bias in Affective Forecasting: The Role of Temporal Focus. *Personality and Social Psychology Bulletin*, 27(11), 1480-1493.
- Caminiti, C., Meschi, T., Braglia, L., Diodati, F., Iezzi, E., Marcomini, B., . . . Schianchi, T. (2013). Reducing unnecessary hospital days to improve quality of care through physician accountability: a cluster randomised trial. *BMC health services research*, 13(1), 14.
- Carmack, A. (2011). Hemodialysis Retrieved September 19, 2012, from [http://www.aurorahealthcare.org/yourhealth/healthgate/getcontent.asp?URLhealthgate="14804.html"](http://www.aurorahealthcare.org/yourhealth/healthgate/getcontent.asp?URLhealthgate=)
- Carrigan, N., Gardner, P. H., Conner, M., & Maule, J. (2004). The impact of structuring information in a patient decision aid. [Article]. *Psychology & Health*, 19(4), 457-477.
- Case, D. O. (2002). *Looking for information : a survey of research on information seeking, needs, and behavior*. San Diego, Calif.: Academic Press.
- Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K., & March, V. (1980). Information and Participation Preferences Among Cancer Patients. [Article]. *Annals of Internal Medicine*, 92(6), 832-836.
- Chang, I. C., Hwang, H.-G., Hung, W.-F., & Li, Y.-C. (2007). Physicians' acceptance of pharmacokinetics-based clinical decision support systems. *Expert Systems with Applications*, 33(2), 296-303.
- Chau, P. Y. K., & Hu, P. J.-H. (2002). Investigating healthcare professionals' decisions to accept telemedicine technology: an empirical test of competing theories. *Information & Management*, 39(4), 297-311.
- Chen, R.-F., & Hsiao, J.-L. (2012). An investigation on physicians' acceptance of hospital information systems: A case study. *International Journal of Medical Informatics*, 81(12), 810-820.
- Christensen, A. J., & Ehlers, S. L. (2002). Psychological factors in end-stage renal disease: an emerging context for behavioral medicine research. *Journal of consulting and clinical psychology*, 70(3), 712.
- Clouston, K., Katz, A., Martens, P. J., Sisler, J., Turner, D., Lobchuk, M., . . . Crow, G. (2014). Does access to a colorectal cancer screening website and/or a nurse-managed telephone help line provided to patients by their family physician increase fecal occult blood test uptake?: results from a pragmatic cluster randomized controlled trial. *BMC cancer*, 14(1), 263.

- Collaboration, I. P. D. A. S. (2005). IPDAS 2005: Criteria for Judging the Quality of Patient Decision Aids from http://ipdas.ohri.ca/IPDAS_checklist.pdf
- Cross, N. (2001). Designerly ways of knowing: Design discipline versus design science. *Design issues*, 17(3), 49-55.
- Cukor, D., Coplan, J., Brown, C., Friedman, S., Newville, H., Safier, M., . . . Kimmel, P. L. (2008). Anxiety disorders in adults treated by hemodialysis: a single-center study. *American journal of kidney diseases*, 52(1), 128-136.
- Dalal, R. S., & Bonaccio, S. (2010). What types of advice do decision-makers prefer? *Organizational Behavior and Human Decision Processes*, 112(1), 11-23.
- Deber, R. B., Kraetschmer, N., & Irvine, J. (1996). What Role Do Patients Wish to Play in Treatment Decision Making? *Archives of Internal Medicine*, 156(13), 1414-1420.
- Degner, L. F., Sloan, J. A., & Venkatesh, P. (1997). The Control Preferences Scale. *The Canadian Journal of Nursing Research*, 29(3), 21-43.
- Dervin, B., & Nilan, M. (1986). Information needs and uses. *Annual review of information science and technology*, 21, 3-33.
- Dolan, J. G., & Frisina, S. (2002). Randomized controlled trial of a patient decision aid for colorectal cancer screening. [Article]. *Medical Decision Making*, 22(2), 125-139.
- Dolan, J. G., Veazie, P. J., & Russ, A. J. (2013). Development and initial evaluation of a treatment decision dashboard. *Bmc Medical Informatics and Decision Making*, 13(1), 51.
- Dougherty, D., & Conway, P. H. (2008). The "3T's" road map to transform US health care: the "how" of high-quality care. *JAMA*, 299(19), 2319-2321.
- Dünnebeil, S., Sunyaev, A., Blohm, I., Leimeister, J. M., & Krcmar, H. (2012). Determinants of physicians' technology acceptance for e-health in ambulatory care. *International Journal of Medical Informatics*, 81(11), 746-760.
- Durand, M. A., Wegwarth, O., Boivin, J., & Elwyn, G. (2012). Design and usability of heuristic-based deliberation tools for women facing amniocentesis. *Health Expectations*, 15(1), 32-48.

- Elwyn, G., Edwards, A., Hood, K., Robling, M., Wensing, M., & Grol, R. (2009). OPTION - Observing patient involvement in shared decision making from [http://www.optioninstrument.com/resources/OPTION_instrument_\(v3_2009\).pdf](http://www.optioninstrument.com/resources/OPTION_instrument_(v3_2009).pdf)
- Elwyn, G., Edwards, A., & Kinnersley, P. (1999). Shared decision-making in primary care: the neglected second half of the consultation. *British Journal of General Practice*, 49(443), 477-482.
- Elwyn, G., Frosch, D., Volandes, A. E., Edwards, A., & Montori, V. M. (2010). Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making*, 30(6), 701-711.
- Elwyn, G., Kreuwel, I., Durand, M. A., Sivell, S., Joseph-Williams, N., Evans, R., & Edwards, A. (2011). How to develop web-based decision support interventions for patients: A process map. *Patient Education and Counseling*, 82(2), 260-265.
- Elwyn, G., Légaré, F., van der Weijden, T., Edwards, A., & May, C. (2008). Arduous implementation: does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice. *Implement Sci*, 3(1), 57.
- Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., Coulter, A., & Collaboration, I. (2006). Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. [Article]. *British Medical Journal*, 333(7565), 417-419.
- Elwyn, G., O'Connor, A. M., Bennett, C., Newcombe, R. G., Politi, M., Durand, M.-A., . . . Edwards, A. (2009). Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards instrument (IPDASi). *PLoS ONE*, 4(3).
- Elwyn, G., Rix, A., Holt, T., & Jones, D. (2012). Why do clinicians not refer patients to online decision support tools? Interviews with front line clinics in the NHS. *BMJ open*, 2(6).
- Elwyn, G., Stiel, M., Durand, M. A., & Boivin, J. (2011). The design of patient decision support interventions: addressing the theory-practice gap. *Journal of Evaluation in Clinical Practice*, 17(4), 565-574.
- Emanuel, E. J., & Emanuel, L. L. (1992). Four Models of the Physician-Patient Relationship. *Journal of the American Medical Association*, 267(16), 22-29.
- Epstein, R. M., Fiscella, K., Lesser, C. S., & Stange, K. C. (2010). Why the nation needs a policy push on patient-centered health care. *Health Affairs*, 29(8), 1489-1495.

- Evans, R., Edwards, A., Coulter, A., & Elwyn, G. (2007). Prominent strategy but rare in practice: shared decision-making and patient decision support technologies in the UK. *Zeitschrift für ärztliche Fortbildung und Qualität im Gesundheitswesen-German Journal for Quality in Health Care*, 101(4), 247-253.
- Evans, R., Edwards, A. G., Elwyn, G., Watson, E., Grol, R., Brett, J., & Austoker, J. (2007). 'It's a maybe test': men's experiences of prostate specific antigen testing in primary care. *British Journal of General Practice*, 57(537), 303-310.
- Evans, R., Elwyn, G., Edwards, A., Watson, E., Austoker, J., & Grol, R. (2007). Toward a model for field-testing patient decision-support technologies: A qualitative field-testing study. *Journal of Medical Internet Research*, 9(3).
- Feldman-Stewart, D., O'Brien, M. A., Clayman, M., Davison, J., Jimbo, M., Labrecque, M., . . . Shepherd, H. (2012). 2012 Updates Chapter B: Providing Information About Options Retrieved Aug 16, 2012, from <http://ipdas.ohri.ca/IPDAS-Chapter-B.pdf>
- Feldman-Stewart, D., Tong, C., Siemens, R., Alibhai, S., Pickles, T., Robinson, J., & Brundage, M. D. (2012). The Impact of Explicit Values Clarification Exercises in a Patient Decision Aid Emerges After the Decision Is Actually Made Evidence From a Randomized Controlled Trial. *Medical Decision Making*, 32(4), 616-626.
- Feroze, U., Martin, D., Reina-Patton, A., Kalantar-Zadeh, K., & Kopple, J. D. (2010). Mental health, depression, and anxiety in patients on maintenance dialysis. *Iran J Kidney Dis*, 4(3), 173-180.
- Freedman, J. L. (1969). Role playing: Psychology by consensus. *Journal of Personality and Social Psychology*, 13(2), 107-114.
- Frosch, D. L., Bhatnagar, V., Tally, S., Hamori, C. J., & Kaplan, R. M. (2008). Internet patient decision support - A Randomized controlled trial comparing alternative approaches for men considering prostate cancer screening. [Article]. *Archives of Internal Medicine*, 168(4), 363-369.
- Frosch, D. L., Moulton, B. W., Wexler, R. M., Holmes-Rovner, M., Volk, R. J., & Levin, C. A. (2011). Shared decision making in the United States: policy and implementation activity on multiple fronts. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 105(4), 305-312.
- Frosch, D. L., Singer, K. J., & Timmermans, S. (2011). Conducting implementation research in community-based primary care: a qualitative study on integrating patient decision support

interventions for cancer screening into routine practice. [Article]. *Health Expectations*, 14, 73-84.

Gigerenzer, G., & Gaissmaier, W. (2011). Heuristic Decision Making. *Annu. Rev. Psychol*, 62, 451-482.

Gilbert, D. T., Driver-Linn, E., & Wilson, T. D. (2002). *The Wisdom in Feeling: Psychological Processes in Emotional Intelligence*. New York: Guilford Press.

Glasspool, D. W., Clettinger, A., Smith-Spark, J. H., Castillo, F. D., Monaghan, V. E. L., & Fox, J. (2007). Supporting medical planning by mitigating cognitive load. [Article]. *Methods of Information in Medicine*, 46(6), 636-640.

Graham, W., Smith, P., Kamal, A., Fitzmaurice, A., Smith, N., Hamilton, N., & Wyatt, J. (2000). Randomised controlled trial comparing effectiveness of touch screen system with leaflet for providing women with information on prenatal tests. *BMJ*, 320(7228), 155-160.

Green, J. A. (1988). Minimizing Malpractice Risks by Role Clarification. [Article]. *Annals of Internal Medicine*, 109(3), 234.

Greenberg, J., & Eskew, D. E. (1993). The role of role playing in organizational research. *Journal of management*, 19(2), 221-241.

Harrison, J. D., Masya, L., Butow, P., Solomon, M., Young, J., Salkeld, G., & Whelan, T. (2009). Implementing patient decision support tools: Moving beyond academia? *Patient Education and Counseling*, 76(1), 120-125.

Härter, M., Müller, H., Dirmaier, J., Donner-Banzhoff, N., Bieber, C., & Eich, W. (2011). Patient participation and shared decision making in Germany—history, agents and current transfer to practice. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 105(4), 263-270.

Harvey, N., & Fischer, I. (1997). Taking advice: Accepting help, improving judgment, and sharing responsibility. *Organizational Behavior and Human Decision Processes*, 70(2), 117-133.

Heller, D., Levin, I. P., & Goransson, M. (2002). Selection of strategies for narrowing choice options: Antecedents and consequences. *Organizational Behavior and Human Decision Processes*, 89(2), 1194-1213.

- Hertzum, M. (2011). Electronic emergency-department whiteboards: A study of clinicians' expectations and experiences. *International Journal of Medical Informatics*, 80(9), 618-630.
- Hevner, A. R., March, S. T., Park, J., & Ram, S. (2004). Design science in information systems research. *MIS Quarterly*, 28(1), 75-105.
- himss.org. (2014). Keynoter to Ask a \$3 Trillion Question at Patient Engagement Summit. Retrieved from <http://www.himss.org/News/NewsDetail.aspx?ItemNumber=37115>
- Hirsch, O., Keller, H., Krones, T., & Donner-Banzhoff, N. (2011). Acceptance of shared decision making with reference to an electronic library of decision aids (arriba-lib) and its association to decision making in patients: an evaluation study. *Implementation Science*, 6.
- Hoffman, A. S., Volk, R. J., Saarimaki, A., Stirling, C., Li, L. C., Härter, M., . . . Llewellyn-Thomas, H. (2013). Delivering patient decision aids on the Internet: definitions, theories, current evidence, and emerging research areas. *Bmc Medical Informatics and Decision Making*, 13(Suppl 2), S13.
- Hollinghurst, S., Emmett, C., Peters, T. J., Watson, H., Fahey, T., Murphy, D. J., & Montgomery, A. (2010). Economic evaluation of the DiAMOND randomized trial: cost and outcomes of 2 decision aids for mode of delivery among women with a previous cesarean section. *Medical Decision Making*.
- Holmes-Rovner, M. (2007). International Patient Decision Aid Standards (IPDAS): beyond decision aids to usual design of patient education materials. [Editorial Material]. *Health Expectations*, 10(2), 103-107.
- Holmes-Rovner, M., Nelson, W. L., Pignone, M., Elwyn, G., Rovner, D. R., O'Connor, A. M., . . . Correa-De-Araujo, R. (2007). Are patient decision aids the best way to improve clinical decision making? Report of the IPDAS symposium. [Article; Proceedings Paper]. *Medical Decision Making*, 27(5), 599-608.
- Iacovetto, M. C., Matlock, D. D., McIlvennan, C. K., Thompson, J. S., Bradley, W., LaRue, S. J., & Allen, L. A. (2014). Educational Resources for Patients Considering a Left Ventricular Assist Device A Cross-Sectional Review of Internet, Print, and Multimedia Materials. *Circulation: Cardiovascular Quality and Outcomes*, 7(6), 905-911.
- Iivari, J. (2007). A paradigmatic analysis of Information Systems as a design science.

- Izquierdo, F., Gracia, J., Guerra, M., Blasco, J. A., & Andradás, E. (2011). Health technology assessment-based development of a Spanish breast cancer patient decision aid. [Article]. *International Journal of Technology Assessment in Health Care*, 27(4), 363-368.
- Izquierdo, F., Gracia, J., Guerra, M., Blasco, J. A., & Andradás, E. (2011). Health technology assessment-based development of a Spanish breast cancer patient decision aid. *International Journal of Technology Assessment in Health Care*, 27(04), 363-368.
- Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *British journal of cancer*, 84(1), 48.
- Jibaja-Weiss, M. L., Volk, R. J., Granchi, T. S., Neff, N. E., Robinson, E. K., Spann, S. J., . . . Beck, J. R. (2011). Entertainment education for breast cancer surgery decisions: a randomized trial among patients with low health literacy. *Patient Education and Counseling*, 84(1), 41-48.
- Kaprowy, J. A. (1991). *A Descriptive Study to Investigate End Stage Renal Disease Patients' Desire for Information and Preferences About Roles in Treatment Decision Making*. Master of Nursing, University of Manitoba, Winnipeg, Manitoba.
- Kasper, J., Heesen, C., Kopke, S., Fulcher, G., & Geiger, F. (2011). Patients' and Observers' Perceptions of Involvement Differ. Validation Study on Inter-Relating Measures for Shared Decision Making. *PLoS ONE*, 6(10).
- Kasper, J., Kopke, S., Muhlhauser, I., Nubling, M., & Heesen, C. (2008). ISRCTN25267500: Informed Shared Decision Making In Multiple Sclerosis Immunotherapy (ISDIMS). A randomised controlled trial to investigate the effects of an evidence-based decision aid on decision-making about immunotherapy in multiple sclerosis. [Article]. *European Journal of Neurology*, 15(12), 1345-1352.
- Keith, D. S., Nichols, G. A., Gullion, C. M., Brown, J. B., & Smith, D. H. (2004). Longitudinal follow-up and outcomes among a population with chronic kidney disease in a large managed care organization. *Archives of Internal Medicine*, 164(6), 659-663.
- Labrecque, M., Paunescu, C., Plesu, I., Stacey, D., & Légaré, F. (2010). Evaluation of the effect of a patient decision aid about vasectomy on the decision-making process: a randomized trial. *Contraception*, 82(6), 556-562.
- Le, T., & Bhushan, V. (2006). *First aid for the USMLE step 2 CS (clinical skills exam)*: McGraw-Hill.

- Lenert, L. A., & Cher, D. J. (1999). Use of meta-analytic results to facilitate shared decision making. [Article]. *Journal of the American Medical Informatics Association*, 6(5), 412-419.
- Levine, M. N., Gafni, A., Markham, B., & MacFarlane, D. (1992). A Bedside Decision Instrument To Elicit a Patient's Preference Adjuvant Chemotherapy for Breast Cancer. *Annals of Internal Medicine*, 117(1), 53-58.
- Levit, K., Smith, C., Cowan, C., Lazenby, H., Sensenig, A., & Catlin, A. (2003). Trends in US health care spending, 2001. *Health Affairs*, 22(1), 154-164.
- Li, L. C., Adam, P., Townsend, A. F., Stacey, D., Lacaille, D., Cox, S., . . . Ho, K. (2009). Improving healthcare consumer effectiveness: an Animated, Self-serve, Web-based Research Tool (ANSWER) for people with early rheumatoid arthritis. *Bmc Medical Informatics and Decision Making*, 9(1), 40.
- Li, L. C., Adam, P. M., Backman, C. L., Lineker, S., Jones, C. A., Lacaille, D., . . . Tugwell, P. (2014). Proof of Concept Study of a Web Based Methotrexate Decision Aid for Patients With Rheumatoid Arthritis. *Arthritis care & research*, 66(10), 1472-1481.
- Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., . . . Payne, S. (2001). Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ*, 323(7318), 908-911.
- Lun, K. C. (1995). New user interfaces. *International Journal of Bio-Medical Computing*, 39(1), 147-150.
- Melas, C. D., Zampetakis, L. A., Dimopoulou, A., & Moustakis, V. (2011). Modeling the acceptance of clinical information systems among hospital medical staff: An extended TAM model. *Journal of Biomedical Informatics*, 44(4), 553-564.
- Miller Jr, D. P., Spangler, J. G., Case, L. D., Goff Jr, D. C., Singh, S., & Pignone, M. P. (2011). Effectiveness of a Web-Based Colorectal Cancer Screening Patient Decision Aid: A Randomized Controlled Trial in a Mixed-Literacy Population. *American Journal of Preventive Medicine*, 40(6), 608-615.
- Miller, K. M., Brenner, A., Griffith, J. M., Pignone, M. P., & Lewis, C. L. (2012). Promoting decision aid use in primary care using a staff member for delivery. *Patient Education and Counseling*, 86(2), 189-194.

- Morris, D., Drake, E., Saarimaki, A., Bennett, C., & O'Connor, A. (2008). Can people find patient decision aids on the Internet? *Patient Education and Counseling*, 73(3), 557-560.
- Ng, C. J., Lee, Y. K., Lee, P. Y., & Abdullah, K. L. (2013). Health innovations in patient decision support: Bridging the gaps and challenges. *The Australasian medical journal*, 6(2), 95.
- O'Connor, A. M., Bennett, C., Stacey, D., Barry, M. J., Col, N. E., Eden, K. B., . . . Rovner, D. R. (2007). Do patient decision aids meet effectiveness Criteria of the international patient decision aid standards collaboration? A systematic review and meta-analysis. *Medical Decision Making*, 27(5), 554-574.
- OHRI. (2012). Decisional Conflict Scale Retrieved September 24, 2012, from http://decisionaid.ohri.ca/eval_dcs.html
- Ormandy, P. (2008). *Chronic Kidney Disease: Patient Information Need, Preferences and Priorities*. Doctor of Philosophy, University of Salford.
- Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., . . . Hagerty, R. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*, 34(1), 81-93.
- Protheroe, J., Bower, P., Chew-Graham, C., Peters, T. J., & Fahey, T. (2007). Effectiveness of a computerized decision aid in primary care on decision making and quality of life in menorrhagia: results of the MENTIP randomized controlled trial. *Medical Decision Making*, 27(5), 575-584.
- Pynoo, B., Devolder, P., Duyck, W., van Braak, J., Sijnave, B., & Duyck, P. (2012). Do hospital physicians' attitudes change during PACS implementation? A cross-sectional acceptance study. *International Journal of Medical Informatics*, 81(2), 88-97.
- Quill, T. E., & Cassel, C. K. (1995). Nonabandonment: a central obligation for physicians. *Annals of Internal Medicine*, 122(5), 368-374.
- Rahimi, A., Ahmadi, F., & Gholyaf, M. (2008). The Effects of continuous care model on depression, anxiety, and stress in patients on hemodialysis. *Nephrology nursing journal*, 35(1), 39-44.
- Reinhardt, U. E., Hussey, P. S., & Anderson, G. F. (2004). US health care spending in an international context. *Health Affairs*, 23(3), 10-25.

- Reyna, V. F. (2008). A theory of medical decision making and health: fuzzy trace theory. *Medical Decision Making*.
- Rowe, J. W. (2006). Pay-for-performance and accountability: related themes in improving health care. *Annals of Internal Medicine*, 145(9), 695-699.
- Ruffin IV, M. T., Fetters, M. D., & Jimbo, M. (2007). Preference-based electronic decision aid to promote colorectal cancer screening: Results of a randomized controlled trial. *Preventive Medicine*, 45(4), 267-273.
- Safran, C. (2003). The collaborative edge: patient empowerment for vulnerable populations. *International Journal of Medical Informatics*, 69(2), 185-190.
- Schapira, M. M., Gilligan, M. A., McAuliffe, T., Garmon, G., Carnes, M., & Nattinger, A. B. (2007). Decision-making at menopause: A randomized controlled trial of a computer-based hormone therapy decision-aid. *Patient Education and Counseling*, 67(1-2), 100-107.
- Schwitzer, G. (2002). A Review of Features in Internet Consumer Health Decision-support Tools. [Review]. *Journal of Medical Internet Research*, 4(2).
- Scott, G. C., & Lenert, L. A. (1998). Extending contemporary decision support system designs to patient-oriented systems. [Article]. *Journal of the American Medical Informatics Association*, 376-380.
- Scott, G. C., & Lenert, L. A. (2000). What is the next step in patient decision support? [Article; Proceedings Paper]. *Journal of the American Medical Informatics Association*, 784-788.
- Sepucha, K., & Mulley, A. G. (2009). A perspective on the patient's role in treatment decisions. *Medical Care Research and Review*, 66(1 suppl), 53S-74S.
- Sepucha, K., Thomson, R., Borkhoff, C. M., Lally, J. J., Levin, C. A., Matlock, D. d., . . . Wills, C. E. (2012). 2012 Updated Chapter L: Establishing The Effectiveness
- Sepucha, K. R., Stacey, D., Clay, C. F., Chang, Y. C., Cosenza, C., Dervin, G., . . . Levin, C. A. (2011). Decision quality instrument for treatment of hip and knee osteoarthritis: a psychometric evaluation. *BMC Musculoskeletal Disorders*, 12.

- Shaffer, A. V., Owens, J., & Zikmund-Fisher, J. B. (2013). The Effect of Patient Narratives on Information Search in a Web-Based Breast Cancer Decision Aid: An Eye-Tracking Study. *J Med Internet Res*, *15*(12).
- Shafik, D., & Ramsey, B. (2007). *Zend PHP 5 Certification Study Guide*: Marco Tabini.
- Simon, D., Kriston, L., von Wolff, A., Buchholz, A., Vietor, C., Hecke, T., . . . Härter, M. (2012). Effectiveness of a web-based, individually tailored decision aid for depression or acute low back pain: a randomized controlled trial. *Patient Education and Counseling*, *87*(3), 360-368.
- Sivell, S., Edwards, A., Manstead, A. S., Reed, M. W., Caldon, L., Collins, K., . . . Elwyn, G. (2012). Increasing readiness to decide and strengthening behavioral intentions: Evaluating the impact of a web-based patient decision aid for breast cancer treatment options (BresDex: www.bresdex.com). *Patient Education and Counseling*, *88*(2), 209-217.
- Smyth, N. (2010). *PHP Essentials*: eBookFrenzy.
- Snyder, L., & Neubauer, R. L. (2007). Pay-for-performance principles that promote patient-centered care: an ethics manifesto. *Annals of Internal Medicine*, *147*(11), 792-794.
- Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmes-Rovner, M., . . . Thomson, R. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*(10).
- Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., . . . Thomson, R. (2014). Decision aids for people facing health treatment or screening decisions. *The Cochrane Library*.
- Svenson, O. (1992). Differentiation and consolidation theory of human decision making: A frame of reference for the study of pre-and post-decision processes. *Acta Psychologica*, *80*(1), 143-168.
- Thomson, M. D., & Hoffman-Goetz, L. (2007). Readability and cultural sensitivity of web-based patient decision aids for cancer screening and treatment: A systematic review. *Medical Informatics and the Internet in Medicine*, *32*(4), 263-286.
- Thomson, R. G., Eccles, M. P., Steen, I. N., Scheme, J., Stobbart, L., Murtagh, M. J., & May, C. R. (2007). A patient decision aid to support shared decision-making on anti-thrombotic treatment of patients with atrial fibrillation: randomised controlled trial. *Quality & Safety in Health Care*, *16*(3), 216-223.

- Tomko, C., Davis, K. M., Luta, G., Krist, A. H., Woolf, S. H., & Taylor, K. L. A Comparison of Web-Based Versus Print-Based Decision Aids for Prostate Cancer Screening: Participants' Evaluation and Utilization. *Journal of General Internal Medicine*, 30(1), 33-42.
- Trenaman, L., Bryan, S., & Bansback, N. (2014). The cost-effectiveness of patient decision aids: A systematic review. *Healthcare*, 2(4), 251-257.
- Ubel, P. A., Loewenstein, G., & Jepson, C. (2005). Disability and Sunshine: Can Hedonic Predictions be Improved by Drawing Attention to Focusing Illusions or Emotional Adaptation? *Journal of Experimental Psychology: Applied*, 11(2), 111-123.
- Van Aken, J. E. (2005). Management research as a design science: articulating the research products of mode 2 knowledge production in management. *British journal of management*, 16(1), 19-36.
- Volk, M. L., Roney, M., & Fagerlin, A. (2014). Pilot test of a patient decision aid about liver transplant organ quality. *Liver Transplantation*, 20(7), 850-855.
- Volk, R. J., Jibaja-Weiss, M. L., Hawley, S. T., Kneuper, S., Spann, S. J., Miles, B. J., & Hyman, D. J. (2008). Entertainment education for prostate cancer screening: A randomized trial among primary care patients with low health literacy. *Patient Education and Counseling*, 73(3), 482-489.
- Walter, Z., & Lopez, M. S. (2008). Physician acceptance of information technologies: Role of perceived threat to professional autonomy. *Decision Support Systems*, 46(1), 206-215.
- Wang, L.-J., & Chen, C.-K. (2012). The Psychological Impact of Hemodialysis on Patients with Chronic Renal Failure.
- WebMD. (Ed.) (2006) Stedman's Medical Dictionary.
- Weymiller, A. J., Montori, V. M., Jones, L. A., Gafni, A., Guyatt, G. H., Bryant, S. C., . . . Smith, S. A. (2007). Helping patients with type 2 diabetes mellitus make treatment decisions: statin choice randomized trial. *Archives of Internal Medicine*, 167(10), 1076-1082.
- Williams, L., Jones, W., Elwyn, G., & Edwards, A. (2008). Interactive patient decision aids for women facing genetic testing for familial breast cancer: a systematic web and literature review. [Article]. *Journal of Evaluation in Clinical Practice*, 14(1), 70-74.

- Wilson, T. D., & Gilbert, D. T. (2005). Affective Forecasting. *Current Directions in Psychological Science (Wiley-Blackwell)*, 14(3), 131-134.
- Wilson, T. D., Wheatley, T., Meyers, J. M., Gilbert, D. T., & Axson, D. (2000). Focalism: A source of durability bias in affective forecasting. *Journal of Personality and Social Psychology*, 78(5), 821-836.
- Yi, M. Y., Jackson, J. D., Park, J. S., & Probst, J. C. (2006). Understanding information technology acceptance by individual professionals: Toward an integrative view. *Information & Management*, 43(3), 350-363.
- Yu, C. H., Stacey, D., Sale, J., Hall, S., Kaplan, D. M., Ivers, N., . . . Straus, S. E. (2014). Designing and evaluating an interprofessional shared decision-making and goal-setting decision aid for patients with diabetes in clinical care-systematic decision aid development and study protocol. *Implementation science: IS*, 9(1), 16.
- Zheng, K., Padman, R., Johnson, M. P., & Diamond, H. S. (2005). Understanding technology adoption in clinical care: Clinician adoption behavior of a point-of-care reminder system. *International Journal of Medical Informatics*, 74(7-8), 535-543.
- Zhou, F., & Jiao, R. J. (2013). An improved user experience model with cumulative prospect theory. *Procedia Computer Science*, 16(0), 870-877.
- Zhuang, Z. Y., Wilkin, C., & Ceglowski, A. (2012). A framework for an intelligent decision support system: A case in pathology test ordering. *Decision Support Systems*.

APPENDICES

APPENDIX A: ADAPTATION EXERCISE

Think back to one emotionally difficult life experience that happened to you at least 6 months ago (e.g. divorce, death of a loved one, setback in school or work). Immediately after this emotionally difficult experience, you probably felt pretty awful. But think about how you felt six months after the event.

At the end of those six months, how did you feel compared to what you would have predicted immediately after it happened?

- I felt much worse than I would have predicted.
- I felt about the same as I would have predicted.
- I felt much better than I would have predicted.

Compared to the first few weeks after the event, how strong were your emotions six months later?

- Much stronger than before.
- About the same as before.
- Much weaker than before.

When you imagine what it would be like to be on dialysis, do you think it would become more or less upsetting over time?

- Much more upsetting over time.
- Equally as upsetting over time.
- Much less upsetting over time.

APPENDIX B: DECISIONAL CONFLICT SCALE

Considering the option you prefer, please answer the following questions:					
	Yes [0]	Probably yes [1]	Unsure [2]	Probably no [3]	No [4]
1. Do you know which options are available to you?					
2. Do you know the benefits of each option?					
3. Do you know the risks and side effects of each option?					
4. Are you clear about which benefits matter most to you?					
5. Are you clear about which risks and side effects matter most to you?					
6. Are you clear about which is more important to you (the benefits or the risks and side effects)?					
7. Do you have enough support from others to make a choice?					
8. Are you choosing without pressure from others?					
9. Do you have enough advice to make a choice?					
10. Are you clear about the best choice for you?					
11. Do you feel sure about what to choose?					
12. Is this decision easy for you to make?					
13. Do you feel you have made an informed choice?					
14. Does your decision show what is important to you?					
15. Do you expect to stick with your decision?					
16. Are you satisfied with your decision?					

APPENDIX C: IPDAS CRITERIA CHECKLIST – CONTENT SECTION

Provide information about options in sufficient detail for decision making?

Does the patient decision aid describe the health condition?

Does the patient decision aid list the options?

Does the patient decision aid list the options of doing nothing?

Does the patient decision aid describe the natural course without options?

Does the patient decision aid describe procedures?

Does the patient decision aid describe positive features [benefits]?

Does the patient decision aid describe negative features of options [harms / side effects / disadvantages]?

Does the patient decision aid include chances of positive / negative outcomes?

Does the patient decision aid describe what test is designed to measure?

Does the patient decision aid include chances of true positive, true negative, false positive, false negative test results?

Does the patient decision aid describe possible next steps based on test result?

Does the patient decision aid include chances the disease is found with / without screening?

Does the patient decision aid describe detection / treatment that would never have caused problems if one was not screened?

APPENDIX D: ONLINE DIALYSIS TREATMENT SELECTORS

Dialysis - NHS Choices

This online treatment selector instrument was created by the United Kingdom's National Health Service (NHS). It does not state if its development has been influenced by the International Patient Decision Aids Standards criteria. However, the instrument does contain some of the checklist items of the published international standards. This online tool contains dialysis patient testimonials who compare their lives pre- and post-treatment. It can be argued that patient testimonials are a form of emotional adaptation, which relieves anxiety by demonstrating to renal failure patients that dialysis treatment is meant to improve the overall quality of life. The instrument gives a general description of the condition and the available treatment options. It does state that although both treatment forms are considered medically equivalent, one may be more fitting to a particular individual than the other. This dialysis treatment selector seems to stress the fact that individual treatment choice will be ultimately affected by the patient's current medical condition and not necessarily the alignment of the treatment and personal values. It also does not personalize the decision making strategies based on readiness to participate in the treatment selection process. It does not let end-users control the amount of information they wish to review. Finally, the instrument seems disconnected from clinical visits, and no apparent clinical utility to practicing physicians is provided.

Kidney Failure: What Type of Dialysis Should I Have?

This treatment selector was developed by Healthwise and is the only tool designed in accordance with the IPDAS criteria. This instrument is listed as containing the majority of the IPDAS checklist items from the Content, Development Process, and Effectiveness sections. The Healthwise decision aid lets patients evaluate in-center hemodialysis and peritoneal dialysis treatment options. This tool only mentions the possibility of having hemodialysis done in a home setting, but it does not provide any specific information for appraising it as an

option. Additionally, the tool only notes that patients may be able to switch between dialysis types to closer reflect their changing needs, but it does not elaborate any further. The Healthwise decision aid informs patients that both options increase infection risks. However, it does not associate peritonitis risk with any specific activities, such as swimming in public pools or soaking in bathtubs. This is the only of the three instruments, which offers patients the option to review testimonials of real-life patients. The interactive Healthwise decision aid is an online instrument containing tabs for general disease and treatment information, head-to-head option comparison, and patient values clarification. The Healthwise instrument does not utilize any pictures to facilitate the comprehension of the reading material. Even though this decision aid does not provide evidence references, it gives the names of the primary and specialist medical reviewers and openly displays the most recent revision date.

Chronic Kidney Disease Option Grid

This online instrument takes the form of an option grid, where all of the gathered information is presented in a single table. Some studies find that such tabular formats are effective when used for direct comparisons of the available alternatives (Carrigan, Gardner et al., 2004; Lalonde, O'Connor et al., 2004). The Option Grid instrument was created in collaboration with Professor Glyn Elwyn who led the consortium that developed the recognized IPDAS criteria. This instrument, however, does not fit a patient decision aid definition because it simply lists treatment alternatives and neither assists in clarifying patient values nor guides a structured deliberation process. The Option Grid instrument compares three treatment choices, which are 1) peritoneal dialysis, 2) hemodialysis at the hospital, and 3) hemodialysis at home. Only this instrument reveals that peritoneal dialysis is capable of sparing the remaining kidney function, which allows patients to pass urine for a few more years. Additionally, the Option Grid previews two available hospital hemodialysis schedules, which typically involve three-day sets of Monday, Wednesday, and Friday or Tuesday, Thursday, and Saturday. The table takes a unique approach of describing how the impending treatments are expected to affect the existing work commitments. While peritoneal dialysis and hemodialysis at home may fit around patients' work rosters, hospital hemodialysis will dictate a set schedule. The Option Grid clarifies that while hospital hemodialysis does not have any equipment storage requirements, home hemodialysis needs water and electric

connections and peritoneal dialysis depends on monthly supply deliveries. The grid states that even though both hemodialysis and peritoneal dialysis require preliminary surgeries, a peritoneal catheter also necessitates a certain level of continuing cleaning. The Option Grid is the only instrument of the three sharing that it may be more difficult to switch from hemodialysis to peritoneal dialysis because the prolonged utilization of the former reduces the overall effectiveness of the latter. Finally, the Option Grid provides clear references to the evidence used in the document and reports the last as well as the upcoming revision dates.

DaVita Treatment Evaluator

The DaVita Treatment Evaluator is an interactive online tool emphasizing the alignment of patients' personal values with the most fitting alternatives. The Treatment Evaluator does not make an explicit effort to follow IPDAS criteria or provide references to the used evidence. The instrument utilizes simple language and accompanying photographs to facilitate comprehension of the presented material. The Treatment Evaluator abbreviates hemodialysis to just 'hemo' and lets users view the pictures of dialysis access sites. In addition to home hemo, in-center hemo, and peritoneal dialysis, the Treatment Evaluator introduces in-center nocturnal hemo and in-center self-care hemo as two other treatment options. This interactive aid asks patients simple preference questions, which can often be answered with 'yes' or 'no' answers. Some of the questions feature short additional explanations located at the bottom of each page. The DaVita Treatment Evaluator is the only of the three instruments, which explicates that sanitary requirements of peritoneal dialysis disallow patients to enjoy such water activities as swimming in public pools and lakes as well as soaking in bathtubs and hot tubs. Another unique piece of information of this particular tool reveals that home hemodialysis typically requires that a patient either trains or hires a volunteer to assist with treatment sessions. Finally, this instrument shares with users that some treatments offer more frequent or longer sessions, which closer mimics healthy kidney function and may improve the feeling of well-being between each treatment. It is unclear if this particular aid makes a specific effort to evaluate patients' treatment involvement desires; however, it explicitly asks patients to state their intentions to be involved in the treatment.

None of the three online decision instruments utilize such tools as the Control Preferences Scale or the Information Styles Questionnaire in order to pursue individualization

of the presented treatment information. Additionally, none of the three draw a complete picture of treatment features, which a patient seeking maximum amount of pertinent information could require. Finally, it is unknown if a decision-making theory was used to guide the design of either Healthwise or DaVita instruments as suggested by the team of UK researchers (Elwyn, Stiel et al., 2011).

APPENDIX E: OPTION INSTRUMENT

OPTION Observing patient involvement © March 2009

1. The clinician draws attention to an identified problem as one that requires a decision making process.

0 = No attempt to draw attention to a need for a decision making process (*there is no clarity about problems, or at least no clarity about the decisions to be taken about the problem or problems identified*).

1 = Very brief or perfunctory attempts to draw attention to the need to embark on a decision making process. 2 = Baseline skill level: Clinician draws attention to a problem that requires a decision making process.

3 = Clinician puts emphasis on the decision making process required.

4 = The skill is exhibited to a high standard (*e.g. supplementary explanations and evidence of patient recognizing the need to engage in the process of decision making*).

2. The clinician states that there is more than one way to deal with the identified problem ('equipoise').

0 = The clinician does not state that there is more than one way of managing problems. 1 = Perfunctory attempt to convey the existence of more than one option.

2 = Baseline skill level: Clinician conveys the sense that the options are valid and need to be considered in more depth. 3 = Explains 'equipoise' in more detail and that options have pros and cons that need to be considered.

4 = The clinician also explains 'why' choices are available (e.g. there is genuine professional uncertainty as to the 'best' way of managing the problem – clinical equipoise); the skill is exhibited to a high standard.

3. The clinician assesses patient's preferred approach to receiving information to assist decision making (e.g. discussion in consultations, read printed material, assess graphical data, use videotapes or other media).

0 = The behaviour is not observed.

1 = A minimal attempt is made to exhibit the behaviour.

2 = Baseline skill level: Clinician asks for patient's preferred method of receiving information.

3 = Doing this behaviour well (e.g. states that there are many ways in which information can be conveyed; provides reading for outside of consultation).

4 = Gives many examples of the types of information formats and media available for the patient, and then provides an opportunity for the patient to select their preferred method or methods.

4. The clinician lists 'options', which can include the choice of 'no action'.

0 = The behaviour is not observed (listing options is different from providing details about each option).

1 = Minimal or perfunctory attempt is made to list options.

2 = Baseline skill level: Clinician lists options as distinct possibilities that are available (e.g. using 'either / or' phrasing to describe the existence of options).

3 = Careful listing of all possible options, including the choice of taking no action, or deferring the decision. 4 = Clinician exhibited this behaviour to a high standard.

5. The clinician explains the pros and cons of options to the patient (taking 'no action' is an option).

0 = No explanation.

1 = The clinician fails to provide information about more than one option (according to the extent that each option is described). 2 = Baseline skill level: The clinician provides details about the pros and cons of the options.

3 = The behaviour is exhibited to a good standard.

4 = The skill is exhibited to a high standard (e.g. by description of options followed with discussion).

6. The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed.

0 = No attempt to ascertain patient's views about their expectations.

1 = Unskilled or perfunctory attempts to uncover patient's ideas or expectations about management.

2 = Baseline skill level: The clinician explicitly asks the patient what they expected (thought) about the actions required to manage the problem(s). Skilled clinicians are able to explore these expectations and ideas (using open ended questions, suggesting a range of common expectations, using pauses, being alert to verbal and physical cues and so on).

3 = This behaviour is exhibited and leads to supplementary questions to clarify expectations or ideas (e.g. exploration of expectations takes place). The behaviour is performed to a good standard.

4 = The behaviour is achieved to high standards and patient's views are discussed and addressed.

7. The clinician explores the patient's concerns (fears) about how problem(s) are to be managed.

0 = No attempt to ascertain patient's views about their fears or concerns.

1 = Unskilled or perfunctory attempts to uncover patient's fears or concerns about management.

2 = Baseline skill level: Clinician explicitly asks the patient to voice their fears or concerns about the possible actions required to manage the problem(s). Skilled clinicians are able to explore these fears and ideas (using open ended questions, suggesting a range of common fears, using pauses, being alert to verbal and physical cues and so on).

3 = Exhibits behaviour and leads to supplementary questions to clarify concerns.

4 = Achieved to high standards where patient's fears/concerns discussed and addressed.

8. The clinician checks that the patient has understood the information.

0 = No attempt to ascertain patient has understood the information.

1 = Perfunctory attempt to check patient has understood relevant information.

2 = Baseline skill level: Explicit question posed to the patient asking whether they had understood the information provided or obtained from other sources.

- 3 = The clinician explores nature of the patients understanding by using statements like: “I’d like to check that you have understood the information about the possible options. Would you like to let me know what you now understand about this issue?”
- 4 = The behaviour is observed and executed to a high standard.

9. The clinician offers the patient explicit opportunities to ask questions during decision making process.

- 0 = No attempt to offer opportunities to ask questions.
- 1 = Clinician provides pauses, or other opportunities for queries to be raised (e.g. appropriate pace within the discourse).
- 2 = Baseline skill level: Clinician explicitly asks patient to voice a question (e.g. “Do you have any questions?”).
- 3 = The clinician is more specific and asks the patient whether they have questions about the options and the management of the identified problem(s).
- 4 = The behaviour is observed and executed to a high standard. The clinician will allow time for the patient to respond and will check if there are any other or supplementary questions.

10. The clinician elicits the patient’s preferred level of involvement in decision making.

- 0 = No attempt made to clarify.
- 1 = Perfunctory or rushed attempt to elicit the patient’s preferred role (active or passive) in decision making.
- 2 = Baseline skill level: Clinician explicitly asks patient about their preferred role.
- 3 = Clinician provides further explanation and continues to assess patients role preference.
- 4 = Clinician asks this question in a way that is easy for patient to understand and which signals that the clinician is sensitive to the decisional responsibility that is being expected of the patient.

11. The clinician indicates the need for a decision making (or deferring) stage (how the decision is made is not evaluated – could be paternalistic. How the decision is made between the participants and who takes ‘control’ is not evaluated).

0 = The clinician does not clearly indicate that a time has come where a decision (or deferment) is required. 1 = Perfunctory or unclear attempt to indicate need for a decision making state.

2 = Baseline skill level: Clear statement such as, “Perhaps it’s time now to make a decision about what should be done.” 3 = Exhibiting this behavior to a good standard.

4 = Clinician that achieves this task to a high standard and will have signaled the transition from consideration of information and views to one of deliberation and closure.

12. The clinician indicates the need to review the decision (or deferment).

0 = No attempt to indicate a need to review or defer.

1 = Perfunctory (e.g. that the patient should be seen again) or rushed attempt.

2 = Baseline skill level: Clinician indicates that the patient should be seen again to re-consider the decision. 3 = The behaviour is performed to a good standard.

4 = The behaviour is observed and executed to a high standard (e.g. makes it very explicit and encourages this approach).

For psychometric data see: Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing M, Cheung WY, Grol R. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations*, 8: 34-42, 2005. **Acknowledgements:** Laurie Pencille and Lilisbeth Perestelo Pérez (Mayo Clinic, Rochester, MN, USA) who worked on improving this.

For further information:

Decision Laboratory

www.DecisionLaboratory.com

www.OptionInstrument.com

Cardiff University

Email: ElwynG@cardiff.ac.uk

APPENDIX F: DATA

Group	DMType	DCSTotal	DCSedSub	DCSInfSub	DCSuncSub	DCSq1	DCSq2	DCSq3	DCSq4	DCSq5	DCSq6	DCSq7	DCSq8	DCSq9	DCSq10	DCSq11	DCSq12	DCSq13	DCSq14	DCSq15	DCSq16
1	1	12.5	6.3	8.3	33.3	1	0	0	0	1	1	0	0	0	0	1	3	1	0	0	0
1	2	14.1	18.8	0.0	33.3	0	0	0	0	0	0	1	1	0	1	1	2	1	1	1	0
1	0	10.9	12.5	0.0	16.7	0	0	0	1	1	1	0	0	0	0	1	1	0	0	1	1
1	1	0.0	0.0	0.0	0.0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1	1	59.4	56.3	16.7	91.7	0	1	1	3	3	4	2	1	3	3	4	4	3	1	2	3
1	0	21.9	25.0	25.0	41.7	1	1	1	0	0	0	0	0	2	1	1	3	1	1	1	1
1	1	62.5	25.0	100.0	100.0	4	4	4	4	4	4	0	0	0	4	4	4	4	0	0	0
1	2	17.2	6.3	8.3	25.0	0	0	1	0	1	1	2	1	1	0	1	2	0	0	1	0
1	1	57.8	56.3	50.0	75.0	2	2	2	2	2	2	3	2	2	2	3	4	3	2	2	2
1	0	12.5	12.5	8.3	8.3	1	0	0	0	1	1	1	0	1	0	0	1	1	1	0	0
1	2	20.3	25.0	16.7	33.3	0	1	1	0	0	0	1	0	2	2	1	1	1	1	1	1
1	0	10.9	12.5	16.7	8.3	0	1	1	0	1	1	0	0	0	0	1	1	1	0	0	1
1	0	21.9	25.0	0.0	41.7	0	0	0	0	0	0	0	3	2	3	1	1	1	1	0	2
1	1	29.7	18.8	0.0	66.7	0	0	0	1	1	2	1	2	1	2	2	4	1	0	0	2
1	1	15.6	0.0	33.3	16.7	0	2	2	2	2	0	0	0	0	0	0	2	0	0	0	0
1	1	40.6	81.3	0.0	58.3	0	0	0	1	1	0	1	2	1	1	3	3	3	3	3	4
1	1	17.2	25.0	8.3	16.7	0	1	0	1	1	0	1	0	1	1	1	0	1	0	1	2
1	1	18.8	18.8	8.3	33.3	1	0	0	0	1	0	1	1	1	1	1	2	1	1	1	0
1	2	18.8	18.8	0.0	33.3	0	0	0	1	0	2	0	1	1	2	2	0	0	1	1	1
1	2	14.1	6.3	25.0	25.0	1	0	2	1	0	0	1	0	0	1	1	1	0	0	1	0
1	1	10.9	0.0	0.0	25.0	0	0	0	1	2	1	0	0	0	0	0	3	0	0	0	0
1	1	23.4	25.0	25.0	33.3	1	0	2	1	1	1	0	1	0	2	1	1	0	2	1	1
1	1	20.3	25.0	0.0	33.3	0	0	0	2	1	1	0	0	1	1	1	2	1	1	1	1
1	1	3.1	0.0	0.0	0.0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
1	2	34.4	37.5	41.7	75.0	2	2	1	1	0	1	0	0	0	2	3	4	1	2	1	2
1	1	18.8	25.0	16.7	33.3	2	0	0	0	0	1	0	0	1	1	1	2	1	1	1	1
1	1	34.4	43.8	66.7	33.3	4	1	3	0	0	0	0	0	3	2	2	0	1	2	2	2
1	1	17.2	0.0	41.7	33.3	2	1	2	0	0	0	2	0	0	0	0	4	0	0	0	0
1	1	6.3	12.5	8.3	0.0	0	0	1	1	0	0	0	0	0	0	0	0	2	0	0	0
0	0	75.0	68.8	100.0	66.7	4	4	4	3	2	3	2	4	3	2	2	4	3	3	1	4
0	1	39.1	37.5	33.3	58.3	1	2	1	2	1	1	1	1	2	2	2	3	2	1	1	2
0	2	84.4	81.3	100.0	83.3	4	4	4	3	3	2	4	3	4	3	3	4	3	3	3	4
0	2	100.0	100.0	100.0	100.0	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
0	1	37.5	25.0	8.3	91.7	1	0	0	0	0	1	2	2	3	4	3	4	1	2	0	1
0	1	32.8	50.0	25.0	25.0	0	1	2	1	0	3	2	1	0	0	1	2	3	2	1	2
0	1	17.2	18.8	0.0	33.3	0	0	0	2	1	0	0	0	1	2	1	1	0	1	1	1
0	0	71.9	50.0	100.0	50.0	4	4	4	4	4	4	4	2	2	2	2	2	2	2	2	2
0	1	7.8	0.0	0.0	25.0	0	0	0	1	0	0	0	0	1	1	1	1	0	0	0	0
0	2	84.4	81.3	75.0	100.0	3	3	3	4	2	3	4	4	3	4	4	4	3	3	3	4
0	2	79.7	81.3	83.3	75.0	4	3	3	3	3	4	3	4	2	2	4	3	4	3	3	3
0	1	57.8	43.8	50.0	75.0	0	4	2	2	2	2	2	4	3	3	2	4	2	2	1	2
0	1	42.2	43.8	33.3	41.7	2	1	1	1	1	2	1	4	2	2	1	2	2	2	1	2
0	1	39.1	25.0	33.3	66.7	0	0	4	1	2	2	1	1	2	2	2	4	1	1	0	2
0	0	82.8	81.3	91.7	66.7	3	4	4	4	3	3	3	4	4	2	3	3	4	3	3	3
0	1	20.3	18.8	25.0	25.0	1	1	1	0	1	0	2	1	0	1	0	2	1	1	1	0
0	1	17.2	25.0	0.0	33.3	0	0	0	0	0	0	0	2	1	1	3	0	1	1	2	0
0	1	9.4	18.8	0.0	16.7	0	0	0	0	0	0	0	0	1	1	1	0	1	0	1	1
0	2	54.7	43.8	50.0	91.7	2	2	2	3	2	2	1	0	3	4	3	4	2	2	2	1
0	1	12.5	6.3	8.3	16.7	1	0	0	0	0	0	1	2	1	1	1	0	0	0	1	0
0	2	64.1	50.0	50.0	83.3	1	2	3	4	4	4	1	1	3	3	3	4	2	2	2	2
0	1	18.8	0.0	16.7	41.7	0	1	1	0	1	1	2	0	1	3	1	1	0	0	0	0
0	1	14.1	18.8	25.0	16.7	1	1	1	0	0	0	0	0	1	1	1	0	1	2	0	0
0	1	34.4	25.0	25.0	50.0	1	1	1	2	1	1	2	1	2	1	2	3	1	1	1	1
0	2	68.8	43.8	58.3	100.0	1	3	3	4	4	3	2	3	2	4	4	4	2	2	1	2
0	0	59.4	62.5	41.7	75.0	2	1	2	2	2	2	3	2	3	2	3	4	4	4	1	1
0	1	14.1	12.5	8.3	0.0	1	0	0	1	1	1	0	3	0	0	0	0	0	0	1	1
0	1	25.0	43.8	0.0	66.7	0	0	0	1	0	0	0	0	0	2	2	4	2	3	0	2

Figure 20. Decisional Conflict Scale Data for All Patient Types

Group	DMType	DCSTotal	DCSedSub	DCSinfSub	DCSuncSub	DCSq1	DCSq2	DCSq3	DCSq4	DCSq5	DCSq6	DCSq7	DCSq8	DCSq9	DCSq10	DCSq11	DCSq12	DCSq13	DCSq14	DCSq15	DCSq16
1	0	10.9	12.5	0.0	16.7	0	0	0	1	1	1	0	0	0	0	1	1	0	0	1	1
1	0	21.9	25.0	25.0	41.7	1	1	1	0	0	0	0	0	2	1	1	3	1	1	1	1
1	0	12.5	12.5	8.3	8.3	1	0	0	0	1	1	1	0	1	0	0	1	1	1	0	0
1	0	10.9	12.5	16.7	8.3	0	1	1	0	1	1	0	0	0	0	1	1	1	0	0	1
1	0	21.9	25.0	0.0	41.7	0	0	0	0	0	0	0	3	2	3	1	1	1	1	0	2
0	0	75.0	68.8	100.0	66.7	4	4	4	3	2	3	2	4	3	2	2	4	3	3	1	4
0	0	71.9	50.0	100.0	50.0	4	4	4	4	4	4	4	2	2	2	2	2	2	2	2	2
0	0	82.8	81.3	91.7	66.7	3	4	4	4	3	3	3	4	4	2	3	3	3	4	3	3
0	0	59.4	62.5	41.7	75.0	2	1	2	2	2	2	3	2	3	2	3	4	4	4	1	1

Figure 21. Decisional Conflict Scale Data for Informative Patient Type

Group	DMType	DCSTotal	DCSedSub	DCSinfSub	DCSuncSub	DCSq1	DCSq2	DCSq3	DCSq4	DCSq5	DCSq6	DCSq7	DCSq8	DCSq9	DCSq10	DCSq11	DCSq12	DCSq13	DCSq14	DCSq15	DCSq16
1	1	12.5	6.3	8.3	33.3	1	0	0	0	1	1	0	0	0	0	1	3	1	0	0	0
1	1	0.0	0.0	0.0	0.0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1	1	59.4	56.3	16.7	91.7	0	1	1	3	3	4	2	1	3	3	4	4	3	1	2	3
1	1	62.5	25.0	100.0	100.0	4	4	4	4	4	4	0	0	0	4	4	4	4	0	0	0
1	1	57.8	56.3	50.0	75.0	2	2	2	2	2	2	3	2	2	2	3	4	3	2	2	2
1	1	29.7	18.8	0.0	66.7	0	0	0	1	1	2	1	2	1	2	2	4	1	0	0	2
1	1	15.6	0.0	33.3	16.7	0	2	2	2	2	0	0	0	0	0	0	2	0	0	0	0
1	1	40.6	81.3	0.0	58.3	0	0	0	1	1	0	1	2	1	1	3	3	3	3	3	4
1	1	17.2	25.0	8.3	16.7	0	1	0	1	1	0	1	0	1	1	1	0	1	0	1	2
1	1	18.8	18.8	8.3	33.3	1	0	0	1	0	1	0	1	1	1	1	2	1	1	1	0
1	1	10.9	0.0	0.0	25.0	0	0	0	1	2	1	0	0	0	0	0	3	0	0	0	0
1	1	23.4	25.0	25.0	33.3	1	0	2	1	1	1	0	1	0	2	1	1	0	2	1	1
1	1	20.3	25.0	0.0	33.3	0	0	0	2	1	1	0	0	1	1	1	2	1	1	1	1
1	1	3.1	0.0	0.0	0.0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
1	1	18.8	25.0	16.7	33.3	2	0	0	0	0	1	0	0	1	1	1	2	1	1	1	1
1	1	34.4	43.8	66.7	33.3	4	1	3	0	0	0	0	0	3	2	2	0	1	2	2	2
1	1	17.2	0.0	41.7	33.3	2	1	2	0	0	0	2	0	0	0	0	4	0	0	0	0
1	1	6.3	12.5	8.3	0.0	0	0	1	1	0	0	0	0	0	0	0	0	2	0	0	0
0	1	39.1	37.5	33.3	58.3	1	2	1	2	1	1	1	2	2	2	2	3	2	1	1	2
0	1	37.5	25.0	8.3	91.7	1	0	0	0	0	1	2	2	3	4	3	4	1	2	0	1
0	1	32.8	50.0	25.0	25.0	0	1	2	1	0	3	2	1	0	0	1	2	3	2	1	2
0	1	17.2	18.8	0.0	33.3	0	0	0	2	1	0	0	0	1	2	1	1	0	1	1	1
0	1	7.8	0.0	0.0	25.0	0	0	0	1	0	0	0	0	1	1	1	1	0	0	0	0
0	1	57.8	43.8	50.0	75.0	0	4	2	2	2	2	2	4	3	3	2	4	2	2	1	2
0	1	42.2	43.8	33.3	41.7	2	1	1	1	1	2	1	4	2	2	1	2	2	2	1	2
0	1	39.1	25.0	33.3	66.7	0	0	4	1	2	2	1	1	2	2	2	4	1	1	0	2
0	1	20.3	18.8	25.0	25.0	1	1	1	0	1	0	2	1	0	1	0	2	1	1	1	0
0	1	17.2	25.0	0.0	33.3	0	0	0	0	0	0	0	2	1	1	3	0	1	1	2	0
0	1	9.4	18.8	0.0	16.7	0	0	0	0	0	0	0	0	1	1	1	0	1	0	1	1
0	1	12.5	6.3	8.3	16.7	1	0	0	0	0	0	1	2	1	1	1	0	0	0	1	0
0	1	18.8	0.0	16.7	41.7	0	1	1	0	1	1	2	0	1	3	1	1	0	0	0	0
0	1	14.1	18.8	25.0	16.7	1	1	1	0	0	0	0	0	1	1	1	0	1	2	0	0
0	1	34.4	25.0	25.0	50.0	1	1	1	2	1	1	2	1	2	1	2	3	1	1	1	1
0	1	14.1	12.5	8.3	0.0	1	0	0	1	1	1	0	3	0	0	0	0	0	0	1	1
0	1	25.0	43.8	0.0	66.7	0	0	0	1	0	0	0	0	0	2	2	4	2	3	0	2

Figure 22. Decisional Conflict Scale Data for Collaborative Patient Type

Group	DMType	DCSTotal	DCSedSub	DCSinfSub	DCSuncSub	DCSq1	DCSq2	DCSq3	DCSq4	DCSq5	DCSq6	DCSq7	DCSq8	DCSq9	DCSq10	DCSq11	DCSq12	DCSq13	DCSq14	DCSq15	DCSq16
1	2	14.1	18.8	0.0	33.3	0	0	0	0	0	0	1	1	0	1	1	2	1	1	1	0
1	2	17.2	6.3	8.3	25.0	0	0	1	0	1	1	2	1	1	0	1	2	0	0	1	0
1	2	20.3	25.0	16.7	33.3	0	1	1	0	0	0	1	0	2	2	1	1	1	1	1	1
1	2	18.8	18.8	0.0	33.3	0	0	0	1	0	2	0	1	1	2	2	0	0	1	1	1
1	2	14.1	6.3	25.0	25.0	1	0	2	1	0	0	1	0	0	1	1	1	0	0	1	0
1	2	34.4	37.5	41.7	75.0	2	2	1	1	0	1	0	0	0	2	3	4	1	2	1	2
0	2	84.4	81.3	100.0	83.3	4	4	4	3	3	2	4	3	4	3	3	4	3	3	3	4
0	2	100.0	100.0	100.0	100.0	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
0	2	84.4	81.3	75.0	100.0	3	3	3	4	2	3	4	4	3	4	4	4	3	3	3	4
0	2	79.7	81.3	83.3	75.0	4	3	3	3	3	4	3	4	2	2	4	3	4	3	3	3
0	2	54.7	43.8	50.0	91.7	2	2	2	3	2	2	1	0	3	4	3	4	2	2	2	1
0	2	64.1	50.0	50.0	83.3	1	2	3	4	4	4	1	1	3	3	3	4	2	2	2	2
0	2	68.8	43.8	58.3	100.0	1	3	3	4	4	3	2	3	2	4	4	4	2	2	1	2

Figure 23. Decisional Conflict Scale Data for Paternalistic Patient Type

APPENDIX G: INSTRUMENT SCREENSHOTS

Adaptation Exercise

Think back to one emotionally difficult life experience that happened to you at least 6 months ago (e.g. divorce, death of a loved one, setback in school or work). Immediately after this emotionally difficult experience, you probably felt pretty awful. But think about how you felt six months after the event.

At the end of those six months, how did you feel compared to what you would have predicted immediately after it happened?

- I felt *much worse* than I would have predicted.
- I felt *about the same* as I would have predicted.
- I felt *much better* than I would have predicted.

Compared to the first few weeks after the event, how strong were your emotions six months later?

- Much stronger* than before.
- About the same* as before.
- Much weaker* than before.

When you imagine what it would be like to be on dialysis, do you think it would become more or less upsetting over time?

- Much more* upsetting over time.
- Equally as* upsetting over time.
- Much less* upsetting over time.

Answer

Anonymous Demographics Data

Have you ever had to use patient decision aid for selecting a medical treatment?

- Yes
- No

What is your gender?

- Male
- Female

What is your highest level of education?

What is your age?

Answer

Introductions to Role Playing and Scenario Objectives

Role Playing

Role playing is a technique used to study human behavior patterns in particular settings. Role playing allows for creation of an experimental atmosphere without exposing the participants to the apparent risks of some real-life situations. Analysis of role playing data enables suggestions for new corrective actions prior to the actual human interaction.

Study Purpose

The purpose of this exercise is to learn about computer assisted clinical decision-making processes. Your participation in this study will help to improve future patient decision aids. We hope that such decision instruments will guide patients during complex treatment selection processes. Your participation in this study will serve an important purpose and is much appreciated!

Your Objective

Imagine that you are a patient with kidney failure. Your objective is to choose between two available treatment options. Both options are medically identical. However, one of them may be more fitting to you as an individual.

Begin Exercise

The entire exercise will be anywhere between 15 and 30 minutes in length at the end of which your opinions will be collected. Click on the button "Next" at the bottom of this page in order to begin.

Next

- Dialysis is a process that does the work of healthy kidneys when you have kidney failure.
- Dialysis filters wastes, removes extra fluid, and restores the proper balance of chemicals in the blood.
- There are two basic types of dialysis: hemodialysis and peritoneal dialysis.
- Dialysis can help you feel better and live longer, but it is not a cure for kidney failure. After you start dialysis, you will need to keep doing it to stay as healthy as possible.

What is involved?

Hemodialysis


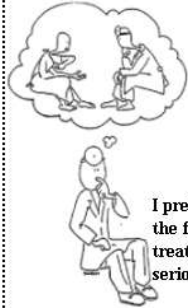
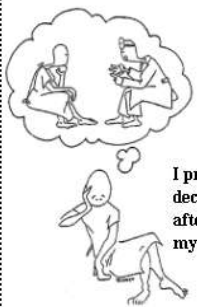


- Before hemodialysis treatments can begin, your doctor will need to create a site where blood can flow in and out of your body.
- Hemodialysis uses a man-made membrane called a dialyzer to clean your blood. You are connected to the dialyzer by tubes attached to your blood vessels.
- You will probably go to a hospital or dialysis center on a fairly set schedule. Hemodialysis usually is done 3 days a week and takes 3 to 5 hours a day.
- In some cases, hemodialysis can be done at home.

Peritoneal dialysis

- You will have a catheter placed in your belly (dialysis access) before you begin dialysis.
- Peritoneal dialysis uses the lining of your belly, which is called the peritoneal membrane, to filter your blood.
- The process of doing peritoneal dialysis is called an exchange. You will usually complete 4 to 6 exchanges every day.
- You will be taught how to do your treatment at home, on your own schedule.

Next

**In terms of making decisions about your health care with your doctor,
which one of the following best describes how you would like to make decisions?**

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

What are the benefits?

What are the risks and side effects?

Hemodialysis

- It is most often done by trained health professionals who can watch for any problems.

- It causes you to feel tired on the day of the treatments.

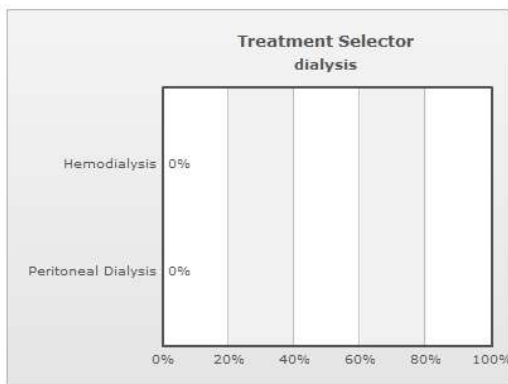
Peritoneal dialysis

- It gives you more freedom than hemodialysis.
- It can be done at home or in any clean place.

- The procedure may be hard for some people to do.

Would you like to continue reviewing information?

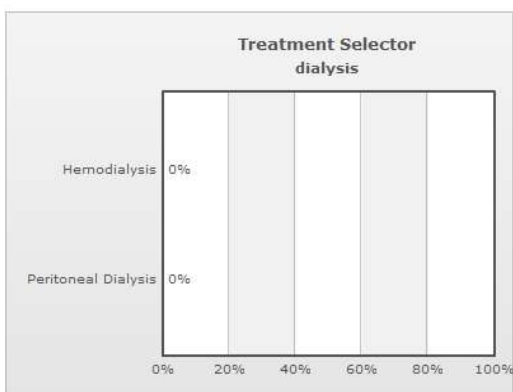
Yes No



I feel more comfortable having professionals handle the procedure.

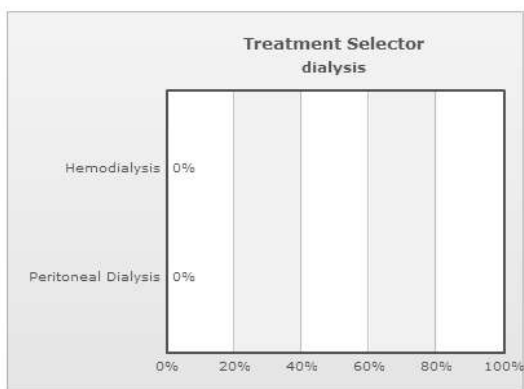
Note: Hemodialysis is most often done by trained health professionals who can watch for any problems. You can do peritoneal dialysis by yourself.

True False



Are you physically active?

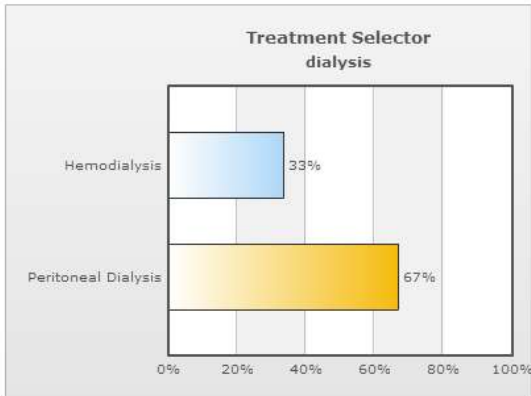
Yes No



Would you like to continue answering questions?

Note: There are 2 questions remaining

Yes No



System recommends Peritoneal dialysis.

Next

Which form of dialysis do you prefer?

- Hemodialysis
- Peritoneal Dialysis
- Unsure

Considering the option you prefer, please answer the following questions:

	Yes [0]	Probably yes [1]	Unsure [2]	Probably no [3]	No [4]
1. Do you know which options are available to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Do you know the benefits of each option?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Do you know the risks and side effects of each option?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Are you clear about which benefits matter most to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Are you clear about which risks and side effects matter most to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Are you clear about which is more important to you (the benefits or the risks and side effects)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Do you have enough support from others to make a choice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Are you choosing without pressure from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Do you have enough advice to make a choice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Are you clear about the best choice for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Do you feel sure about what to choose?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Is this decision easy for you to make?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Do you feel you have made an informed choice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Does your decision show what is important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Do you expect to stick with your decision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Are you satisfied with your decision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Send Answers