Primary care patients’ preferred roles in treatment decision-making in an era of increased health information

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Institute of Health Policy Management and Evaluation

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Primary care patients’ preferred roles in treatment decision-making in an era of increased health information: implications for patients, practitioners, policy-makers

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Abstract

**Background:** Patient engagement has become a priority for health care providers. This study examined primary care patients’ preferred roles in health care decision-making in an era of increased health information and how these preferences related to perceived health information literacy and trust in their physician.

**Methods:** This research applied a multi-methods design. The first phase involved quantitative surveys in a primary care clinic (N=141); the surveys examined patients’ preferred roles, perceived health information literacy, trust in the physician, and demographic variables. The second phase involved follow-up with semi-structured interviews with a subgroup of these patients (N=11). Preferred roles were measured for two vignettes: ‘current health condition’ and ‘chest pain’. T-tests compared the perceived health information literacy and trust in physician scores between shared and passive patients. A binary logistic regression was computed to see whether trust in physician and perceived health information literacy could predict patients’ preferred roles. Thematic analysis was done for qualitative interviews.
**Results:** The results of this research showed that most patients surveyed preferred a shared role, had a high level of perceived health information literacy, and had high levels of trust in their physician. Patients who preferred a shared role had a higher mean perceived health information literacy compared to those who preferred a passive role. Results of the binary logistic regression showed that trust in the physician was the only variable that predicted patients’ preferred roles for the chest pain and current health condition vignettes. Qualitative themes included: frequency of website use, patients’ preferred roles & factors that influence them, factors that influence the patient-physician relationship, and patients’ preferred forms of communication.

**Conclusion:** The findings of this research showed that even in this sample of highly educated patients with high levels of perceived health information literacy, most patients preferred a shared role. Almost none wanted an autonomous role. Trust in the physician was significantly associated with patients’ preferred roles in this sample of patients that had high levels of trust in their doctor.
Acknowledgements:

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“Wherever the art of the medicine is loved, there is also a love for humanity. The wise person considers health to be one of the greatest of human blessings.”

~Hippocrates
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List of Abbreviations:

- Problem-Solving: (PS)
- Decision-Making (DM)
- Problem-Solving and Decision-making (PSDM)
- e-Heals (e-Health literacy)
CHAPTER 1: BACKGROUND, DEFINITIONS, OBJECTIVES

1.1 Real-world research problem and thesis outline

This dissertation examined primary care patients’ preferred roles in their health care decisions. Patient engagement has attracted considerable attention in recent years. Although previous research has found that most patients wanted to collaborate with their physician in their health care decisions, it is important to see whether these preferences have changed given the increased availability of online health information. This research considers potential relationships between patients’ perceived health information literacy, trust in the physician, and their preferred roles in treatment decision-making. A better understanding of the relationships between these variables and patients’ preferred roles is helpful to those planning patient engagement initiatives to ensure that activities are suited to the needs of patients.

The thesis consists of the following five chapters:

- **Chapter 1** describes a brief outline of the thesis, and then gives a definition of person-centered care and the various levels of patient engagement. It provides the hypothesis and research questions.

- **Chapter 2** provides a description of the theoretical framework related to patient engagement with a focus on the direct care level of the Carman et al. framework. It describes the key variables that are examined in this dissertation, which include patients’ preferred roles, their perceived health information literacy, their trust in the physician, and demographic variables such as age, gender, marital status, highest level of completed education, and ethnicity. It includes a review of the literature on patients’ preferred roles and perceived health information literacy.
Chapter 3 provides a description of the methods used for this thesis dissertation. This dissertation applied a multi-methods approach. This chapter describes the primary care population at St. Michael’s Hospital in Toronto, Canada, where the study was conducted. It also provides information about the scales used and the data collection and analysis process for the quantitative surveys and qualitative interviews.

Chapter 4 describes the findings from the quantitative surveys and the results of the thematic analysis from the qualitative interviews.

Chapter 5 provides the discussion, limitations, suggestions for future research, and conclusions of this thesis.

Why is this research important?

There is a focus on patient-centered care and patient engagement in the health care system. This thesis is focused on the primary care setting in Ontario. In primary care settings, patients may have a variety of health conditions. In Ontario, 94% of patients have a regular primary health care provider, which they can visit for their ongoing health care. (1) However, the particular primary care population in this thesis may or may not be typical of all Ontario primary care patients.

This study examined patients’ preferred roles, perceived health information literacy, and trust in the physician. With the increased availability of health information online, it is important to see if patients’ preferred roles have changed with the availability of increased health information. The term “Doctor Google” is sometimes used to refer to patients using the Internet to diagnose their own conditions and determine what treatments they should receive. As will be noted in section 2.2, a number of authors have suggested that this should be the new preferred model. (2, 3) Others are concerned that this increases the likelihood of patients not receiving accurate
There is also a middle ground where patients are encouraged to work with health care teams; one example is the Chronic Care Model. This research will help add to the knowledge about what role patients wish to take in making treatment decisions.

1.2 Background: The context of patient engagement

Understanding the extent to which patients want to participate in their health care decisions is an important feature of a high quality, patient-centered health care system. There have been multiple system-wide attempts to integrate the patients’ perspective in health care decisions. For example, in the Canadian province of Ontario, many health care organizations are conducting patient engagement activities. However, it is not always clear if these patient engagement activities match patients’ needs and preferences.

Patient-centered care, which includes patient values and preferences, has been explored by the scientific community for many years. Balint acknowledged the importance of communication and patient-clinician relationships and Engel noted that illness (as opposed to disease) has biological, psychological, and social dimensions. The book *Patient-centered medicine: transforming the clinical method* includes a comprehensive set of principles for patient centered care. More recently, understanding patients’ preferred roles has considered two possible options: paternalism (where the physician knows best), and autonomous (where the patient knows best). Research by Carter and Entwistle explored concepts of social interactions between patients and physicians to consider the idea of paternalism in medicine. More recent approaches to patient engagement focus on a shared and collaborative approach and reflect a change from the paternalistic model. Research by Charles et al. has shown that patient-physician partnerships open up options beyond paternalism for approaching the task of treatment.
decisions. Researchers defined a partner as, “a person who shares or takes part with another or others.” The concept of partnership and involving patients implies that both the doctor and the patient should share in the decision making process. (14) A consideration of partnership and patients’ preferred roles is central to this thesis. With the availability of increased health information online and easy access to this health information, this thesis examined whether patients’ preferred roles have changed over time.

At the clinical level, as new technology has improved, patients may bring additional information to their medical appointment that is related to their health condition or selected treatment option. (15) The literature has suggested that patients can (and should) be informed about their health condition and review their treatment options online. (16) For example, patients can now use their iPhone to ask the Google What’s App text messaging application to search for more information about their diagnosis. This application asks the patient questions and then dispenses advice on possible next steps. (17) Accordingly, this tool may challenge the expert advice of health care provider(s). Furthermore, when patients have additional knowledge of treatment options, this may also change the nature of the interaction between patients and their care providers; for example, patients may ask more questions of their health care providers or come better prepared to the clinical appointment. (18) It is important to understand patients’ preferences in order to tailor patient engagement activities to suit these preferences.

There are many implications for patients’ preferred roles. These implications include better knowledge and understanding that the physician has on the roles that patients prefer in their health care decisions. For example, Palma, an oncologist, has advocated for a patient-centered approach, where patients should take charge of their own health condition, read their
medical records, and gain increasing levels of autonomy for managing serious conditions such as cancer. (19) Patients may also have various preferred roles when visiting their health care providers. These roles may include: passive, shared, and autonomous roles. For example, in a book by Goetz the author discusses options and approaches for treating health care conditions. Patients and families have increased access to information and knowledge when they read books such as the one by Goetz. (20) This may then impact their preferred roles when interacting with their health care provider.

1.3 Definition of patient-centered care

There is an extensive literature on patient-centered care, which uses multiple terms, including: person centered care, shared decision making, and patient engagement. (21-23) This dissertation builds on the definition by the Institute of Medicine;

“Providing care that is respectful and responsive of individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. (24)”

In this definition, patient engagement is a part of patient-centered care. A related definition by Entwistle et. al focuses on ensuring that care is “person-centered”, which they defined as, “care that recognizes and cultivates the capabilities associated with the concepts of persons.” This allows care to be applicable to a diverse patient population and various different vignettes. In this definition of person-centered care, patient engagement is required for positive contributions towards an individual’s health. (25) This thesis dissertation focuses on three key variables: patients’ preferred roles, perceived health information literacy, and trust in the physician. The definitions of problem-solving and shared decision-making are discussed in sections 2.2 to 2.4. of the thesis.
### 1.4 Levels of patient engagement: macro, meso, and micro and Carman et. al framework

A number of frameworks have been developed to examine patient engagement. They recognize that there are multiple meanings of the term. When engaging patients, a consideration of the level of engagement is central to successful engagement efforts. For example, the Saskatchewan Health Quality Council divides patient engagement into following levels: macro, meso, and micro. (26) Although these levels are not always distinct (depending on whether patients are being involved within individual organizations or within larger units), macro level patient engagement entails considering health policy, including how it interfaces with other policy questions. Meso level engagement refers to health organizations, such as how to improve care pathways. Micro level engagement is at the patient and physician level in the clinical encounter. This thesis focuses on the micro or direct care level.

Examples of macro and meso level engagement include involving citizen deliberations in the health technology assessment process, (27) or involving patients in health services research planning. (28) A similar model was created by Carman et al. They proposed three ‘levels of engagement’: direct level, organizational and design level, and policy making level. At the direct care, micro-level, patients interact directly with their health care provider. At the organizational and health care management level, or meso-level, patients may form advisory councils to help inform system development. At the policy-making level or macro-level, patients may form advisory councils with government decision-makers to provide agencies with patient-centered decisions regarding health care quality through their experiences. (29)
In Carman’s model, each level involves three elements, which they term consultation, involvement, and partnership. This framework and the direct care level will be further described in section 2.1.

1.5 Patients’ preferred roles

As noted above, some analyses of patients’ preferred roles consider only two possible options: paternalism (where the physician knows best), and autonomous (where the patient knows best). The recent focus on patient engagement reflects in part a change towards a shared or collaborative approach as compared to the paternalistic model.

A related approach disaggregates these roles to consider two dimensions in health-related decisions at the micro level, which they termed problem-solving (PS) and decision-making (DM). PS tasks are defined as being preference independent; they relate to the factual information of a clinical situation and its potential treatments. In contrast, DM tasks must also deal with patients’ preferences, including such issues as views about the importance (and benefits) of particular outcomes, and attitudes about risk. PS tasks include: suggesting likely diagnoses; identifying proposed treatments and their risks and benefits; and identifying potential outcomes of these various treatment options. DM tasks would thus consider whether these outcomes would matter most to patients. For example, when deciding between a surgical or medical treatment options, patients may consider and apply the clinical evidence but then also incorporate their own perspectives about various risks vs. benefit tradeoffs, and the importance that they attach to particular treatment outcomes. Further information about PS and DM are provided in section 2.2 to section 2.4 of the thesis.
There are several implications for separating the problem-solving and decision-making (PSDM) tasks. For example, when researchers separate these tasks, it is valuable for both the patient and clinician to understand the associated responsibilities within the PS and DM tasks. Patients’ preferred roles may also impact the type of care that they receive. For example, if a physician knows that the patients prefer more of an autonomous, shared, or passive role, the type of care they receive might be impacted by the physician’s knowledge of their patients’ preferences.

As will be noted in section 3.6.2 and Table 3.1, the PSDM scale can be used to measure preferences for preferred role in PS and DM tasks, and to divide people into three major categories: autonomous, shared, and passive (12). Passive patients wish to hand off both the PS and DM tasks when working with their health care provider. If a patient wants to hand off or share PS but share or keep DM, then they prefer a shared role. Autonomous patients want to have control of PS and either share or keep DM. Based on their scores on the PSDM, patients were placed into a preferred role category as seen in Table 3.1. The categories are: passive; shared [which can be sub-classified into leaning passive, divide and share, equally, or leaning autonomous]; or autonomous [which can be sub-classified into leaning shared, consumerist]. Table 3.1 defines each of these roles in further detail.

Previous research had shown that most people preferred either a passive or shared role. (30) With the increased availability of health information online, patients have access to more medical information and can gain more knowledge about their health condition. This dissertation seeks to understand whether the relationship between patients’ preferred roles, perceived health
information literacy scores, and the trust that they have in their physician has changed since this previous research.

1.6 Perceived health information literacy

Another key variable analyzed in this dissertation is health information literacy. There are two types of literacy discussed in the literature: health literacy, and health information literacy (which is sometimes referred to as e-health literacy). In 1999, the American Medical Association’s ad hoc committee defined health literacy as, “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in a health care environment. (31)” As seen in this definition, health literacy focuses on people’s skill and ability required by patients to make a health-related decision and this is not confined to electronic sources of health information. Health literacy is focused on the health of patients. The health literacy level of patients is central to consider when selecting decision aids. Some literature suggests that the average patient reads at the grade 6 elementary level, while most of the online health care information is written at the college (or undergraduate studies in Canada) level. (32)

Health information literacy, which is often referred to as e-health literacy, has been defined by the American Medical Library Association as, “the set of abilities needed to: recognize a health information need; identify likely sources of information and use them to retrieve relevant information; assess the quality of the information, and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions. (33)” Central to health information literacy is the “information” component and how people search for, retrieve, and evaluate the available health information resources. (34) Norman and Skinner defined e-health literacy as a set of skills required to effectively engage information
technology for health. (35)

This thesis focuses on perceived health information literacy, rather than health information literacy. Patients’ perceived health information literacy was measured using the e-HEALs scale, which is a subjective, self-reported measure. Further information on health information literacy and the e-HEALs scale that was applied in this thesis, and the levels of perceived health information literacy are described in section 2.3.

Other variables were also important to consider in this research. Several demographic factors and their influence on trust formation in Web-based health information seeking behaviours were explored. For example, Sbaffi et al. found that although that there was variation across studies, women, people with higher education level, people with higher income and younger people tended to use the internet more. (36) In another study, authors examined how the expertise of online information sources was established by readers of these sources. They also examined how this influenced the perceived credibility of the online information. (37) Results showed that those who sought online health information were aware of author’s credentials and perceived authors with medical credentials to have a higher level of expertise and their information was seen as more credible.

The credibility of the health information, as evaluated by the authors and organization listed on the website, was central to participants’ trust in that particular source of health information. In the literature, there has been much research on credibility of health information. For example, in a comprehensive literature review that examined appropriate terminology, criteria, and implementation, authors found that a common term, credibility, was used. (36) In a systematic review by Sbaffi et al., authors looked for empirical studies on trust and credibility in
the use of web-based health information. Key factors that they found increased credibility included the following: website design, clear layout, interactive features, and authority of the owner. Including advertising on the website had a negative influence on credibility.

Perceived self-efficacy is concerned with judgements of how well one can execute courses of action required to deal with prospective situations. In the field of psychology, there has been a move from one larger concept of self-efficacy to multiple self-efficacies that can impact patients’ preferred roles. Perceived health information literacy can be viewed as a specific type of efficacy. For example, if a person believes that he or she can find information, understand and appraise it, they might be more likely to prefer an autonomous role.

One key facilitator of shared decision-making is ensuring that patients have access to the necessary information that is required. Within the literature, there is a wide variety of information on decision aids and patient-centered resources. This concept is linked to health literacy because it is vital that health decision aids are suited to the literacy levels of patients. An example of an intervention or initiative to promote shared decision-making is the Ask Share Now program. In another study, researchers tested the feasibility, uptake, and acceptability of a consumer program, Ask Share Know, to encourage consumers to ask three questions: 1) What are my options? 2) What are the possible benefits and harms of those options? 3) How likely are each of those benefits and harms to happen to me? These three questions have been shown to have important effects on the quality of information provided during a consultation and in facilitating patient involvement. (54)

A follow-up cross-over trial showed that asking these questions improved information given by the family physicians and increased physician facilitation of patient involvement. In
terms of practice implications, these questions can help drive evidence-based practice, improve safety and quality of care, and strengthen patient-physician communication. (54) This is one example of a communication tool from the scientific literature that has enabled shared decision-making between patients and health care providers. Other literature has focused on tools to promote shared decision-making. A systematic review that focused on decision aids found several clinical trials of decision tools. Examples of these tools were for palliative care, goals of care communication, and feeding options available for those who have dementia. These evidence-based tools can be used by clinicians to engage patients with serious conditions in the process of shared decision-making. (54)

1.7 Trust in the physician

Trust is an important concept when considering the patient-physician relationship. This thesis adapted the following definition of trust in the physician, which was developed by Wallston, Wallston, and Gore in 1973, “a person’s belief that the physician’s words and actions are credible and can be relied upon.” (38) Note that trust is related to the interpersonal relationship rather than an objective analysis of whether the trust is warranted. These concepts are also not in the trust in physician scale, which is further characterized in section 1.7. Patients who trust their physician would believe that the physician would act in their best interest and provide support and assistance in medical and treatment decision-making as it is related to the ongoing relationship. Anderson et al. have developed the trust in physician scale, which focuses on the patient-clinician interaction and acknowledges that there is a key element of interpersonal trust that impacts this relationship. The trust in physician scale and scoring mechanism are further described in sections 2.4 and 3.4.1.
1.8 Hypotheses

This thesis investigates the relationships between patients’ preferred roles, trust in the physician, and their perceived health information literacy. We hypothesized that, despite the availability of increased health information online that would make it easier to take an autonomous role, few patients would prefer an autonomous role. They may place a high level of trust in their physicians to make decisions regarding their care. (12) However, the increased availability of health information could also mean that fewer wish a passive role.

1.9 Research questions

The following research questions were the focus of this dissertation:

Research questions that were answered using a quantitative study design (Research questions 1-3):

1. In this sample of primary care patients, what are their: preferred roles, trust in physician, and perceived health information literacy?

2. What are the differences in patients’ preferred roles, perceived health information literacy and their trust in physician between different genders and highest level of completed education?

3. What are the relationships between patients’ preferred role, trust in physician, perceived health information literacy?

3.A. What are the differences in patients’ trust in physician and perceived health information literacy scores between patients whose preferred role is passive vs. shared?
3B. What are the differences in trust in physician, perceived health information literacy gender, age, and perceived health information literacy between patients with passive and shared preferred roles? Is there a difference between the current condition and the chest pain vignettes?

Research questions that were answered using a qualitative study design (4A-4C):

4A) How are primary care patients’ perceptions of their perceived e-health literacy and sources of health information literacy related to their preferred roles?

4B) How do primary care patients assess the trust that they have in their physician, the credibility of online sources of health information and also their communication with their health care provider?

4C) How do primary care patients’ preferred roles influence their views of the patient-physician relationship?

Questions 4a through 4c will be addressed in section 4.2. In the next chapter we describe the theoretical framework and review key references from the literature. These research questions are important to investigate and understand in the digital era of access to online health information.
CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Academic databases and the grey literature were searched for research related to person-centered care, conceptual and theoretical frameworks, trust in physician, patients’ preferred roles, and perceived health information literacy. Search key words included: patient engagement, person-centered care, theoretical frameworks, trust in physician, preferred roles, health information literacy, and e-health literacy. The purpose of this section of the thesis is to share the key findings of the literature review and identify several gaps within the literature.

2.1 Theoretical framework

From the academic and grey literature, several theoretical frameworks on patient engagement were analyzed for this dissertation. (8, 23, 39-41)

As noted in section 1.4, we applied the Carman et al. framework, which defined three levels of patient engagement. They referred to these levels as: direct care, organizational design and governance, and policy making. These levels correspond to what we term micro, meso, and macro levels of engagement. Table 2.1 below presents and describes each of these levels. Within each of these levels, there are three stages on the continuum of engagement, which Carman et al. have referred to as: consultation, involvement, partnership and shared leadership. (29)

For example, at the direct care level, consultation means that patients receive a diagnosis of their health condition and discuss their diagnosis and treatment options with their clinician. Involvement refers to patients being asked about their preferences in treatment plans. Partnership and shared leadership refers to when treatment decisions are based on patients’ preferences, medical evidence, and clinical judgment; it is at this stage that treatment decisions are reviewed with the patient and the patient and physician play a leadership role in ensuring optimal care for
the patient. (29) At the organizational design and governance level, “consultation” could involve organizations surveying patients about their care experience, “involvement” could mean bringing patients in as advisory members, and “partnership” could involve having patients lead committees, such as patient safety and quality improvement, within hospitals. At the policy making level, “consultation” involves having public agencies conduct focus groups with patients, “involvement” entails having patients help make priority recommendations to guide funding priorities, and “partnership and shared leadership” means that patients have equal partnership with agencies in making funding decisions. (29) This thesis focused on the direct care level.
<table>
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<th>Consultation</th>
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<td>Direct care</td>
<td>Patients receive information about diagnosis</td>
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<td>Policy making</td>
<td>Public agency conducts focus groups with patients to ask opinions about a health care issue</td>
<td>Patients’ recommendations about research priorities are used by public agency to make funding decisions</td>
<td>Patients have equal representation on agency committees that make decisions about how to allocate resources to health care programs.</td>
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**Factors influencing engagement:**

1. **Patient** (beliefs about patient role, health literacy, education)

2. **Organization** (policies and practices, culture)

3. **Society** (social norms, regulation, policy)
The Carman et al. framework suggests several factors that influence patient engagement, which they divide into Patient (including beliefs about patient role, health literacy, and education), Organizational (including policies and practices, and culture), and Society (including social norms, regulation, and policy). Our literature review suggests that this model might be augmented by adding trust (42) as a patient (and possibly as an organization) factor that influences engagement. Trust is a central factor that could be examined primary at the patient physician level in Table 2.1 above.

The next sections define key variables used in the analysis, including methodological information about the scales used.

2.2 Shared decision-making, patient-physician power relationships, patient autonomy & self-management, and patients’ preferred role

Shared decision-making

There has been considerable emphasis on determining what roles patients wish to take in treatment decisions about their health care. In many jurisdictions, there has been a shift from a paternalistic form of medicine, where the physician knows best, to a shared decision-making approach, where the patient and physician work together to decide on an optimal approach. (13) A consideration of patients’ preferred roles is central to this thesis.

For the purpose of this thesis, a shared role is defined as, “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions and where patients are supported to consider options to achieve informed preferences”. (43) This
definition was chosen because it emphasizes patients and physicians working together in an environment where patients are supported.

Shared decision-making is a process refers to engaged patients in collaboration with their clinician to make decisions. According to research by Berwick et al., patient engagement and shared decision-making had impacts on patient outcomes and clinical costs associated with health care. (44-46) According to the literature, most patients preferred to discuss treatment options with their health care provider. Patients who preferred a shared role often opted for two-way communication about the risks and benefits associated with treatment options. (47) Patients who preferred a shared role wanted to leave the PS tasks to the health care provider but wished to be informed and often engaged in the decision-making process. (12)

Shared decision-making has several features. In a research study by Charles et al., the key features of shared decision-making emphasized the process of sharing of information with patients, involving them in health care decisions, and ensuring that there was consensus between patients and physicians on the preferred treatment option. Researchers noted the limitations in measuring shared decision-making. (48) Understanding the features of shared decision-making and various models is central to patient engagement efforts.

In a follow-up study, when considering shared-decision making, Charles et al. have created a revised framework that includes: 1) explicitly identifying different analytic steps in the treatment decision-making process; 2) providing a dynamic view of treatment decision-making by recognizing that the treatment decision-making approach has been adopted at the outset of a medical encounter may change as the interaction evolves; 3) identifying decision-making approaches which lie between the three predominant models they suggest (which they term...
paternalistic, shared, and informed) and; 4) practical application for clinical practice, research, and medical education. (14) Note that these models are similar to those arising from the PSDM scale. For example, paternalistic resembles a passive role.

The clinical context is central to consider when looking at decision-making in health care. Preferences may vary, depending upon the health condition and the possible consequences of different diagnoses and treatment options. For example, some analyses of shared decision-making examined emergency health conditions, while others examined the general practice setting. Murray et al. noted that in the general practice setting, it was important to examine shared decision making. The information transfer component of this model would need to acknowledge that doctors may not be the only, or even main, source of health information for patients. (49)

Accordingly, the literature agrees that models of shared decision-making must consider the clinical context, patient population, and the nature of the medical interaction between patients and health care providers. Entwistle et al. explored the involvement of patients in treatment decision-making. For example, in a study of patients in Scotland who had diabetes, they associated involvement in treatment decision-making with features relating to the ethos and feel of healthcare encounters. These feelings included those of providers being welcoming, respectful, facilitative of patients’ contributions, and non-judgmental. Physicians gave clear treatment rationales in ways that patients understood and enabled patients to feel that they had a say in the decisions. Researchers recommended that models and taxonomies of patient involvement in decision-making need to be developed to accommodate the two elements of problem-solving and decision-making. (50) Different patient populations in different contexts
will have their own features of shared decision-making.

Patients may also prefer an active role in their partnership with physicians during the process of shared decision-making. For example, in a study by Pomey et. al, researchers conducted qualitative interviews of 16 patients who had chronic illnesses. (51) Results showed that patients proactively engaged in three processes during their encounters with their health care professionals. First, patients participated in continuous learning about their health, which included both the medical and scientific knowledge about their health condition. Second, patients assessed their own health care that they received in terms of quality and alignment with their personal preferences. Finally, patients built on learning assessments and compensated for and adapted to what were optimal or non-optimal health care circumstances. Patients with chronic diseases may find themselves compelled to assume an autonomous role. Pomey et al. found that patients preferred an active role regardless of the reciprocity of partnership or the degree to which their health care professional encouraged patients. (51)

In another study by Charles et al, researchers interviewed twenty women with early stage breast cancer attending a regional cancer center in southwestern Ontario. (52) Their results showed that when interpreting probabilistic information on risks and benefits, some women retained the idea of probability but thought that they could beat the odds. Others converted the information into a more meaningful form for them and still others weighed their risk status by comparing to friends and relatives who have the disease. Therefore, when health care providers work with breast cancer patients, they may need to consider the social factors of health care. Another study found that many women preferred shared treatment decision-making over both passivity and autonomy when meeting with their oncologist. (50)
Charles et. al have also examined the barriers and facilitators to applying a shared treatment decision-making approach with oncologists and surgeons. Barriers included lack of time, patient anxiety, patients lacking information and/or having misinformation, and also patients’ unwillingness or inability to participate. Facilitators to shared treatment decision-making included patients’ emotional readiness, support, information, and trust in physician. (53) Implementing a shared decision-making approach requires consideration of these facilitators and barriers.

Patient-physician power relationships

Patient-physician power relationships and patients participating in their health care decisions is also important to the process of shared decision-making. Physicians trained in post-graduate medical training programs today are taught shared decision-making and encouraged to involve patients in treatment options. The medical training that physicians receive allow them to be updated on the latest medications and surgical treatment options that are available to patients. When patients arrive at an appointment with misinformation that they obtained online, physicians may need to provide better education to their patients. Roter et al. have explored this idea further and claim that the medical dialogue that occurs between the patient and physician establishes this power dynamic and relationship.(54, 55) Furthermore, to better understand the balance of power between the patient and physician, Quill et al. recommend a “enhanced autonomy” model, which encourages patients and physicians to actively exchange ideas, explicitly negotiate differences, and share power and influence to serve in the patients’ best interests. (56)
Patient autonomy & self-management

There is a large body of literature on patient autonomy and self-management. Self-management is directly relevant to this thesis and a brief overview of the literature on these topics is provided. The autonomous role is directly linked to concepts of self-management and patient autonomy. Medicine Net defines patient autonomy as, “The right of patients to make decisions about their medical care without their health care provider trying to influence the decision.” This does allow for health care providers to educate the patient but does not allow them to make the decision for the patient. (57) The concept of “patient autonomy” is defined in relation to the decision-making role of patients. There is a connection between the concept of patient autonomy and the autonomous role that patients’ may prefer in the PSDM scale.

In a paper by Entwistle et al., researchers examined the concept of supporting patient autonomy and the importance of the patient-physician relationship. A good patient-physician relationship respects the patients’ autonomy. (58) A broader conceptual framework has been recommended by Entwistle et al. This framework acknowledged that patients can be involved not only because what patients say and do influences a decision but also because what patients think and feel about their roles, efforts, and contributions to decision-making impacts their relationships with their clinicians. (59) The idea of patient autonomy and their ability to select health care treatment preferences and choices together with their physician is important to consider when examining patients’ preferred roles.

Self-management is a central feature of some definitions of patient autonomy. In a critical interpretative synthesis of the literature from 2000-2014, Morgan et al. focused on the purpose of the support provided to patients. They identified two types of approaches, which they termed narrower and broader approaches. (60) Narrower forms of support allowed people to manage
their condition in terms of disease control and were associated with hierarchical views of the patient-physician relationship. Examples of narrower approaches were didactic education or persuasive motivation. Broader approaches supported people’s ability to manage well with their health condition and were necessary for self-management and patient empowerment. Broader approaches, which were less evident in practice, supported a more diverse and flexible strategy where the patient-physician relationship is collaborative and is a source of support. (60)

Knowledge exchange and patient education is important to self-management. In a critical interpretative synthesis review by Kazimierczak et al., researchers looked at crucial tools for the support of cancer patients, facilitating their involvement in care management and decision-making. (61) Research found that the concept of “support for navigating the knowledge landscape” offered a useful way of envisaging information services for people with cancer. This idea incorporates the diverse, changing and relational nature of patients’ values, needs and preferences. This approach allowed for the provision of health care information and navigation tools that were personally relevant and matched the patients’ needs. Information sharing and exchange was a vital part of both self-management and shared decision-making. (61)

Patients’ preferred roles and the PSDM Scale

There are a number of scales in the literature that measured patient preferences. (62-64) One of these scales, the control preference scale, was developed from grounded theory. It focuses on how treatment decisions are made among people with life threatening illnesses. (52) Additionally, as noted above, Charles et al., created a framework based on decision-making domains, role perspectives, and levels of participation for conceptual clarity about the key dimensions and goals of participation in health care. (65, 66)

The problem-solving and decision-making (PSDM) scale (12) was chosen for this thesis
because it is a well-validated scale that measures patients’ preferred roles; it was noted in section 1.4 and is described in section 3.6.2. Categories of the PSDM model include: passive, shared (leaning passive), shared (equally), autonomous (leaning shared), shared (divide and share), shared (leaning autonomous), autonomous (consumerist), autonomous (leaning shared). These categories will be further defined in section 3.4.

In another research study it was found that the majority of respondents who reported using complementary and alternative medicine (CAM) for their prostate cancer were classified as preferring a shared role. (67) These findings are similar to this research study in that most people preferred a shared decision-making role with their physician.

2.3 Patients’ use of information resources and health information literacy

Patients use a variety of information resources. Health information literacy (whether subjectively or objectively measured) is one of the factors that could affect patients’ use of information resources as well as their preferred roles. As seen in the literature, people may rely on different sources of information such as the Internet, health care providers, patient educational material, or friends and families. It was found that more than 50% of adults who responded to a national survey provided health information to their friends and families. (68) Other types of health information included personal experiences from other patients. In a qualitative study, researchers investigated people’s view of using ‘general facts’ and information about other people’s ‘personal experiences’ for health-related decision-making. Results of this research showed that people use ‘personal experience’ information in various ways to support their decision-making, and exercise some discrimination as they do. (69) In a research study by France et al., 36 women and 9 of their male partners demonstrated the various ways that
participants gleaned knowledge from their own and other individuals’ experience. The participants searched for biomedical or clinical-epidemiological research about the probability of having a child affected by health problems or the probability of diagnostic tests that showed a miscarriage. This analysis demonstrated the various ways that people respond to and reflect on different types of information for treatment decision-making. (70)

2.4 Measurement of perceived health information literacy

Health information literacy can be measured either objectively or subjectively using self-reported measures such as the e-HEALS scale. The details of the scale and scoring are provided in the methods section 3.6.2. Measuring perceived health information literacy is central to this thesis. This thesis uses the definition of perceived health information literacy as described in section 1.6. The e-HEALs literacy scale was chosen to measure patients’ perceived health information literacy. This scale measures patients’ ability to identify and utilize sources of online health information. The authors refer to the e-Heals scale as a measure of health information literacy. However, it is important to note that the e-Heals scale is a self-reported measure that reports subjective health information literacy as opposed to objective health information literacy. (35) The e-HEALS scale was applied in 216 Chinese school-aged children and shown to have good internal consistency reliability (Cronbach’s alpha=0.92). It was significantly associated with computer skills including the ability to use the web to search for information. (71)

In a study by Mitsutake et al., the perceived e-health literacy of Japanese internet users and their knowledge of colorectal cancer (CRC) and screening practices was investigated. (72) These researchers showed that if patients had a higher level of (perceived/ self-reported) health information literacy, they were more likely to ask physicians to be screened for colorectal cancer.
Findings of this study suggest that perceived e-health literacy may be linked to patients’ screening-related decisions. This means that a patient’s ability to understand screening practices may impact their choice of selecting to be screened or not. The scale and scoring will be further described in the methods section 3.6.3.

As seen in the literature, low health literacy impacts patients’ interactions with their health care professionals. In a two-stage qualitative study by Easton et al., researchers examined the health literacy of 29 adults recruited from an Adult Learning Centre in the United Kingdom. Results showed that low health-literacy related stigma may seriously impair people’s spoken interaction with health professionals and their potential to benefit from health care services. With a rise towards patient participation and shared decision-making, services need to consider simplifying the literacy requirements to offer non-judgmental (universal) literacy-sensitive support and to promote positive health care experiences and outcomes.

There are few studies that examine the relationship between primary care patients’ self-reported health information literacy level and their preferred role in treatment decisions. This thesis adds knowledge to health services research in examining these relationships.

2.5 Trust in physician

Research has shown that trust in physician impacts patients’ preferred role in treatment decisions. For example, in a study by Deber at al., although almost no patients preferred an autonomous role, those who did had lower levels of trust in their physician.(12) Similar to these findings, a study by Thom et. al showed that patients who had lower levels of trust in physician were more likely to request services such as diagnostic tests and referrals to other physicians when compared to patients who trusted their physicians. (73)
A study by Trachtenberg et al. showed that there is a strong connection between patients’ preferred involvement in medical care and trust in the medical profession. Increased trust in physician is associated with a greater willingness to seek care, follow recommendations by the physician. This may grant physicians decisional authority to the physicians. Higher levels of trust corresponded to greater adherence and more active patients who sought medical care and adhered to their treatment plans. Patients who are adherent to their treatment plans fell into several categories including active or passively compliant. Researchers found that the views varied by sex, age, health, education, income, number of visits/year with physician, past disputes with a physician, and satisfaction with care. (74)

In a study of 20 community-based primary practices over 6 months, baseline trust predicted continuity with the physician, self-reported adherence to medication, and satisfaction at 6 months after adjustment for gender, age, education, length of the relationship, active choice of the physician, and preferences for care. Even after additional adjustment for baseline satisfaction with physician care, trust was a significant predictor for continuity, adherence, and patient satisfaction. (75) Another study of African Americans and their trust and health information literacy found that older participants had more trust in their physicians when compared to the younger participants. (47) Therefore, trust in physician may impact both patients’ preferred roles and the management of their health condition.

In a systematic review by Brennan and Entwistle et al, results showed that most papers that they analyzed reported on patients’ trust in their healthcare provider and collected data in the family care or oncology/palliative care setting. Authors selected empirical studies carried out in the health-care settings that explicitly examined trust or reported trust-related findings as a
secondary outcome. Since trust in physician is subjective, most studies used questionnaires and interviews to elicit patients’ perspectives. (76)

Overall, the above studies show that trust in physician may impact both patients’ preferred roles and the management of their health condition. There are limited studies within the literature on the impact that trust has on patients’ preferred role. This thesis fills this gap by examining primary care patients’ levels of trust in their primary care provider and the impact that this has on their preferred role in problem-solving and decision-making. The trust in physician scale and its scoring are described further in section 3.6.4.

2.6 Communication and patients’ preferred roles

Patient-physician communication is an important concept that has been explored in the academic literature (see section 1.3). Another research study used discrete choice experiments to measure the value that patients place on different aspects of person-centered care. (77) Communication is included in frameworks such as the Can Meds roles and the Accreditation Council of Graduate Medical Education. (78, 79) Although communication was not directly measured in the quantitative component of this study, there were several qualitative interview questions that addressed this concept. For this reason, it has been included in this literature review. Results showed that participants valued and were more likely to choose services that had a higher level of person-centered care attributes. Communication is a central feature and important concept.

Patient-clinician communication has been associated with patient health outcomes. A review of the literature by Stewart showed that most of the studies demonstrated a relationship between effective patient-physician communication and improved patient health outcomes. (80)
In particular, the quality of communication both in the history taking segment of the visit and during the discussion of the management plan was found to influence patients’ health outcomes. The outcomes that were affected (in order of descending order of frequency) include emotional health, symptom resolution, function, physiologic measures (i.e. blood pressure and blood sugar level) and pain control. This study emphasizes the importance of patient-physician communication on patient outcomes.

A conceptual article by Street et al suggested the mechanisms by which patient-physician communication impacts health outcomes are mostly through indirect roots. (81) Proximal outcomes of the patient-physician interaction include patient understanding, trust, and clinician-patient agreement. These proximal outcomes influenced intermediate outcomes such as increased adherence and better self-care skills, which in turn affected overall health and well-being. These findings have clinical practice implications because both patients and clinicians can work together to maximize the therapeutic effects of communication by explicitly orienting communication to achieve intermediate outcomes of trust, mutual understanding, adherence, social support, and self-efficacy, which are associated with improved health. (81)

One of the guiding statements in communication between the patient-physician is the Kalamazoo consensus statement. In 1999, 21 leaders from major medical and professional organization gathered to delineate a coherent set of essential elements in patient physician communication. These elements include: 1) build the doctor-patient relationship; 2) open the discussion 3) gather information; 4) understand the patient’s perspective; 5) share information; 6) reach agreement on problems and plans; and 7) provide closure. These elements are a framework for communication-oriented curricula and standards. (82)
Communication can also relate to patients’ preferred roles because it is central to shared decision-making. An example of communication style impacting patient preferences from the literature is seen in a study by Kehl et. al. (83), in which researchers examined cancer patients’ reporting of the quality of care and communication with their physician. Although that study did not measure preferred roles, their results showed that when physicians were seen as too controlling, the patients gave lower ratings to their quality of care and physician communication. (83) In a meta-analysis by Singh et al., roughly half of the patients with cancer indicated that they preferred a shared role with their physician. This study showed that individualized communication styles should be incorporated into treatment plans. (84) In their cross-sectional, they found that of the 113 colorectal cancer patients, 40% preferred a passive role, while the remaining patients preferred a shared role. Researchers suggested that communication between patients and physicians should be customized to accommodate the patients’ desired level of involvement. (84)

When communicating with physicians, patients may bring their own agenda to the appointment, which may be informed by their search of online health information. In a paper by Charles et al., authors examined how the agenda that a patient brings to the clinical appointment with their physician influences the consultation. In this paper, Charles et al. characterized the patients’ agendas as topics that they bring for discussion with their doctor at a forthcoming consultation; they recommended educational interventions targeted at doctors to improve communication with their patients in the treatment decision-making process. These interventions should address different types of communication issues between patients and physicians. (85) Communication skills of health care professionals influence the treatment decision-making process between patients and physicians.
The way physicians communicate with their patients may also be related to how engaged the patients are in their health care decisions. In a study by Collins et al., researchers examined how physicians communicate with their patients about treatment options. Conversation analyses of decision-making sequences in consultation about diabetes in primary care revealed that the physician’s approach can range from ‘bilateral’ to ‘unilateral’. A bilateral approach meant that both the patient and physician interacted with one another. On the other hand, a unilateral approach was defined as an approach that physicians took to provide information to patients with no further discussions. This study outlined insights about the implications of patient participation in decision-making and key communicative and organizational features of both approaches. Bilateral approaches were associated with increased levels of patient engagement and patient-centered care. This study defined patient engagement as participation in decision-making according to the Entwistle framework. The type of communication approach chosen by physicians impacts patient involvement in their health care decisions.

Involving other family members or companions in communication could be a valuable strategy. In a systematic review by Laidsaar-Powell et al., researchers searched for quantitative and qualitative studies that explored physician-adult patient-adult companion (triadic) communication and/or decision making in medical encounters. In their study, patients with increased needs were accompanied by companions. Results showed that family members who were companions in the patients’ health care decisions were perceived as helpful and supportive to patients. Helpful behaviors by companions included informational support to patients including note-taking during the encounter. Less helpful behaviors included being dominating or demanding when interacting with the physician. Strategies for health care professionals included: 1) encouraging and involving companions; 2) highlighting helpful companion behaviors; 3)
clarifying and agreeing upon role preferences of patients/companions. (54)

The next sections describe a number of demographic characteristics that have been examined in the literature and are incorporated into this study. These characteristics include highest level of completed education, ethnicity and preferred spoken language, nature of the health condition, gender, age, and marital status.

2.7 Highest level of completed education

The highest level of completed education is an important variable to consider when analyzing patients’ preferred roles. Multiple research studies have shown that the higher the level of education, the more active a role patients preferred in their treatment decisions. (12, 62, 87, 88) Degner et al. sampled 1,012 Canadian women with breast cancer and found that those who were more educated and younger preferred a more active role. (62) In a study of 140 Italian patients with multiple sclerosis, education level and length of follow-up were associated with an active role among participants. (88) In another study of Norwegian women older than 18 years, a higher education level was associated with better self-rated health, fewer prescription medications, and more active involvement in their health decision-making. (87) In contrast to these findings, some studies showed that education did not consistently predict patients’ role preferences. (89-92) Since there is mixed evidence in the literature, it is important to consider the impact of the highest level of education on primary care patients’ preferred roles. Therefore, highest level of education was selected as a variable in the demographic survey as noted in the methods section 3.4.1.

2.8 Ethnicity & preferred spoken language

Another variable in this dissertation is patients’ preferred spoken language and ethnicity
as noted in methods section 3.4.1. The evidence on the impact of ethnicity on patients’ preferred roles is mixed. If English is not the first spoken language, but this is the only language spoken by the health care provider, then this may impact patients’ preferred level of engagement with their health care provider. For example, it is plausible that if patients cannot communicate clearly with their physician, then this may limit them to more passive roles. Some research evidence has shown that language is an important factor in the process of shared decision-making. (93)

Participants’ ethnicity is also associated with their preferred role. For example, in a study conducted at the New York State Psychiatric Institute, being Hispanic was associated with selecting a passive role. (94) In a Canadian study by Degner et al (62), which surveyed 1,012 breast cancer patients of English Canadian, Ukranian, French, and other ethnicities at a tertiary oncology referral clinic in two community hospitals in Winnipeg, Manitoba, ethnicity was a significant predictor of patients’ preferred roles. In a conceptual paper by Charles et. al, researchers looked at written examples of where cultural influences were taken into account when discussing patient-physician encounters or when designing instruments such as decision aids to help patients participate in their health-related decisions. Results showed that research in this area has not been culturally sensitive and there needs to be more research focusing on cultural variations in the meaning of and preferences for shared decision-making across cultural groups of decision aids that facilitate patient-physician interactions and treatment decision-making. They concluded that clinicians and researchers should consider how culture can impact the needs and preferences of patients from diverse cultural groups. (95) In another study of HIV patients, results showed that active engagement in decision-making about therapy may vary with the patients’ sociocultural background. (96)
However, other research has shown that ethnicity does not impact participants’ preferred role. For example, in a study of the three year follow-up of decisional role preferences of cancer patients by Hack et al., ethnicity had no impact on participants’ preferred roles for problem-solving and decision-making. (97) Due to the mixed research evidence on the impact of ethnicity and patients’ preferred roles, ethnicity was included in the study so that we could understand its impact on primary care patients’ preferred roles.

2.9 Nature of the health condition

According to research, the nature and severity of the health condition is another important variable to consider. In a study by Deber et al, the nature of the health condition impacted patients’ preferred roles. Patients’ preferences varied across different health care settings and by the nature of the health condition. Researchers applied three separate vignettes. There was some variation for preferences for a passive role was significantly greater for the vignette involving potential mortality (chest pain) than for the vignettes involving quality of life (fertility). (12) Familiarity with a clinical condition increased the desire for a shared (as opposed to passive) role. (30) For this reason, the nature and severity of the health condition is another important variable included in this study. The chest pain vignette was selected as a control to allow comparison with other research using the PSDM scale.

2.10 Gender

The research evidence on the impact of gender is mixed. Some research has shown that gender may impact the role that patients want to play in shared-decision making and the amount of information they receive. For example, in a study that examined the differences in health information needs and decisional preferences after an acute ischemic coronary event, there was a
difference in health information received between men and women. Women were more likely than men to receive less information than they wanted from their health care provider. (98) However, multiple other studies have shown that gender does not consistently predict patients’ preferred roles. Most of the studies have shown that there were no statistically differences between male and female preferences for role in treatment decision-making. (89-92, 99, 100) Since the research evidence is mixed on the impact of gender, it is important to see the impact that this variable has on primary care patients’ preferred roles.

2.11 Age

Age is another factor that may affect primary care patients’ preferred roles. (90) For example, in a population-based survey of 2,765 adults younger than 45 years, younger age was associated with the patient preferring more of an active role. In congruence with these findings, in a survey of Norwegian women, older age was associated with a lower likelihood of preferring an active role. (87) In a meta-analyses by Singh et al. looking at 3,941 patients with cancer who had completed the 2-item Control Preferences Scale, older patients preferred a passive role in treatment decision-making compared to younger patients (age<50 years). (84)

In a study by Deber et. al, results of patients’ preferred roles showed that preferences for a passive role varied across study subgroups as a function of both age and education. It was suspected that the relationship between age and preferred role may largely reflect educational differences. (12) Similar to other research evidence, in another research study looking at the information needs of cancer patients, it was found that patients required additional health information and preferred an active role in decision-making. (101) Due to this research evidence, age was included as a demographic variable in this thesis so that we could examine the impact of
age on primary care patients’ preferred roles.

2.12 Marital status

Marital status is another factor that may affect primary care patients’ preferred roles. However, in a study by Shields et al., researchers looked at 1,014 patients diagnosed with a variety of cancers who were treated at the University of Rochester Cancer Centre Community Clinical Oncology Program. In this study, marital status was not related to the decision-making preferences of patients. (102) Another study also showed that a person’s marital status was not related to their preferred roles. (103)

2.13 Gaps in the literature

This thesis addresses several gaps within the literature. First, there are a lack of studies within the literature that examine the relationship between primary care patients’ self-reported health information literacy and their preferred role in treatment decision-making. With the availability of increased health information online, it is not clear whether patients’ preferred roles in treatment decision-making have changed over time. This thesis fills that gap and examines the relationship between perceived health information literacy and patients’ preferred roles in decision-making. The second gap that this thesis fills is by examining the relationships between the three variables (patients’ preferred roles, trust in physician, and perceived health information literacy) in a sample of primary care patients. The research questions and hypothesis that address these the research gaps associated with those research questions is presented in sections 1.8 and 1.9
CHAPTER 3: METHODS

3.1 Overall study design

This dissertation applied a multi-method study design with both quantitative and qualitative components. (104) The study began with a quantitative survey that was followed by in-depth qualitative interview with a subset of participants. These two components were analyzed separately and the findings were then integrated in the discussion section.

A multi-method research design was chosen because it is well suited to the research question of understanding primary care patients’ preferred roles in making treatment decisions. There are some advantages of using a multi-methods research approach. Quantitative research questions (research question 1-3) help to answer question about patients’ preferred roles and its relationship to the other variables. On the other hand, qualitative methods help to explore primary care patients perspectives in further detail through interviews (research questions 4-5).

The quantitative survey within this research study allows the researcher to measure patients’ preferred roles, perceived health information literacy, and trust in physician. (105) The purpose of the qualitative interviews was to explore each of these concepts in further detail. The qualitative interviews explored factors that were not yet included in the quantitative surveys and added further depth to the research. For example, the qualitative interview allowed the researcher to better understand the sources of information that patients used for their health care decisions, and how they assessed these sources for credibility. The interviews also explored the various factors that influenced patients’ preferred roles. In this multi-methods approach, the inclusion of both quantitative and qualitative methods may enhance the validity and reliability of this study. (104)
The final part of this study was a synthesis of the findings from both the qualitative and quantitative approaches in the discussion to see whether or not there was congruency of findings. Pope et al. have considered how methods could be mixed at various stages of the research process to inform the next phase of the study or after the data collection or data analysis phase for mixed methods studies. (106) Multi-method study designs are defined as, “a conduct of two or more research methods, each conducted rigorously and complete in itself, in one project. In a multi-method study design, the results are then triangulated to form a complete whole.” (107) This thesis applied a multi-methods study design.

The next section describes the study sample and inclusion criteria for this thesis.

3.2 Study sample, recruitment, sampling procedure

This study sample included adult patients attending an evening primary care clinic at St. Michael’s Hospital in Toronto. Ethics approval for the study was obtained from the research ethics boards of the University of Toronto and St. Michael’s Hospital. The sample included patients with different types of health care conditions such as asthma, hypertension and diabetes. A population of primary care patients was selected because there are many health conditions in primary care. Also, there is limited research on primary care patients’ preferred roles in health care decision-making, their perceived level health information literacy, and their trust in physician.
Inclusion criteria for participation in this research study were as follows:

1. Patients were attending the primary care clinic.
2. Patients were able to understand English to complete the survey.
3. Patients were 18 years of age or older.
4. Patients were willing to dedicate 20-30 minutes for survey completion.

The inclusion criteria for the qualitative interviews was as follows: having completed the quantitative survey and being willing to participate in a follow-up 20-30-minute phone call at a mutually convenient time.

Another exclusion criterion in the study was an inability to complete the survey. Patients with major visual impairments were excluded. However, in the case of minor visual impairments, the researcher provided assistance to patients by reading the survey questions and noting patients’ answers on the survey. If this was not possible, then these patients were excluded from the study. Some patients also were excluded from the study because they were called to their clinical appointment before completing their survey. The researcher monitored the number of patients that accepted and declined participation to calculate a response rate for this research study. Of the 158 people who agreed to participate, 141 completed the full survey (89%).

The researcher was present in the waiting rooms of the primary care clinic to recruit potential participants. Patients were given the opportunity to review the consent form. If they were not sure about certain elements in the form, the researcher explained the study objectives and the consent form and gave patients an opportunity to ask questions. Informed consent was obtained from the patients prior to participation in this research study. The consent form is found
in Appendix 3. Patients were asked for a reason that they did not want to participate, and the only reason provided was due to a lack of time and availability. No information was given to their doctor about whether they participated in the research study. Additionally, identifiable survey results were not shared with their health care provider.

A convenience sampling approach was applied to recruit patients that met the inclusion criteria stated above. Convenience sampling refers to including patients that are the easiest to access. It is a type of non-probability sampling. Voluntary participation in this research study was a central feature of the sampling process. One potential disadvantage to convenience sampling is that it is often associated with volunteer bias. For example, healthier patients or patients with high levels of perceived health information literacy may have been more likely to volunteer for this study. To mitigate this, effort was made to approximate random selection as much as possible. (108) Moreover, because theory predicts that these patients would be more likely to want to play an autonomous role in their health care decisions, this volunteer bias may strengthen our research findings if we find that even these populations did not prefer an autonomous role in treatment decisions.

3.3 Quantitative study phase

As noted above, the quantitative survey was administered by the researcher. Patients were informed about the study goals, their privacy and confidentiality, and signed an informed consent form. This form was developed in conjunction with the ethics forms and guidelines of St. Michael’s Hospital and the University of Toronto and approved by both ethics committees. The informed consent form and recruitment poster can be found in Appendix 3. A data transfer agreement was also created so that information can be shared between St. Michael’s Hospital
and the University of Toronto. It is found in Appendix 4. The ethics approval letters from St. Michael’s Hospital and the University of Toronto are in Appendix 5.

As noted above, during data collection, the researcher was present in order to clarify any questions that patients may have had about the research. Surveys were completed in person, on paper in the waiting area of the evening primary care clinic. All surveys were immediately collected upon completion and stored securely at the Li Ka Shing Knowledge Institute at St. Michael’s Hospital for further analysis. The survey consisted of a short demographic survey, application of the PSDM scale to two vignettes to understand patient’s preferred roles (current health condition and chest pain vignettes), the e-HEALS perceived health information literacy scale, and the trust in physician scale. The survey is in Appendix 1. Each of these scales is further outlined in section 3.4-3.6 below. Results of our pilot research study showed that together all of these surveys took patients approximately 20-30 minutes to complete.

3.4 Quantitative data collection measurement instruments & scales

Patients completed a brief demographic survey, which included: age, preferred spoken language, gender, ethnicity, nature of current health condition, marital status, and highest level of completed education. The potential impacts of these variables on patients’ preferred roles have been discussed in section 2.-2.11.

Next, patients completed the quantitative survey, which included the PSDM tool, the perceived health information literacy e-HEALS scale and the trust in physician scale. All of the survey instruments for the quantitative part of this study are found in Appendix 1.
3.4.1 Patients’ preferred roles in problem-solving (PS) and decision-making (DM)

To identify patients’ preferred roles the PSDM scale developed by Deber et. al (12) was applied. Appendix 1.1 outlines the questions of the PSDM scale. This scale and relevant literature related to patients’ preferred roles are described in sections 2.2, and 3.6.2 of this thesis. As noted by previous research studies, the PSDM is a valid and reliable scale for measuring patients’ preferred roles. (67, 109, 110)

The PSDM consists of six items. Each asks “who should decide” on a 5 point scale from “doctor only” to “you only”. Responsibilities for all PS and DM items were measured on the following scale: 1=doctor alone; 2=mostly the doctor; 3=doctor and you equally, 4=mostly you, 5=you alone. The PSDM tool asks these questions about two vignettes: one that asks about the patients’ current health condition, and one which asks about chest pain. (12) The control vignette (chest pain) allowed the researcher to compare findings to previous research to see how this sample was similar or different to other populations.

As noted above, the PSDM tool is used to classify patients into their preferred roles. For each vignette, the mean scores are computed separately for the PS and DM domains for each patient. A mean score of less than 3 meant that patients wish to “hand over” that responsibility to physicians. A mean score of 3-3.99 would imply that patients want to “share” this responsibility with their physician; and a mean score of greater than 4 meant that patients wanted to “keep” that responsibility. (30) Based on these scores, patients were placed into a preferred role category as seen in Table 3.1. The categories are: passive; shared [which can be sub-classified into leaning passive, divide and share, equally, or leaning autonomous]; or autonomous [which can be sub-classified into leaning shared, consumerist]. Although Table 3.1 has options for those who wish
to keep responsibility for PS tasks but share or completely hand over DM, this is theoretically implausible, and previous studies have found that respondents do not fall into this category. (30) It is important to note that there might be a disconnect between patients’ hypothetical and actual behavior. This thesis did not look at the actual behaviour of patients nor was there a longitudinal follow-up with primary care patients.

Table 3.1: Problem-solving and Decision-making classification categories

<table>
<thead>
<tr>
<th>Responsibility for DM</th>
<th>Hand over (mean score &lt;3)</th>
<th>Share (mean score 3 - 3.99)</th>
<th>Keep (mean score ≥ 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand over (mean score &lt;3)</td>
<td>Passive</td>
<td>Theoretically implausible</td>
<td>Theoretically implausible</td>
</tr>
<tr>
<td>Share mean score between 3 and 3.99)</td>
<td>Shared (leaning passive)</td>
<td>Shared (equally)</td>
<td>Autonomous (leaning shared)</td>
</tr>
<tr>
<td>Keep (mean score that dimension ≥ 4)</td>
<td>Shared (divide and share)</td>
<td>Shared (leaning autonomous)</td>
<td>Autonomous (consumerist)</td>
</tr>
</tbody>
</table>

3.4.2 Patients’ perceived health information literacy (e-HEALS scale):

The Norman & Skinner e-HEALS scale was chosen to measure patients’ perceived health information literacy. The e-HEALS scale included 10 questions that related to a patients’ ability to find and use helpful online health resources. Appendix 1.2 provides the list of 10 questions and possible responses within the e-HEALS scale. The first two questions of the e-HEALS scale
are only meant to better understand the patients’ consumer and internet related behaviors. The responses on the e-HEALS scale ranged from strongly agree (rated as 1) to strongly disagree (rated as 5). The final score combined each patients’ knowledge, comfort, and perceived skills at finding, evaluating and applying health information to their health-related problem. (35) Therefore, with 8 total questions each with 5 choices, the minimum possible score was 8 and the maximum score was 40. Although this scale is a relative scale, the scale developer, Dr. Norman, has confirmed that typically the scale is reported as: 5-20 (low), 21-30 (medium) and 31-40 (high) (personal correspondence, Feb, 13, 2017).

3.4.3 Trust in physician scale

The final scale that was applied within this dissertation was the trust in physician scale developed by Thom et al. (75) This is a well-validated 11-item scale that quantifies situation-specific measures to determine the patients’ level of trust in their physician. Items are scored on a 5-point Likert Scale ranged from 1 (strongly disagree) to 5 (strongly agree). Of note, to avoid response bias, questions 1, 5, 7, and 11 on the scale were framed in the negative and therefore were reversed upon scoring. A trust in physician average score was calculated for each patient. The total score was added and divided by the total number of questions. Higher scores on the scale reflect a higher level of trust in physician. When completing the questions for trust in physician, patients were asked to think about the health care provider whom they saw on a regular or ongoing basis for their health care. For most people, this was their family physician. The minimum possible score is 11 and the maximum possible score on this scale was 55. From the literature, there is no known gradient of higher, medium or lower levels of trust. (64) The specific items of this scale are in Appendix 1.3.
3.5 Pilot testing & fielding the survey instruments

All scales were initially pilot tested in healthy individuals at the University of Toronto. The pilot studies helped to clarify the time required to complete the quantitative survey. It took participants 20-30 minutes to finish. The pilot study also helped ensure that the survey was simple, clear, and easily understood by study participants. The pilot showed that the scales were clear to participants.

3.6 Confirming scale reliability and validity

The e-HEALS scale, trust in physician scale, and PSDM scale have already been validated in previous studies. (30, 35, 75, 111) Psychometric testing of the PSDM scale, e-Heals scale, and trust in physician scale consisted of testing two components: reliability and validity. Scale testing in this research project was completed in two steps: First, reliability of all three scales (PSDM, e-HEALS, and the trust in physician scale) was tested with the Cronbach $\alpha$ score using the survey data. Second, we tested the construct validity of the PSDM scale using factor analysis. (112) We did not test the other types of validity because the other scales did not have relevant components and factor domains. However, since construct validity helps one understand how the survey instruments perform in a multitude of settings and sample populations, we analyzed construct validity in our sample to clarify that the scale still applies in this primary care population.

The literature indicates that to be reliable, the Cronbach $\alpha$ for a scale should be at least 0.7. (113) As seen in Table 3.2, the results of this analysis indicated that all of the scales that we used were reliable in our sample of primary care patients.
Table 3.2: Scale reliability (Cronbach $\alpha$) for the PSDM, e-Heals, Trust in Physician Scales

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach $\alpha$</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSDM Scale– Current Condition vignette</td>
<td>0.703</td>
</tr>
<tr>
<td>PSDM Scale – Chest pain vignette</td>
<td>0.780</td>
</tr>
<tr>
<td>Perceived Health Information Literacy Scale</td>
<td>0.909</td>
</tr>
<tr>
<td>Trust in Physician scale</td>
<td>0.813</td>
</tr>
</tbody>
</table>

An exploratory factor analysis was completed for the PSDM scale for both the current condition and chest pain vignettes. An exploratory factor analysis is a statistically appropriate method for finding latent variables in data when a dataset contains many variables. Confirmatory factor analysis is a method of confirming that certain structures in the data are correct. Since we were not confirming a hypothesized model due to theory, it is appropriate to not to apply a confirmatory factor analysis. (113) The e-health literacy and trust in physician scales do not have domains. Therefore an exploratory factor analysis was not done on these scales.

As noted in detail in Section 2.2, the PSDM constructs consisted of problem-solving (measured by questions A-D) and decision-making (questions E-F) domains. As seen in Tables 3.3 and 3.4, Principal axis factoring with Promax with Kaiser normalization rotation was
completed. The initial factor analysis produced two factors with Eigen-values >1, which explained 45% of the variance of the original variables. Tables 3.3 and 3.4. present the factor analysis findings for the chest pain and current health condition vignettes.

Table 3.3: Factor Analysis of PS and DM Domains for the Chest Pain Vignette

Extraction Method: Principal Axis Factoring, Rotation Method: Promax with Kaiser Normalization, Rotation converged in 3 iterations.

<table>
<thead>
<tr>
<th>Item Letter</th>
<th>Factor Loadings</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factor 1 (Problem-Solving)</td>
<td>Factor 2 (Decision-making)</td>
<td></td>
</tr>
<tr>
<td>Problem-solving questions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-A</td>
<td>0.497</td>
<td>0.069</td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-B</td>
<td>0.697</td>
<td>0.083</td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-C</td>
<td>0.812</td>
<td>-0.082</td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-D</td>
<td>0.817</td>
<td>-0.022</td>
<td></td>
</tr>
<tr>
<td>Decision-making questions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-E</td>
<td>0.102</td>
<td>0.778</td>
<td></td>
</tr>
<tr>
<td>PSDM-CP-F</td>
<td>-0.070</td>
<td>0.876</td>
<td></td>
</tr>
</tbody>
</table>
Table 3.4 Factor Analysis of PS and DM Domains for the Current Condition Vignette


<table>
<thead>
<tr>
<th>Item Letter</th>
<th>Factor Loadings</th>
<th>Factor 1 (Problem Solving)</th>
<th>Factor 2 (Decision Making)</th>
</tr>
</thead>
<tbody>
<tr>
<td>C-A</td>
<td></td>
<td>.115</td>
<td>.271</td>
</tr>
<tr>
<td>CB</td>
<td></td>
<td>.294</td>
<td>.368</td>
</tr>
<tr>
<td>CC</td>
<td>.823</td>
<td></td>
<td>-.060</td>
</tr>
<tr>
<td>CD</td>
<td>.712</td>
<td></td>
<td>.058</td>
</tr>
<tr>
<td>CE</td>
<td>.037</td>
<td></td>
<td>.739</td>
</tr>
<tr>
<td>CF</td>
<td>-.117</td>
<td></td>
<td>.778</td>
</tr>
</tbody>
</table>

For the current condition, rotation converged on two factors after 3 iterations. The two decision making items loaded on the same factor (Factor 2). Two of the problem solving questions (C and D) loaded on the other factor (Factor 1), but the other two questions (questions
A and B) loaded on Factor 2 with the decision-making items. However, the factor loadings for these questions are low. Because of this and because the scale has been previously validated in the literature and construct validity has been confirmed for the chest pain situation, we deemed it appropriate to use in this study without modification. (12)

In the next chapter, we provide the research questions and the quantitative data analysis that provides the results for these research questions.

3.7 Data analysis – quantitative

SPSS statistical software was used to compute all statistical analyses of the quantitative surveys. First, descriptive statistics were completed to analyze the sample characteristics. The sample characteristics are provided in Chapter 4. We also computed the mean and standard deviation for the trust and health information literacy scores. Cross tabulations were used to compute the distribution of preferred roles for the current condition and chest pain vignettes. A correlation matrix examined the relationships between perceived health information literacy, patients’ preferred roles, and trust in physician.

Because patients’ perceived roles are an ordinal variable, we conducted a Spearman’s correlation. A Pearson’s correlation was used for trust in physician, perceived health literacy, and age, which are continuous variables. In interpreting these correlations, a value of .00-.19 indicates a very weak correlation; .20-.30 indicates a weak correlation; .40-.59 indicates a moderate correlation; .60-.79 indicates a strong correlation, and .80-1.0 indicates a very strong correlation. (113) As shown in Table 4.7 in Chapter 4, independent samples t-tests were conducted to compare the differences in trust in physician and perceived health information literacy scores between patients who preferred a shared vs. passive role.
A binary logistic regression was computed to see which variables (trust in physician or patients’ perceived levels of health information literacy) predicted patients’ preferred roles (passive or shared) in treatment decision making. Both the t-test and logistic regression did not include patients who preferred an autonomous role because there were not enough patients who preferred an autonomous role to include them in the statistical analysis.

The results of the binary logistic regression are described in section 4.1.9 and in Table 4.14 and Table 4.15 of the thesis. They include the following features: Wald criterion, Nagelkere $R^2$, degrees of freedom, and standard error. The results of these findings are presented in Chapter 4, section 4.1.9. A Nagelkerke $R^2$ value indicates the strength of a relationship between the variables. A value of 0-0.15 indicates a weak relationship. The Wald criterion is a parametric statistical test that looks at the relationship within or between data items can be expressed as a statistical model with parameters to be estimated from a sample. The standard error is a measure of statistical accuracy of an estimate, equal to the standard deviation of the theoretical distribution of a large population of such estimates. Degrees of freedom (df) is a statistical measure that looks at each of a number of independently variable factors affecting the range of states in which a system may exist. (113)

3.8 Qualitative interviews

Semi-structured one-on-one interviews with a random sample of respondents who had agreed to participate were conducted using a follow-up phone call at a mutually convenient time. This random sampling was used to help avoid bias. To preserve anonymity, we did not link the qualitative interviews to the quantitative surveys. The purpose of the qualitative interviews was to explore themes that were not yet captured in the quantitative surveys. For this purpose, a semi-
structured interview guide (Appendix 2) was developed by the researcher to further explore the following issues:

- Sources of health information
- Credibility and trustworthiness of online health care information
- Reasons for patients’ preferred roles
- Sources of information that patients used to make health-related decisions
- Factors that influenced the patients’ preferred roles and increased the trust that they had in their health care provider

Follow-up questions and prompts were used to either further explore some concepts in depth or re-direct patients’ answers to the topic of interest. For example, one question asked, “What are the sources of information that you consider when looking for more information on your health care condition? How do these vary by the type of health care condition?” Patients were given prompts such as online sources, websites, or family physicians that could be specific examples of sources of health information if they were not able to answer the question directly. To help ensure clarity, the first several patients interviewed were asked whether the questions were clear. These questions were clear to the participants and it was not necessary to modify the semi-structured interview guide. A pilot of the qualitative interview questions was conducted with primary care patients to ensure that interview questions were clear and that the interview was completed within a 20-30-minute time frame. The qualitative interview questions were pilot tested for the same two reasons: timing and to ensure clarity of the questions within the interview.
3.8.1 Data collection: semi-structured interviews

With consent and permission from patients, the interviews were audio recorded and transcribed verbatim. In addition, or if permission to record was not granted, the interviewer took notes during the interview. Patients were interviewed until theoretical saturation was reached. If patients required family members to be present in the interview for the purpose of translation or assisting with questions, this was allowed.

3.8.2 Qualitative interviews data analysis

The researcher transcribed the audiotapes of the qualitative interviews and annotated her findings after conducting semi-structured interviews. Annotation involved understanding and interpreting the findings within each interview transcript. After annotation, the researcher used open coding and searched for the broader themes that emerged. Coding is a process of organizing and sorting qualitative data. (108) The first part of the coding process involved analyzing transcripts for broader concepts and codes. From the interview transcripts, a sub set of codes was created. The codebook can be found in Appendix 9. The coding was done by hand in a MS Word document using the comments function and memos. Coding was done in an inductive way. These codes were then analyzed to synthesize patterns and themes amongst these codes using constant comparisons. The constant comparison method involved breaking down data into discrete “incidents” or “units” and coding the data into categories. (114, 115) During the coding process, categories emerged from the data. (114, 116, 117) This process of analysis involved reading the transcripts, considering the codes, units and other categories to inductively derive the themes from the qualitative data.
A coding scheme was used and the codes were organized into a tree structure to help guide the process of coding and thematic analysis. This coding tree structure emerged from the data. (108) A systemic set of procedures was used to analyze the data for a set of codes. For example, after interview transcription, recurrent concepts were grouped in the same code. Through this process of inductive reasoning and coding, we analyzed the recurrent patterns and themes from the qualitative interviews. (108) After concepts were broken down into units or categories, they were then re-built in the process of thematic analysis. Thematic analyses were important to discover patterns from the qualitative interviews. The themes that arose from the qualitative interviews provided further insights into patients’ preferred role in treatment decision-making, their level of reported health information literacy, and their level of trust in physician. The interview subjects were given codes of (R1-R11), which were used to anonymously identify the sources of quotes used in the analysis.

To ensure consistency in coding, another graduate student reviewed 3 of the transcripts and coded them independently. This was done to see if he agreed on the codes for the transcript or had additional suggestions about more codes. Both researchers agreed 85% of the time. For the codes where there was disagreement, both researchers discussed the options and came to a consensus on the most relevant code and theme. Any new and emerging codes were reviewed by the research team.

3.9 Ensuring privacy & confidentiality

Throughout data collection and analysis, we ensured privacy and data protection in accordance with the Personal Health Information Protection Act (PHIPA) and Personal Information Protection & Electronic Documents Act (PIPEDA), as well as institutional ethics
These guidelines adhere to privacy legislation in Ontario, which recommends that patient personal identifiers such as a patients’ name, age, and date of birth are kept confidential and limited to the research team. Thus, patient surveys were de-identified for the purpose of data analysis. Each patient was assigned a “patient code”, which removed the patients’ name, age, and other identifiers for the purpose of confidentiality in this research study. All data was kept in a locked filing cabinet at the Li Ka Shing Knowledge Institute in Dr. Persaud’s office. Only the core research team had access to this data. Demographic data was kept separate from the survey data so that research team doing the analysis did not have access to the personal identifying information of those being surveyed. During the process of informed consent, patients were notified of their privacy and confidentiality rights. Participants were notified that their name would not be included in data analysis.

3.10 Synthesis of quantitative and qualitative research

As per multi-method study design, the results of the quantitative and qualitative findings are reported separately. The synthesis of these results occurs in the discussion of the thesis.
CHAPTER 4: RESULTS

4.1 Quantitative results

4.1.1 Descriptive statistics

We approached 158 people in the primary care clinic at St. Michael’s Hospital of whom 141 agreed to participate in this research study (89% response rate). When asked about the reason for non-participation, all of the patients stated that it was due to lack of time.

One patient completed all but the e-HEALS scale; because he or she did not use a computer, the e-HEALS scale was not applicable to that patient. Therefore, a total score of 0 was assigned for the e-HEALS scale for this patient. Of the 141 respondents, 5 began but did not complete the survey due to time limitations. All of the patients completed the PSDM scale, but some did not complete the e-Heals and or the trust in physician scale. This was because these patients were called into their medical appointment, and were not available to complete the survey afterwards. Therefore, for these patients, only the completed components of the survey were included in the analysis.

Table 4.1 describes the characteristics of the 141 patients in the primary care clinic who participated in the study. In compliance with ethical requirements including privacy legislation, and in order to maintain confidentiality, if the cell count was less than or equal to 5, we grouped these cells so that respondents were not identifiable.

As noted in Table 4.1, of the 141 participants, 60% were female, and 40% were male. Most spoke English as their first language. Almost half of the participants were married or had common-law partners, and almost half were single. When considering the ethnicity of patients,
the sample reflected the ethnic and cultural diversity of Toronto; only 36% of participants self-reported as being of Caucasian origin. The vast majority of patients had some level of post-secondary education. Patients’ ages ranged from 18 to 81 (mean age = 43).

Table 4.1: Demographic characteristics of sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N=141)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>56 (40%)</td>
</tr>
<tr>
<td>F</td>
<td>85 (60%)</td>
</tr>
<tr>
<td><strong>First Language Spoken</strong></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>129 (91.5%)</td>
</tr>
<tr>
<td>Other Languages (Mandarin, French, Tamil, Spanish, Italian, Korean, Nepali)</td>
<td>12 (8.5%)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married or common-law partner</td>
<td>66 (47%)</td>
</tr>
<tr>
<td>Single</td>
<td>66 (47%)</td>
</tr>
<tr>
<td>Other (Engaged, Widow, Not-Reported)</td>
<td>9 (6%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian (British, Canadian)</td>
<td>51 (36.1%)</td>
</tr>
<tr>
<td>Variable</td>
<td>n (%)</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>(N=141)</td>
<td>(N=141)</td>
</tr>
<tr>
<td>Latino</td>
<td>21 (14.8%)</td>
</tr>
<tr>
<td>South Asian</td>
<td>6 (4.2%)</td>
</tr>
<tr>
<td>Not reported</td>
<td>6 (4.2%)</td>
</tr>
<tr>
<td>Other (First Nations + Mixed Ethnicity, East Asian, African American, Chinese, Dutch, Jewish, Polish, Irish, First Nations)</td>
<td>57 (40.4%)</td>
</tr>
</tbody>
</table>

**Highest Level of Completed Education**

<table>
<thead>
<tr>
<th>Highest Level of Completed Education</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School</td>
<td>17 (12%)</td>
</tr>
<tr>
<td>Community College Level</td>
<td>41 (29%)</td>
</tr>
<tr>
<td>Undergraduate Studies</td>
<td>40 (28.3%)</td>
</tr>
<tr>
<td>Graduate Level Studies – MSc, PhD</td>
<td>29 (20.6%)</td>
</tr>
<tr>
<td>Post-graduate Professional Training Programs (RN, MD, JD)</td>
<td>14 (9.9%)</td>
</tr>
</tbody>
</table>

**Age Group**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-20</td>
<td>5 (3.5%)</td>
</tr>
<tr>
<td>21-30</td>
<td>19 (14.5%)</td>
</tr>
</tbody>
</table>
Patients had visited the clinic for a variety of reasons, including for a regular health checkup, immunizations, mental health concerns, pregnancy, medication change or to manage their current health condition. Some patients had multiple co-morbidities. Common co-morbidities included hypertension or diabetes.

The results reported in sections 4.1.2-4.1.4 relate to research question 1: “In this sample of primary care patients, what are their: preferred roles, trust in physician, and perceived health information literacy?”

### 4.1.2 Patients preferred roles

As described in the scoring strategy in section 3.4.1, patients’ responses to the PSDM scale were computed for both the current condition and chest pain vignette. As described in Chapter 3, the scores categorize patients into: **passive; shared** (which can be sub-classified into

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N=141)</td>
<td></td>
</tr>
<tr>
<td>31-40</td>
<td>50 (35%)</td>
</tr>
<tr>
<td>41-50</td>
<td>26 (18%)</td>
</tr>
<tr>
<td>51-60</td>
<td>20 (14%)</td>
</tr>
<tr>
<td>61-70</td>
<td>11 (7.8%)</td>
</tr>
<tr>
<td>71-90</td>
<td>10 (7.09%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>141 (100%)</strong></td>
</tr>
</tbody>
</table>
leaning passive, divide and share, equally, or leaning autonomous), or *autonomous* (which can be sub-classified into leaning shared, consumerist). (30) Table 4.2 presents patients’ preferred roles for the current health condition. Table 4.3 presents patients’ preferred roles for the chest pain vignette. Figure 4.1 summarizes the findings for both vignettes. Figure 4.1 summarizes the findings for both conditions. The current health conditions reported by patients (for which they were seeing their doctor) included: respiratory conditions (asthma), cardiovascular conditions, and mental health conditions.

**Table 4.2: Patients’ preferred role; current health condition vignette**

<table>
<thead>
<tr>
<th>Decision-Making</th>
<th>Problem-Solving</th>
<th>Hand over</th>
<th>Share</th>
<th>Keep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand over</td>
<td>Passive</td>
<td>n= 28 (20%)</td>
<td>Theoretically implausible</td>
<td>n= 0 (0%)</td>
</tr>
<tr>
<td></td>
<td>n= 80 (57%)</td>
<td>n=16 (11%)</td>
<td>Autonomous (leaning shared)</td>
<td>n= 0 (0%)</td>
</tr>
<tr>
<td>Keep</td>
<td>Shared (divide and share)</td>
<td>n= 14 (10%)</td>
<td>Shared (leaning autonomous)</td>
<td>n=0 (0%)</td>
</tr>
</tbody>
</table>
For the current health care vignette, it is notable that most patients ((n=113); (80%) of patients preferred a shared role, 20% preferred a passive role, and none of them preferred an autonomous role.

There are slight differences for the chest pain vignette, which could be life threatening. Table 4.3 presents patients’ preferred roles for the chest pain vignette.

**Table 4.3: Patients’ Preferred role; chest pain vignette**

<table>
<thead>
<tr>
<th>Decision-Making</th>
<th>Patients’ Preferred Roles (N=141)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Problem Solving</td>
</tr>
<tr>
<td></td>
<td>Hand over</td>
</tr>
<tr>
<td>Hand over</td>
<td>Passive</td>
</tr>
<tr>
<td></td>
<td>n= 45 (32%)</td>
</tr>
<tr>
<td></td>
<td>Theoretically implausible</td>
</tr>
<tr>
<td></td>
<td>n=0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Theoretically implausible</td>
</tr>
<tr>
<td></td>
<td>n=0 (0%)</td>
</tr>
<tr>
<td>Share</td>
<td>Shared (leaning passive)</td>
</tr>
<tr>
<td></td>
<td>n= 59 (42%)</td>
</tr>
<tr>
<td></td>
<td>Shared (equally)</td>
</tr>
<tr>
<td></td>
<td>n= 8 (6%)</td>
</tr>
<tr>
<td></td>
<td>Autonomous (leaning shared)</td>
</tr>
<tr>
<td></td>
<td>n=0 (0%)</td>
</tr>
<tr>
<td>Keep</td>
<td>Shared (divide and share)</td>
</tr>
<tr>
<td></td>
<td>n= 23 (16%)</td>
</tr>
<tr>
<td></td>
<td>Shared (leaning autonomous)</td>
</tr>
<tr>
<td></td>
<td>n=4 (3%)</td>
</tr>
<tr>
<td></td>
<td>Autonomous (consumerist)</td>
</tr>
<tr>
<td></td>
<td>n=2 (1%)</td>
</tr>
</tbody>
</table>
The differences between the two vignettes are summarized in the next section.

**Comparison between current condition and chest pain vignettes:**

The following graph summarizes preferred roles using the three main categories: passive, shared (which incorporates the four sub-categories of shared leaning passive, shared divide and share, shared equally, and shared leaning autonomous), and autonomous (which incorporates the two sub-categories of autonomous leaning shared, and autonomous consumerist). These main groupings will be used for the remainder of the analyses.

Comparing results for the current condition and chest pain vignettes, we note that the results were similar. The majority of the patients surveyed (67%) preferred a shared role. However, in the chest pain scenario, two patients (1.4%) preferred an autonomous role, whereas none had for the current condition vignette. However, a higher percentage of people preferred to take a passive role in the chest pain vignette as compared to the current condition (32% vs. 20%).
Figure 4.1: Preferred role – current condition vs. chest pain vignettes (N=141)

4.1.3 Perceived health information literacy analysis

Patients’ perceived health information literacy was measured using the e-HEALS scale described in section 3.4.1 B. Scores ranged from 8 to 40 on a scale that ranges from 0 to 40, with higher scores indicating a greater level of perceived skill at finding, evaluating, and applying online health information when making health decisions (35). The mean perceived health information literacy for patients in this sample was 27 with a standard deviation of 6. As noted in section 4.1, five patients were unable to complete the e-health literacy scale due to timing of their clinical appointment. One person did not have a computer and was therefore deemed to have a
score of 0 on the e-HEALS scale. Therefore, for this scale, these responses were counted as missing data. The mean perceived health information literacy for patients in this sample was 27 with a standard deviation of 6; and the median score was 28. This indicates a medium level of perceived health information literacy. As seen in Figure 4.2, the distribution was skewed to the right. Table 4.4 provides the breakdown of patients’ perceived health information literacy (low, medium, and high). As can be seen by this table, most of the patients had a medium (n=71; 52%) or high (n=50; 37%) level of perceived health information literacy.

Table 4.4: Perceived health information literacy distribution of patients

<table>
<thead>
<tr>
<th>Level of perceived health information literacy</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (0-20)</td>
<td>15/136 (11%)</td>
</tr>
<tr>
<td>Medium (21-30)</td>
<td>71/136 (52%)</td>
</tr>
<tr>
<td>High (31-40)</td>
<td>50/136 (37%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>5/141 (3.5%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>141 (100%)</strong></td>
</tr>
</tbody>
</table>
4.1.4 Trust in physician analysis

As described in section 3.4.1, a trust in physician score was computed for each patient. The scale ranged from 11-55. During the creation and validation of this scale, the authors of the scale did not specify cut-offs to classify into low, medium, or high levels of trust. (119) As noted above, five patients did not complete the trust in physicians scale and this was counted as missing data, leaving n=136 respondents for this scale. The mean trust score was 43 ±7 (M ± SD). As shown in Figure 4.3, provides the trust in physician scores are skewed to the right.
This means that primary care patients in this sample had high levels of trust in their health care provider.

Figure 4.3: Trust in physician score histogram

Sections 4.1.5 and 4.1.7-4.1.8 answer research question 3B, “What are the differences in trust in physician, perceived health information literacy, gender, age, and perceived health information literacy between patients with passive and shared preferred roles? Is there a difference between the current condition and the chest pain vignettes?”
4.1.5 Group comparisons of perceived health information literacy and trust in physician, between preferred roles

Table 4.5 shows the trust and perceived health information literacy scores by patients’ preferred roles for patients’ current health condition vignette; table 4.6 shows the same analysis for the chest pain vignette. Autonomous patients were not included in this analysis because there were too few in that category. The table reports the mean, SD, and confidence intervals for each of these variables for the passive and shared patients. It then reports the results of an independent samples t-test, which compares the means for these two groups (for the perceived health information literacy score, and the trust in physician score) in order to determine whether there is statistical evidence that the associated means are significantly different for passive vs. shared patients. It then reports the effect size (Cohen’s d).
Table 4.5 Perceived health information and trust in physician by patients’ preferred roles for the current condition vignette

<table>
<thead>
<tr>
<th>Patients’ Preferred Role for Current Condition</th>
<th>Passive Patients (n=28)</th>
<th>Shared Patients (n=113)</th>
<th>t (p-value)</th>
<th>Effect Size Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Health Information Literacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean± (SD)</td>
<td>26±(6); [24, 29]</td>
<td>28±(7); [2,29]</td>
<td>1.12 (0.269)</td>
<td>-0.306</td>
</tr>
<tr>
<td>95% CI [low, high]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in Physician Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean±(SD)</td>
<td>46±(6); [44, 49]</td>
<td>42±(7); [41,44]</td>
<td>-0.31 (0.003)</td>
<td>0.613</td>
</tr>
<tr>
<td>95% CI [low, high]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patients who preferred a shared role showed a trend of having a higher level of perceived health information literacy than those in who preferred a passive role (M± (SD)) (28 ±(7)) and (26±6), respectively. This difference was not statistically significant (t=1.12, p=0.269). The effect size was small (Cohen’s d=0.306).

Although both levels were high, patients in the passive category had a statistically significant higher level of trust in physician compared to those in the shared category (M±SD of 46± (6) and 42± (7), respectively; t=-0.31, p=0.03). The effect size was large (Cohen’s d=0.613).

Table 4.6 shows the trust and perceived health information literacy scores by patients’ preferred roles for chest pain vignette. An Independent samples t-test was conducted to test whether there were statistically significant differences in perceived health information literacy.
and trust in physician scores between passive and shared patients for the chest pain vignette. Autonomous patients were not included in this analysis because there were too few in that category.

Table 4.6 Perceived health information and trust in physician by patients’ preferred roles for the chest pain vignette

<table>
<thead>
<tr>
<th>Patients’ Preferred Role for Chest Pain</th>
<th>Passive Patients (n=45)</th>
<th>Shared Patients (n=94)</th>
<th>t (sig.)</th>
<th>Effect Size Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Health Information Literacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean ± (SD)</td>
<td>27±(7); 95% [25, 29]</td>
<td>28±(6); 95% [27, 29]</td>
<td>0.893 (0.374)</td>
<td>-0.153</td>
</tr>
<tr>
<td>95% CI [low, high]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in Physician Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean± (SD)</td>
<td>45±(7); 95% [43, 48]</td>
<td>42±(7); 95% [41, 44]</td>
<td>-2.5 (0.013)</td>
<td>0.428</td>
</tr>
<tr>
<td>95% CI [low, high]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the chest pain vignette, in terms of perceived health information literacy, patients who preferred a shared role had a slightly higher mean perceived health information literacy (28 ±(6); (M ± (SD)) than those who preferred a passive role ((27±7(M ± (SD)). This difference was not statistically significant (t=0.893, p=0.374). The effect size was small (Cohen’s d= -0.153).
Similarly, although both levels were high, patients in the passive category had a statistically significant higher level of trust in physician compared to those in the shared category (M±SD of 45± (7) and 42± (7), respectively; t=-2.5, p=0.013). The effect size was moderate (Cohen’s d=0.428) for the trust in physician score. As can be seen in Table 4.5 and 4.6, when comparing patients who preferred a shared vs. passive role, there was a statistically significant difference in the trust in physician score for both the current condition and chest pain vignette. Of note, the Cohen’s d for the trust in physician score was high for the current condition vignette. Both the vignettes provided the same result, which was that only trust in the physician differed significantly between the passive and shared patients.

Section 4.1.6 answers the research question 3: “What are the relationships between patients’ preferred role, trust in physician, perceived health information literacy?”

4.1.6 Pearson and Spearman’s correlations between patient’s trust in physician, perceived health information literacy scores and preferred roles

To further test the relationship between the various variables, Pearson or Spearman correlations were calculated for continuous and non-continuous variables, respectively. Table 4.7 below reports the Pearson or Spearman’s correlation (r) for correlations between continuous and non-continuous variables, respectively and the 2-tailed significance (p) for each of the correlations.

As can be seen in Table 4.7 below, there was a weak but statistically significant correlation between patients’ problem-solving (current condition) score and their trust in physician score (Spearman’s r=0.202, p=0.020). There was also a weak but statistically significant correlation between patients’ DM (current condition) score and their PS (current condition) score (r=0.299,
p=0.000). There was a weak but statistically significant relationship between patients DM (chest pain) and their PS score (chest pain) (r=0.327, p=0.000). There was also a strong correlation between patients’ PS (chest pain) score and their PS current condition score (r=0.706, p=0.000). There was a strong correlation between patients’ DM (chest pain) score and their DM score for the current condition (r=0.955, p=0.000).
Table 4.7 Correlation matrix of key variables

<table>
<thead>
<tr>
<th></th>
<th>1. Age</th>
<th>2. DM score (chest pain)</th>
<th>3. DM score (current condition)</th>
<th>4. PS score (chest pain)</th>
<th>5. PS score (current condition)</th>
<th>6. Perceived health information literacy score</th>
<th>7. Trust in physician score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. DM score (chest pain)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r=-0.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. DM score (current condition)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r=-0.12</td>
<td></td>
<td></td>
<td>r=0.955***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. PS score (chest pain)</td>
<td></td>
<td></td>
<td>r=0.327***</td>
<td>r=0.299**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r=0.130</td>
<td></td>
<td></td>
<td>r=0.327***</td>
<td>r=0.299**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. PS score (current condition)</td>
<td></td>
<td></td>
<td>r=0.237**</td>
<td>r=0.293**</td>
<td>r=0.706***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r=0.158</td>
<td></td>
<td></td>
<td>r=0.237**</td>
<td>r=0.293**</td>
<td>r=0.706***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Perceived health information literacy score</td>
<td>r=-0.102*</td>
<td>r=0.150</td>
<td>r=0.185</td>
<td>r=0.029</td>
<td>r=0.161</td>
<td>r=0.070*</td>
<td></td>
</tr>
<tr>
<td>7. Trust in physician score</td>
<td>r=0.032*</td>
<td>r=-0.151</td>
<td>r=-0.203*</td>
<td>r=0.023</td>
<td>r=-0.202*</td>
<td>r=0.070*</td>
<td>1</td>
</tr>
</tbody>
</table>

**Legend**: In Table 4.7, *=p<0.05, **=p<0.01, ***=p<0.001. A Pearson’s correlation was computed if there is an ‘a’. Otherwise, Spearman’s correlation.
Scatter plots are in Appendix 6 for all of the correlations in Table 4.7 above. As noted in Table 4.2, most patients are within the shared category. Therefore, when looking at the relationship between trust in physician and the DM scores of patients, there is a weak relationship between these two variables as noted in Table 4.17. This might be because this group of patients most people had high levels of trust in their physician, meaning that there was not much variability in the trust in physician scores.

4.1.7 Differences in perceived health information literacy and trust in physician between patients with different demographic characteristics

We did a comparison on key demographic characteristics such as highest level of education and gender to see whether there were statistically significant differences. These comparisons included age, education, and gender.

Education

The next analyses examined differences between patients and their different levels of education. The chi-squared test was first conducted with group-to-group comparisons of patients’ perceived health information literacy based on their highest level of completed education. We divided patients into 5 groups based on their highest level of completed education. We then did a chi-squared test to see whether patients’ perceived health information, and their trust in physician scores varied by the highest level of completed education.

Patients’ mean and standard deviation, perceived health information literacy, and trust in physician scores were computed for their education level. As seen in Table 4.8 below, perceived health information literacy increases as the level of education increases except for those whose
highest level was graduate school who had a slightly lower score than those with undergraduate degrees.

Table 4.8 Patients’ mean and standard deviation perceived health information literacy by level of highest education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Perceived Health Information Literacy (Mean ± (SD))</th>
<th>Trust in physician (Mean ± (SD))</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school</td>
<td>25±(9)</td>
<td>43 ± (6)</td>
</tr>
<tr>
<td>Community college</td>
<td>26±(5)</td>
<td>44± (6)</td>
</tr>
<tr>
<td>Undergraduate studies (Bachelors)</td>
<td>30±(6.5)</td>
<td>43 ± (7)</td>
</tr>
<tr>
<td>Graduate (Masters, undergraduate Medicine)</td>
<td>27 ±(6)</td>
<td>40± (8)</td>
</tr>
<tr>
<td>Post-graduate training (Post-doctoral training PhD)</td>
<td>30 ±(5)</td>
<td>44± (5)</td>
</tr>
</tbody>
</table>

One-way ANOVAs were conducted to see whether there was a significant difference in perceived health information literacy and trust in physician score between patients with different levels of education. Patients’ average trust in physicians score and standard deviation was also
computed by their education level. The difference was significant (F(4)=2.514, p=0.045) for perceived health information literacy. Since the difference was significant, a post-hoc Tukey’s test was conducted. There was no significant difference in the trust in physician scores between patients of different education levels (F(4)=0.958, p=0.434). The post-hoc Tukey’s test was not significant between any of the groups. The post-hoc Tukey’s was statistically insignificant because there was not much variability in the sample.

*Perceived health information literacy: gender comparisons*

The mean perceived health information literacy score for males and females were (28±6.1) (M± (SD)) and (28±6.6) (M± (SD)), respectively. A t-test was completed to look at the differences in health information literacy between genders (male and female patients). The results of this t-test were not statistically significant (t (140)=0.081, p=0.936).

*Trust in physician score: gender comparisons*

The mean perceived trust in physician score for males was (44±6), and for females it was (42±8) (M± (SD)), respectively. A t-test was completed to look at the differences in the trust score between genders (male and female patients). The results of this t-test were not statistically significant (t (122)=1.544, p=0.125).

**4.1.8 Differences in preferred roles based on demographic characteristics (gender, education, age)**

*Gender and preferred role:*

A chi-square test was conducted to look at patients’ gender and their preferred role for the current condition and chest pain vignette (Tables 4.9 and 4.10, respectively). As seen in Table 4.9 below, the majority of both males and females preferred a shared role. The differences
in preferred roles between males and females were not statistically significant $\chi^2(1) = 5.32$, $p=0.466$).

**Table 4.9: Gender and patients’ preferred role – current health condition vignette**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Passive</th>
<th>Shared</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>17 (20%)</td>
<td>68 (80%)</td>
<td>84 (100%)</td>
</tr>
<tr>
<td>Male</td>
<td>11 (20%)</td>
<td>45 (80%)</td>
<td>56 (100%)</td>
</tr>
<tr>
<td>Total</td>
<td>28 (20%)</td>
<td>113 (80%)</td>
<td>141 (100%)</td>
</tr>
</tbody>
</table>

**Table 4.10: Gender and patients’ preferred role – chest pain vignette**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Passive</th>
<th>Shared</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>22 (26%)</td>
<td>62 (74%)</td>
<td>84 (100%)</td>
</tr>
<tr>
<td>Male</td>
<td>23 (42%)</td>
<td>32 (58%)</td>
<td>55 (100%)</td>
</tr>
<tr>
<td>Total</td>
<td>45 (32%)</td>
<td>94 (68%)</td>
<td>139 (100%)</td>
</tr>
</tbody>
</table>

Similarly, the majority of both males and females preferred a shared role for the chest pain vignette (Table 4.10). Note that $n=139$ for Table 4.10, since it omits the 2 patients who preferred an autonomous role. However, looking at the results (%) shows that the difference in the proportion of those who preferred a shared role vs. passive was greater for females. The differences in preferred roles between male and female participants for this condition was statistically significant ($\chi^2 (1) = 4.02$, $p=0.045$).
Education and preferred role

Since there are some small cell counts of \( \leq 5 \), a Fischer’s exact test was applied to test the differences in preferred role between patients with different highest levels of education for the current condition and chest pain vignettes (Tables 4.11 and 4.12, respectively). A Fisher’s exact test was conducted. As seen in Table 4.11, most patients preferred a shared role for the current condition. The differences in preferred roles between patients with different levels of education for the chest pain were not statistically significant \( (\chi^2 (4) = 23, p=0.873) \).

Table 4.11 Education level and patients’ preferred role- current condition vignette

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Preferred Role</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>1</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>College</td>
<td>10</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Undergraduate</td>
<td>10</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Graduate- MSc, PhD</td>
<td>5</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Professional Program</td>
<td>2</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>107</td>
<td></td>
</tr>
</tbody>
</table>
Similarly, the majority of participants preferred a shared role for the chest pain vignette (Table 4.12). In Table 4.12, the total number of patients (shared and passive) is 138; this table omits the two patients who preferred an autonomous role, and one who did not report their education level. Education is not significantly related to preferred roles for the chest pain vignette ($\chi^2 (4) =26, p=0.705$).

**Table 4.12 Education level and patients’ preferred role- chest pain vignette**

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Preferred Role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive</td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
</tr>
<tr>
<td>College</td>
<td>14</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>13</td>
</tr>
<tr>
<td>Graduate- MSc, PhD</td>
<td>14</td>
</tr>
<tr>
<td>Professional Program</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
</tr>
</tbody>
</table>

**Age and preferred role:**

The mean age of patients in the passive and shared category was calculated for both the current condition and chest pain vignettes. Table 4.1.3 presents the mean age and standard deviation for the shared and passive patients.
Table 4.13 Mean age of passive and shared patients for the current condition and chest pain vignette

<table>
<thead>
<tr>
<th></th>
<th>Chest pain vignette</th>
<th>Current condition vignette</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shared role</strong></td>
<td>(Mean± (SD): (43 ± 15)</td>
<td>(Mean± (SD): (44 ± 15)</td>
</tr>
<tr>
<td><strong>Passive role</strong></td>
<td>(Mean± (SD): (46 ± 15)</td>
<td>(Mean± (SD): (44 ± 16)</td>
</tr>
</tbody>
</table>

An independent samples t-test was conducted to examine differences in primary care patients’ mean age between the passive and shared patients for both the current condition and chest pain vignette. No statistically significant differences were found for the chest pain condition (t (140) = -1.69, p=0.094) or for the current health condition vignette (t (140)= -1.34, p=0.083).

4.1.9 Perceived health information literacy and trust in physician as predictors of patients’ preferred roles

This section answers research question, “To what extent do patients’ perceived health information literacy scores and trust in physician scores relate to their preferred roles for their current condition and chest pain vignette”
Binary logistic regression analyses were computed to see whether patients’ perceived health information literacy and trust in physician scores could predict whether they preferred a shared or passive role for the current condition and the chest pain vignettes. There were too few people in the autonomous category (n=2) to include them in this analysis. The details of the binary logistic regression are in Appendix 7.

**Preferred roles: Current Condition**

For the current condition, a test of the full model against a constant only model indicated that this model was statistically significant and can reliably distinguish between participants preferred roles. ($\chi^2 (2) = 10.60, p = 0.005$).

As described in section 3.7, the Nagelkerke $R^2$ and Wald criterion were computed. We looked at whether trust in physician and perceived health information literacy could predict patients’ preferred roles. Only shared and passive patients were included in this analysis. A Nagelkerke’s $R^2$ of .126 indicated a weak relationship between prediction and grouping. With the predictors added, the percentage of correct classification decreased from 79.4% to 78.6% (refer to Appendix 7 for these additional tables). This means that although the binary logistic regression model was statistically significant, it did not have predictive power. As can be seen in Table 4.13, the Wald criterion demonstrated that only the trust score made a significant contribution to prediction ($p = 0.007$). Participants e-Heals score was not a significant predictor ($p=0.132$). Exp (B) value indicates that a patient with one point higher score on the trust in physician scale is 11.4% more likely to prefer a shared role.
Table 4.14 Binary logistic regression: current condition vignette

<table>
<thead>
<tr>
<th>Variables in the Binary Logistic Regression Equation</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Exp (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables in the Regression</td>
<td>Trust in physician</td>
<td>.114</td>
<td>.042</td>
<td>7.304</td>
<td>1</td>
<td>.007</td>
</tr>
<tr>
<td>e-Heals Score</td>
<td>-.054</td>
<td>.036</td>
<td>2.266</td>
<td>1</td>
<td>.132</td>
<td>.947</td>
</tr>
<tr>
<td>Constant</td>
<td>-4.992</td>
<td>2.024</td>
<td>6.080</td>
<td>1</td>
<td>.014</td>
<td>.007</td>
</tr>
</tbody>
</table>

Preferred Role: Chest Pain Situation

For the chest pain vignette, a test of the full model against a constant only model indicated that this model was statistically significant and can reliably distinguish between participants preferred roles ($\chi^2(2) = 9.39$, $p = 0.009$).

Table 4.15 Binary logistic regression chest pain vignette

<table>
<thead>
<tr>
<th>Variables in the Binary Logistic Regression Equation</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables in the Binary Logistic Regression</td>
<td>Trust in physician</td>
<td>.084</td>
<td>.033</td>
<td>6.517</td>
<td>1</td>
<td>.011</td>
</tr>
<tr>
<td>e-Heals score</td>
<td>-.050</td>
<td>.031</td>
<td>2.646</td>
<td>1</td>
<td>.104</td>
<td>.951</td>
</tr>
<tr>
<td>Constant</td>
<td>-3.111</td>
<td>1.584</td>
<td>3.855</td>
<td>1</td>
<td>.050</td>
<td>.045</td>
</tr>
</tbody>
</table>

A Nagelkerke’s $R^2$ of .100 indicated a weak relationship between independent and dependent variables. The predictive power of the model is weak. The correct classification of
the observed cases increased from 68% in the null model to 70% (refer to Appendix 7 for the tables) in the final model. As can be seen in Table 4.14, the Wald criterion demonstrated that only the trust score made a significant contribution to prediction (p = 0.011). Participants’ e-Heals score was not a significant predictor (p=0.104). The Table reports Exp (B) values that indicate that a patient with one point higher score on the trust scale is 8.4% more likely to prefer a shared role.

4.1.10 Post-hoc power calculation

Although post-hoc power analysis has been criticized as a means of interpreting a negative study result, it is recommended as a way to tell whether the study is appropriately powered. (120)

Post-hoc power calculations were done using G*Power 3.1.9.2 software. (121, 122). A post-hoc power calculation was completed for the logistic regression and for the 4 t-tests for the differences in trust in physician and e-Heals score between shared vs. passive patients (for both the chest pain and current condition vignettes) to see if the sample size provided sufficient power for this analysis.

The data for the power calculation (effect sizes and group sizes for shared and passive patients) were taken from Tables 4.5 and 4.6 and the results are presented in Table 4.15 below and in Appendix 8. A numerical value of greater than 0.8 in Table 4.16 indicates a reasonably powered post-hoc test. Results showed that that except for trust in physician for the current condition, the sample size did not supply sufficient power to detect statistically significant differences between the shared and passive patients given the rather small variation in the responses.
For logistic regression, researchers recommend that there be a minimum of 10 outcome events per predictor variable in the analysis. Some authors suggest that even this rule is conservative in some cases. In this study, there were two predictors of patients’ preferred role (shared or passive) in the logistic regression (trust in physician and e-Heals score). Therefore, a minimum sample of 20 people in each category of shared and passive patients would supply adequate power for detecting statistically significant effects of the two predictor variables. The smallest group in the logistic regression had 28 and 45 participants in the passive category for the current condition and chest pain vignettes, respectively. Therefore, based on the rule of 10 outcome events per predictor, for this logistic regression, we had adequate power to detect statistically significant effects of these two predictor variables (trust in physician and e-Heals score).

Section 4.2 below describes the findings of qualitative interviews that were conducted with 11 patients. The findings of this section of the thesis relate to the themes under research questions 4A-C:
4A) How are primary care patients’ perceptions of their perceived e-health literacy and sources of health information literacy related to their preferred roles?

4B) How do primary care patients assess the trust that they have in their physician, the credibility of health information online, and also their communication with their health care provider?

4C) How does this then influence the patient-physician relationship?

4.2 Qualitative findings

Qualitative interviews were completed with 11 primary care patients until we reached thematic saturation. These interviews revealed six major themes including: 1) sources of health information utilized by patients; 2) how patients considered the reliability and trustworthiness of online health information; 3) frequency of websites used; 4) patients’ preferred roles and factors that influence them; 5) factors that influence the patient-physician relationship; and 6) patients’ preferred forms of communication. The following sections describe these themes in detail.

4.2.1 Theme 1: Sources of health information utilized by patients

As noted in Tables 4.4 and 4.5 in section 4.3, primary care patients in this sample reported high levels of perceived health information literacy. They mentioned two main sources of health information in the interviews: online and in person. Sources of health information that were consulted in person included their health care provider, and friends and family members who were also health care providers. These other providers included occupational therapists, dietitians, and physiotherapists. Patients also consulted online sources of health information for both themselves and their friends and family members.
Websites were a common source of online health information for patients. Google was the most frequently mentioned online search engine; eight patients stated that they started with Google and performed keyword searches to find other websites. Patients often accessed multiple websites, including the Mayo Clinic and Medicine-Net websites, which provided information on medications that patients were prescribed for their health condition. A couple who were new parents used an e-book called “When baby comes home” to search symptoms and help them decide when they should take the baby to see the doctor. The couple used this e-Book and websites from Toronto Public Health during the pregnancy to see which medications are safe for the wife to use during her pregnancy. One patient searched the About Kids Health website for information related to their child’s mental health and Attention Deficit Hyperactivity Disorder (ADHD). That patient said, “Well, I will tell you for my kids, I always go to the About Kids Health website, which is very clear. For myself, well I am a registered nurse and I work in Mental Health. So there is a wide variety of different sources that I have to use for my work and my profession in mental health.” (R4). As this example demonstrates, some patients used online health sources for their work, personal, and their family’s health-related conditions.

Other sources of online health information mentioned (each by one patient interviewed) included: WebMD, Cochrane databases, the Heart and Stroke Foundation website, Ontario Medical Association and Registered Nursing Association of Ontario best practice guidelines, Canadian clinical trials registry, the Cleveland Clinic website, Healthy Babies Program website, and Drugs.com.

Patients mentioned a number of purposes for accessing online health information: to look for further information about their health condition, to find information about medications (e.g.,
those that are safe in pregnancy); or to further understand the information provided by their family doctor. For example, seven patients stated that they would use the websites to look up information on a variety of topics including the medications they are taking, side effects, recommended dose and frequency of medications and whether to take them with food. This medication information would normally be communicated by either the family doctor and/or the pharmacists and written instructions would be provided as a label to the patient. Another patient searched the Web for information related to cancer. This patient also used the hospital’s patient portal for specific lab values and health related information. One patient stated that they used a website to look up information about the medicinal herbs that they used for their health condition.

As noted above, in person sources of information mentioned in the interviews included the patients’ family doctor, and family and close friends of the patients who are also health care workers (N=3); as noted above, one patient was a registered nurse. For all patients that were interviewed, the physician(s) were the primary human source of health information. Indeed, according to our interviews, all patients claimed that the information that they searched for online was subsequently verified by their doctor. One patient said, “Ok, so I have cancer. At the moment, and this is due to the cancer issue most of my information comes from three distinct sources. Obviously, I have a medical team at Princess Margaret, which consist of about 4 doctors there and there is the primary care doctor as well. I also have some sort of external team that manages my care path.” As seen in this quote, the patient is relying on the multiple doctors that he sees to manage his cancer. Patients also relied primarily on their physician in cases of more highly specialized care: “Well actually, I am going to be having surgery of my eyes for
cataracts in November. The only information that I got for that was only straight from doctors – I didn’t search the internet or use any other sources really. See, sometimes I don’t even bother to go on the Internet. That is the other thing that I do is that I confirm the information I need from the doctors and learn their medical knowledge rather than looking it up myself.” (R3) As can be seen by this quote, the primary source of information for this patient was their family physician.

4.2.2 Theme 2: Reliability and trustworthiness of online health information

Primary care patients in this sample considered several factors, such as the organization’s credentials, author’s credentials, and other writing by the author, in the process of evaluating the trustworthiness of health information that they read online. The credibility of the author and host organization was a key factor in determining the trustworthiness of health information. For example, one patient said, “Well, I have to look at how reliable the source is. I have to make sure that it is a good and reliable source, not just any source. I don’t know, it can’t be a random site; it depends on who writes the information. I am not sure. Yes, certainly it would impact how much I trust the source for sure. I look at both the author and organization and what I am reading online.” (R10) Although many patients considered the author’s credentials, some patients claimed that even highly credible and reliable sources could publish unreliable health information online. As previously mentioned in section 5.1, as a way to ensure validity of the information, all eleven patients tried to confirm the trustworthiness of health information online with their primary care provider. For example, as seen in this quote, one patient said, “I still confirm everything I read online with the doctor. Like if it affected me directly, I would do the research but then I would talk to my doctor afterwards about it. I’ll read up on it even if it is for somebody else. I would be able to verify across multiple websites. I would try to search different
ones and different websites to see if they have the same kind of information.” (R10) As seen in this quote, the patient also verified the information across multiple websites to see whether they stated the same type of information. Many patients who participated in the qualitative interviews said that they verified information across multiple websites. As noted above, patients used multiple strategies including checking multiple websites, verifying with their doctor, and checking the organization and author’s credentials to judge the trustworthiness of health information online.

As noted above, one patient was a registered nurse. This nurse considered peer-reviewed journal articles as a highly reliable and valid source of health information and applied these articles in her health care decision-making. For example, she said, “Well, I guess, I have pretty good name recognition for a lot of the bigger journals especially around mental health and addiction. So if it is kind of in a reputable peer-reviewed journal, I am going to assume it is more trustworthy. It also depends on the type of literature it is - like is it grey literature or the academic literature? I have a lot of confidence in government issued papers. But that is the kind of thing that I trust, like various best practice guidelines from the RNAO or the OMA has a lot of best practice guidelines or what is it – the College of Physicians and Surgeons of Ontario (CPSO) also has best practice guidelines and those kinds of things I have a high degree of trust in. If it is something in the Cochrane database, I would have a high degree of trust in that. In terms of applying the same standard to something I would read online, you know what it is also probably name recognition of the health care organization. The Capacity for Applied Developmental Research and Evaluation (CADRE) is a great organization: [so is] the Heart and Stroke Foundation. I have a lot of trust in them.” (R4)
However, most patients did not directly consult journal articles or peer-reviewed sources of health information. Unless the material was open access, access to the peer-reviewed literature was an issue since most websites with journal articles or peer-reviewed literature required payment by the individual. Instead, as mentioned above, they searched across multiple websites for consistency of facts to verify their sources of health information from one website. Many patients described this verification and said it was done on an as needed basis.

Participants said that they trusted information from well-known organizations including best practice guidelines. For example, one patient trusted the Mayo Clinic website because it provided more information compared to the other websites that the patient had explored. To summarize, as can be seen in the quotes above, patients placed a higher level of trust in websites and sources they could confirm with their physicians. They also had a higher level of trust in recognizable credible sources and organizations such as the Heart and Stroke Foundation and articles written by health care professionals such as physicians. The content of the website, geographic origin of the website, and the credibility of the professional organizations that provides that information also influenced participants’ trust in the website. This sample of patients represents a highly educated sample. Reviewing and evaluating the trustworthiness of health information online is an important component in patients’ health information literacy. The next theme examined patients’ frequency of use of websites.

4.2.3 Theme 3: Frequency of website use

Patients’ frequency of accessing websites varied from daily to on an as needed basis to rarely. Most patients preferred to consult online health information on an as needed basis when they were interested in finding an answer to a particular question about their current health
condition. For example, one patient said, “When I need. It could be once a month, once every 6 months, it depends on the condition. Not every day, I am not going to be using the Internet every day to learn more about my health condition.” (R2) However, another patient said, “Well, daily (R9).”

It is important to note that frequency of accessing online health information may depend on the nature of patients’ health condition. If the condition was an acute emergency, patients said that they preferred to see the physician immediately instead of searching online for health information. For more chronic conditions such as diabetes or ADHD, patients said that they searched online for resources related to the conversations they had with their physician.

4.2.4 Theme 4: Patients’ preferred roles & factors that influence them

Given the high level of education and perceived health information literacy in this population and the increased health information that is available on the internet, a key finding of this research study was that patients did not want an autonomous role. Their preferred roles included shared and passive. This finding is also supported by the qualitative part of the study. For example, one patient said, “I prefer a partnership, well because it is my own health so I am not going to just allow someone to tell me everything about my input in our discussion. Someone can always have a final say but I will have questions and I won’t take a passive stance.” (R9)

Patients used various synonyms to describe the shared role including “partnership” and “working together with the physician”. For example, one patient said, “I prefer to work together with the physician. It is a shared responsibility and we work as partners.”(R3)

The level of trust in physician is generally high in this sample population. As can be seen in Table 4.5, patients who preferred a passive role had higher levels of trust in physician
compared to those who preferred a shared role. For example, as one patient said, “Yes, it also depends on the depth of expertise and health care professional that I am with. For example, a cardiac surgeon that I am with who is a specialist and has their own niche, I would probably be more passive than with my family doctor.” (R4)

In conversation with patients, it was apparent that many preferred a shared role with their physician due to the high level of trust that they had in their physician. The shared role preference was clear when patients were asked about the type of role they preferred in the health care decisions with their provider. Our respondents often noted that their preferences may vary for the type of health care decision. Examples included whether to begin a medical treatment such as a starting on a prescription medication or undergoing a surgical procedure.

Through the interviews, patients connected their preferred role to the trust that they had in their provider by commenting on elements that affected the trust that they had in their provider. Some patients said that they trusted their doctors when they were promptly referred to a specialist for their follow-up care. The qualitative semi-structured phone interviews also highlighted the idea that patients preferred a shared role in chronic disease management, including the management of asthma, diabetes, and cancer.

4.2.5 Theme 5: Factors that influence the patient-physician relationship

There were many factors that influenced the patient-physician relationship. These factors included the amount of time that the physician spent with the patient in the clinical appointment; clear, coherent, and empathic communication; and appropriate diagnosis and treatment by the physician, which may involve referral to specialists. Allocating enough time for a thorough discussion was a recurrent theme amongst many patients. For example, as one patient said,
“Well, for me, it is about the relationship that I have with the doctor. For example, if the doctor does not spend time rushing me through the appointment then it is good. Usually when I go to the clinic, it can occur many times that they would have information to share with me or solutions. I always like learning these thoroughly.” (R4) As can be seen by this quote, patients appreciated it when the physician sat down and educated their patients through sharing health-related information and solutions.

This idea was expressed by several patients in the interviews and it relates to the fact that physicians could spend more time educating patients, thoroughly explaining their health condition, discussing treatment options, and addressing all of the questions and concerns that patients may have with regards to their health. For example, one patient said the following with regards to time in the clinical appointment, “Well, that is what it is about you know – it is all about communication and having enough time you know. My biggest criticism of the system today is that often, very often, there is not enough time to sit down and talk to people. I can say that and others can say well there are a lot of things. It often feels a tad rushed, but clearly I see it shouldn’t be.” (R6)

There was emphasis on giving information and educating the patient during the consultation. Several patients spoke about information sharing between the patient and health care provider. Sharing information improved the patients’ knowledge, and also increased the trust between the patient and health care provider. Empathy and open and clear communication were also important in improving trust and building the patient-physician relationship. In terms of communication, patients appreciated it when the physician remembered their family history and allowed them to discuss multiple concerns within the same clinical appointment. Patients felt
comfortable asking the physician questions if the physician allowed them to discuss multiple complaints.

Empathy, communication, and discussing the choices and options with patients were key factors that influenced the trust between health care providers and patients. Patients preferred to discuss all available treatment options and weigh the risks and benefits with their health care provider. Communication that was coherent, empathic, timely, and clear was valued by primary care patients. For example, many patients stated that the language the physician chooses to communicate in and clear communication that was easily understood by the patient were central factors to increasing trust between them and their physicians. As one patient said, “I would say that if I see that the treatment that they are providing is working fine then that would increase the trust that I have in my health care provider. It would also increase the knowledge that I have in my health condition. I do some searching but once the doctor explains the side effects and what I am reading online to me that increases my level of trust in the doctor.” (R4)

As shown in the following quote by a patient, the physician communicates in a clear and coherent way: “Their level of compassion, how they talk to you, if I don’t understand something they take the time to explain it as opposed to rushing me out to get a new patient in. Well I don’t mean like that they have to dumb it down, but they do have to explain it so that I understand. You know what I mean? It has to be clear and coherent.” (R10) Patients preferred open, clear, and coherent communication style with their clinician. The patients we had interviewed had high levels of trust in their physician and said this was due in part to the empathy and time for conversation that physicians had for their patients.
An example of when communication increased the trust in physician occurred in the realm of writing prescriptions. In particular, patients appreciated it when physicians shared the side effects and details of a medication with them and helped them to better understand the importance of adhering to the medication. Additionally, when the treatment worked well and improved the patients’ health, this increased the trust between the patient and health care provider.

Other key factors that influenced patients’ preferred role included the knowledge, experience, and background of the physician, their expertise in clinical diagnosis, and the number of years that they had spent in clinical practice. In particular, the idea of expertise during the process clinical diagnosis in the physical examination is highlighted by this quote: “Well, no I don’t even think it is that. What it is that when the doctor examines me physically and looks in my eyes – the specialist knows exactly what it is that I have and what is going on inside my eyes. In other words, they know the cataract that is developing and how to fix it so that I can have better health. The Internet doesn’t know that. So this physical examination and knowledge is specialized and what is required to help me.” (R6) As can be seen by the quote, the patient trusts the physician’s physical examination skills to be able to examine his eyes and come up with a diagnosis and treatment plan. This improved the patient’s trust and also influenced their preferred role.

When considering a physician’s experience, patients trusted physicians who were experienced but also up to date on the latest trends in medical diagnosis and treatment options. For example, one patient said, “I think I gave you two factors right – like expertise of the person providing the care and how to up to date their knowledge is on health care. And also how
serious the decisions are for my health care. Nothing else comes to mind really. Also, I would feel very comfortable asking them questions so I know that there would be no miscommunication or misunderstanding. So that if I am not understanding something from the doctor it is not because the communication is not clear. It is just a knowledge gap that the doctor then explains to me or because I need more information from her.” (R5) As is illustrated in this quote, the patient relied on the expertise of her health care provider and found it valuable to communicate clearly with her in order to ensure that she has the appropriate knowledge to understand the information shared by the physician.

Another key theme in addition to clear communication and time for patient education was the fact that primary care physicians were able to refer their patients to their colleagues and not overstate their knowledge. As one patient claimed, “A doctor who is thorough, asking questions, not jumping to conclusions quickly, even asking for a second opinion from a colleague. That speaks volumes for a doctor. You know that is saying that even though he does not have an answer for sure, that he will consult his colleague to discuss further.” (R8) Similar to this, another patient said, “An interesting thing is that my family doctor is wonderful because she has referred me to a specialist for things. I have extra confidence in her that I know that when she feels like she can manage it then she really can manage it. I know that she would send me out if it was beyond her scope or expertise.” (R5) The referral to another physician was seen by this patient as a genuine sign of the physicians’ ability to seek a correct diagnosis or treatment plan for their health condition.
4.2.6 Theme 6: Patients’ preferred forms of communication

Patients mentioned several forms of communication with their physician including in-person clinical appointments, telephone, and email. All eleven of the primary care patients that we interviewed said that they appreciated the in-person clinical appointment form of communication. All eleven patients who were interviewed said that they also preferred a follow-up phone call appointment, especially if it was to check up on how a patient is doing if they are put on a new medication. For example, one patient said, “Well, I think follow-up phone calls with my care provider would be lovely. There have been 1-2 times in the past year that I have gotten these calls because like say a test result has been off. It is nice to be able to have that. You know I am so busy and I always appreciate that when I have those follow-up phone calls.” (R5) A phone call saved the patient time away from work in order to attend the clinical appointment.

Three patients also preferred to be communicated by email. As one patient said, “Yes, I prefer to be communicated with by email in most cases, that is better than just leaving a phone message as well.” (R7) One patient within this study said that they communicated with their physician through the use of the hospital’s online portal. This portal provided them with information about their lab tests, upcoming appointments, and reminders from their physician. The use of a patient portal was not common. Patients’ preferred form of communication is important to consider when one ensures that patient engagement activities are suited to the needs of patients.

4.2.7 Summary of qualitative interview findings

Results of this thematic analysis helped to further explore the in-depth the “why” questions of why patients prefer certain sources of health information and how they access these sources. They used both online and in person sources of health information. Online sources
included websites, e-books, and peer-reviewed journal articles. It is also important to note that even with online information, patients always wanted information from a qualified medical doctor. Patients visited their health care provider for more information on their health condition. They also spoke to their family and friends, and in some instances, other health care providers besides their physician including dietitians, occupational therapists, and physiotherapists. All patients interviewed in this sample claimed that they verified the information they learned online with their physician.

Another key theme from the interviews was the factors that influenced the patient-physician relationship, which included: open, clear and coherent and empathic communication; time spent in the clinical appointment; and the physicians’ ability to refer to specialists, provide appropriate diagnosis, and explain prescriptions. Physicians educated their patients on their health condition. This included the side effects for medications. These factors are important to consider when analyzing the patient-physician relationship. When considering the form of communication, all patients preferred to communicate by both phone and in the clinical appointment, whereas only a small sample preferred e-mail communication.
CHAPTER 5: DISCUSSION, LIMITATIONS, FUTURE RESEARCH, AND CONCLUSION

5.1 Discussion

There are several key findings from this thesis that merit highlighting. First, our quantitative results showed that most primary care patients in this sample preferred a shared role with their health care provider. Second, the qualitative analysis showed that several factors influenced this preferred role, including communication with their provider, the trust in physician, and patients’ self-perceived health information literacy. This thesis applied a multi-methods design and this section discusses the synthesis of the results of both the quantitative survey and qualitative analysis to address the research questions mentioned in Chapter 1. This section is divided into three areas: patients preferred roles; increasing levels of trust in physician and patient-physician communication; and health information and perceived levels of health information literacy.

In addition to practical insights, this thesis also offers several valuable contributions to the theoretical literature on patient engagement and patients’ preferred roles. The discussion will also outline several implications for theory, practical implications for clinicians, implications for patients, and implications for policy decision-makers. It adds to Carman et al.’s framework and suggests that “trust in physician” should be added as an underlying patient-related factor that influences patients’ preferred roles.
5.1.1. Patients’ preferred roles

In response to research questions 1A-3C as outlined in Chapter 1 of this thesis, we examined primary care patients’ preferred roles in the context of the primary care setting. Even in this sample of highly educated patients with high levels of trust in the primary care physician, most patients preferred a shared role in their health care decision-making, with almost no one selecting an autonomous role. These findings are well-aligned with our original hypothesis that, even with the vast amount of health information that is available online, few people wish to take responsibility for problem solving tasks and prefer an autonomous role. That said, there is merit in additional research that considers the impact of different clinical practice environments on patients’ preferred roles, i.e., whether the same trend would hold true in other settings such as the hospital emergency departments, inpatient wards, or other health care environments.

This thesis did find a significant differences between patients’ preferred roles for the current health condition vignette and for the chest pain vignette for the trust in physician score. This is similar to another study within the literature, which found that patients’ preferences could vary according to the nature of their health condition. (12) Patients were more likely to hand over control to the physician for vignettes involving potential mortality (e.g. the chest pain vignette).

This thesis did not find that patients’ education levels were significantly related to their preferred roles. This was in contrast to some studies that did find that education has impact on patients’ health care decisions. The study by O’Dell et al. showed that education level may impact patients’ screening related decisions (125). In contrast to the findings within the literature, when it came to accepting risks and benefits, as noted in Table 4.12, 3/16 (19%) people preferred more of a passive role and 13/16 (81%) preferred a shared role with their health
care provider. Individuals with graduate-level education preferred (3/16 people or 9%) more of a passive role. These findings may be because this group of educated recognized the expertise of the provider. More than 61.9% of college graduates indicated they wished to retain control, compared with approximately 30% of all other patients.

The next section considers levels of trust and patient-physician communication.

5.1.2. Trust in physician and patient-physician communication

In response to research questions 1-4 C, both the findings of the qualitative and quantitative parts of this study showed that this sample of primary care patients had a high level of trust in their physicians While the results of the survey data analysis showed that passive patients had significantly higher levels of trust in physician than patients who preferred a shared role, the results of the interviews revealed that both shared and passive patients trusted physicians who took the time to communicate in an open, empathic, and clear way with their patients. The qualitative interviews in this study included both patients who preferred a shared role and those who preferred a passive role. Our findings support our original hypothesis, which stated that trust would be an important factor that influences patients’ preferred roles. Our key findings are consistent with a previous research study, which have also found that trust in physician is the main variable that impacts patients’ preferred roles and that most people prefer a shared role. (12) In interviews, patients highlighted several factors that influenced their trust in physician including: the physician’s experience, follow-up with the patient, and prescribing appropriate treatments that improve the patients’ health. The findings of this research are similar to the literature.
5.1.3. Sources of health information and perceived health information literacy

In response to research questions 4A-C, findings from the interview qualitative interview data analysis showed that participants’ perceived health information literacy involved their own evaluation of the trustworthiness of websites. These findings for this primary care population may not apply in all settings. For example, one study of 1,249 hospitalized patients who had cardiovascular found that patients with higher levels of health literacy desired more participation in the PS and DM process when compared to patients that had higher subjective numeracy skills, greater educational attainment, were female, received less perceived social support and had greater health care system distrust. (126)

While the survey data analysis showed that participants had high levels of health information literacy, the interviews helped to further characterize the perceived and actual health information literacy and the various sources of trusted health information. Interview data analysis revealed that the organization and authors’ credentials influenced patients’ trust in the particular source of health information. Sources of health information varied according to the nature of the health condition. For example, as seen by the quantitative results, in an acute condition like chest pain, more people preferred a passive role for the chest pain vignette as compared to the current condition vignette (45 vs. 28, respectively), meaning that they relied more on the health care provider as a source of information in that situation.

One source of health information that was rarely mentioned by patients was a patient portal, which directly links, or is “tethered” to that individual’s electronic health record and accordingly includes such patient information as their medical problems, treatments, and lab test results. (127) Many hospitals are migrating to sharing laboratory results with patients. For
example, Sunnybrook Hospital has implemented the MyChart system. However, only one
participant referred to patient portals in the interview, and that patient had a complex condition
(cancer). One possibility is that most of the other patients interviewed did not have complex
conditions and therefore had lower need to review their own health information on an ongoing
basis.

Similarly, other patient groups were not mentioned in the interviews as a significant
source of health information again, probably because this is a generally healthy sample of
primary care patients who did not have complex or rare conditions for which patient community
support groups are a useful source of health information. Although beyond the scope of this
research, the role of such community support groups, including which types of patients would
find them helpful, would be worth exploring.

When considering the frequency of accessing health information, this may vary based on
the type of health condition and whether it is chronic or acute. As noted above, this research
occurred in a primary care practice, where patients are generally healthy. Of the eleven patients
interviewed for the qualitative portion of the study, only two had chronic conditions. One of the
key considerations is the interface between the primary care doctor and when a specialist is
consulted. Since St. Michael’s Hospital primary care clinic is a hospital based primary care
clinic, the primary care office played a larger role than specialists in ensuring high quality patient
care.

5.2 Limitations

There were some limitations to this research study. The first limitation relates to sample
recruitment, which took place in evening and afternoon clinics in a primary care unit at a large
urban hospital. Although this hospital serves a highly diverse population, including many of lower socioeconomic status, our sample included many highly educated respondents; theory would suggest that this more educated group would be more likely to prefer an autonomous role than less educated groups (72). Generalizability and representativeness is an important consideration. This primary care clinic sample that was surveyed may not be representative of the broader primary care population and their preferred roles. The evening clinic captured a variety of patients, some of whom were working professionals.

The second limitation was that some patients also did not agree to participate in the study. However, given that the response rate was high (89%), it is unlikely that this was a significant source of bias. We only approached the patients who attended the clinic. Staff did not need to provide permission for patients to agree to participate in the study, which also minimized potential bias (e.g., they were not able to exclude those patients likely to be less trusting).

A third potential limitation of this study was that this research was conducted in the Canadian health care system where there is full coverage for medically necessary hospital and physician services. These findings need to be validated in other jurisdictions where coverage for health care services would differ from Canada. Despite these two limitations, these findings have important implications for physicians, patients, and also for those planning patient engagement activities.

A fourth limitation is that the sample size may not be large enough to detect statistically significant differences in perceived health information literacy between shared and passive patients as seen by the post-hoc power calculation in Appendix 8 Figures 1-4. The post-hoc calculations outlined below suggest that the sample size was not adequate for some of the
analyses performed in this study, particularly where there was minimal variation on that measure. If there was a difference on this variable, then it may not be captured (i.e. type 2 error). However, the lack of difference in perceived health information literacy between shared and passive patients is aligned with the findings of the logistic regression, which also showed that perceived health information literacy was not a statistically significant predictor of patients’ preferred roles. Only trust in physician was a significant predictor of patients’ preferred roles as discussed in Section 4.1.9. Therefore, this increases our confidence that this is a true finding of the study. Our findings are consistent with the literature in that trust in physician is a significant predictor of patients’ preferred roles. (12,73)

Other scales measure that trust in physician can be used to measure the trust that patients have in their health care provider. For example, in a teaching hospital study in Australia, trust increased between the patient and the surgeon when the surgeon adopted an open and informative consultation lifestyle. (128) The validated trust in physician scale that was applied focuses primarily on the socioemotional aspects of the relationship, and less on the physician's competence.

There was a clear preference for a shared decision-making roles even amongst this highly educated sample population who were likely to use the internet to access health information; it is important to study different populations of lower socioeconomic status and education, or those seeing other service providers (where trust might be lower) as doing so may yield different results.
5.3 Implications

This thesis has implications for three key stakeholders in the health care decision-making process (practitioners, patients, and patients).

5.3.1 Implications for Patient-Physician Relationship

Trust in physician is a central component of the patient-physician relationship. Historical paternalism models of “doctor knows best” and “patients follow what the doctor says” are less likely to be accepted in the current era of shared decision-making. The high availability and accessibility to patients of health information in the digital age has had vital implications for clinicians. Although the findings of this thesis are based on a primary care population, the results may also be informative for clinical staff within hospitals, community care, and other health care settings. If physicians, for example, were informed about their patients’ preferred roles in shared decision-making and health care, they could respond by designing patient engagement activities that would suit the needs of these patients and families.

Clinicians would want to design their approach with patients and families to suit the health literacy levels of passive, shared, and autonomous needs of their patients and families. The literature suggests that these approaches may need to vary as a result of differences in health literacy and patients’ preferred roles.

The results of this thesis showed that trust in physician was related to patients preferred roles. This has broader implications for how clinical doctors can building a trusting relationship with their patient, which. Building a trust relationship includes empathic, clear, and coherent communication, appropriate prescribing, and timely follow-up.
As patient-centered care approaches move toward the sharing of medical records with patients and providers, the findings of this thesis also have implications for patients. Our results showed that almost no patients preferred an autonomous role. However, many did prefer shared decision-making. Patients should acknowledge that each person may have access to different tools and their preferred roles may change with the availability of health care information. Patients should make use of the accessible health care information that is accessible both online websites and decision-aids. Our findings imply that patients do not wish patient engagement model that shift responsibility for the PS tasks to patients. Rather yet, they wish a shared partnership. Physicians can have this information available for patients and this may then improve the interpersonal communication skills required to engage with patients in the process of shared decision-making.

**5.3.2 Implications for Policy Decision-makers**

Policy makers should consider whether there is appropriate resourcing to enable patient-centered care. It is worth exploring whether it would be cost-effective to ensure that the resources available for patients who are desirous of engaging in shared decision-making are widely available throughout Ontario’s health care system. These resources can include things such as decision-aids and check lists. Mechanisms should be available to ensure that health care information is both available and accurate. One useful approach might be providing physicians with a toolkit on how to share this information with their patients. This literature should be updated on a regular and on-going basis with up-to-date best practices in medical and clinical care. A focus on health systems information and health technology can bring about a coordinated approach to patient-centered activities.
5.4 Future research

Future research can look at other populations to see the extent to which these findings hold true in patients who are less educated or have lower levels of trust in their physicians. Future research also needs to consider what happens when there is not a high level of trust in physician. This research is important to see what role patients in other populations prefer and how or whether their education level and trust in physician impacts their preferred role. It would also help to improve the generalizability of the overall findings of the research.

For this thesis, the e-Heals scale was used to measure perceived health information literacy. Although this scale is validated, there is a new comprehensive scale (e-Health Literacy Questionnaire), that was developed after the research was completed, and is now being used to help understand people’s interaction with digital health services. (129)

Future research could also examine trust in different health care settings including community care and hospital care and also the impact of e-health literacy on the trust that patients have in their provider. The evolution of technology and the creation of online portals has led to the increased availability and accessibility of health information in the digital age. This thesis also has implications for those who design websites and applications and future work can examine the impact of these applications on patients. Lai has examined the use of patient platform portals and tools utilized by patients to learn more about their health condition. These patient portals and platforms provide patients with additional knowledge of their health care condition. The classification and mapping of platform tools is central to the patient engagement process. Research could analyze how to ensure that the types of tools that we offer patients via institutional systems such as portals can best incorporate patients’ preferences. (130) Further to
this idea of online health information, O’Grady et al. have provided future directions for depicting credibility in health care websites. (131)

5.6 Conclusions

The main finding of this thesis is that, in this population of primary care patients with high levels of perceived health information literacy, despite the availability of increased health information online, most people still preferred a shared role, with some preferring a passive role and almost none preferring an autonomous role. Another key finding of this research is focused on the inter-relationships between trust in physician, education, patients’ preferred roles, and perceived health information literacy. Results showed that trust in physician scores were weakly correlated with patients’ preferred roles. Section 4.1.6 of the results in Chapter 4 outlines these interrelationships between the variables in further detail. Our results showed that even in this well-educated population, which made extensive use of the Internet and demonstrated high levels of perceived health information literacy, most primary care patients preferred a shared role with their primary care physician in treatment decision-making. In a binary logistic regression that examined whether trust in physician or perceived health information literacy scores could predict patients’ preferred roles, it was shown that trust in physician predicted patients’ preferred roles in this sample of primary care patients. Perceived health information literacy scores did not predict participants’ preferred roles.

The key findings from the qualitative interviews corroborate the findings from the quantitative analysis. The interviews revealed a number of factors that influenced trust between patients and health care providers including empathy, open and clear communication, follow-up and referral to a specialist, correct diagnosis and treatment by physicians, and leaving enough
time in the clinical appointment for discussion. Most patients verified their online health
information with their health care provider and accessed it on an as needed basis to learn more
about their health condition.

This study suggests that patient engagement models, while recognizing the move away from
paternalistic medicine, should not build on the assumption that patients prefer an autonomous
role. (30) Given that this sample of highly educated patients did not want an autonomous role, the
odds are low that a less educated patient sample would prefer an autonomous role, unless they
distrust their physician or are confronted with a life-threatening condition. The results of this
thesis can help ensure that patient engagement activities suit the health literacy levels and needs
of patients and their preferred roles,
APPENDIX 1: QUANTITATIVE SURVEY SCALES

A1.1 Participant demographics questionnaire:

1. What is your age? ______
2. What is your gender? M
3. What is your preferred spoken language? ____________
4. What is your ethnicity? ________________
5. What is your marital status?
   a. Single
   b. Married
   c. Engaged
6. What is your highest level of education?
   a. High school
   b. College
   c. Undergraduate
   d. Graduate – MSc, PhD
   e. Professional training programs - MD/ JD

A1.2 PSDM Scale

1. What is your current health condition or what is the health care condition for which you are here to see the physician today?
Now please circle the number which best describes how you feel about the statements below assuming you had the medical condition which you described. (scale: 1 = doctor alone, 2 = mostly the doctor; 3 = doctor and you equally; 4 = mostly you; 5 = you alone).

A: Who should determine (diagnose) what the likely causes of your symptoms are?
1  2  3  4  5

B: Who should determine what the treatment options are?
1  2  3  4  5

C: Who should determine what the risks and benefits for each treatment option are?
1  2  3  4  5

D: Who should determine how likely each of these risks and benefits are to happen?
1  2  3  4  5

E: Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?
1  2  3  4  5

F: Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?
1  2  3  4  5
PSDM Scale- Chest Pain Vignette

Now please circle the number which best describes how you feel about the statements below assuming you had the medical condition which is described. (scale: 1 = doctor alone, 2 = mostly the doctor; 3 = doctor and you equally; 4 = mostly you; 5 = you alone).

Suppose you had mild chest pains for three days and decided that you should visit your doctor about this.

A: Who should determine (diagnose) what the likely causes of your symptoms are?

1  2  3  4  5

B: Who should determine what the treatment options are?

1  2  3  4  5

C: Who should determine what the risks and benefits for each treatment option are?

1  2  3  4  5

D: Who should determine how likely each of these risks and benefits are to happen?

1  2  3  4  5

E: Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?

1  2  3  4  5
F: Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?

1  2  3  4  5

How much experience have you had with the clinical situation described in the above scenario?

(Please circle all letters that apply)

A. I have had personal experience with it.

B. I know of family members or close friends who have experienced it

C. I have read/heard about it.

D. I do not know much about it.

A1.3 e-HEALS e-Health Literacy Scale

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience right now. Please check-mark the response that best applies to you within the circle.

1. How useful do you feel the Internet is in helping you in making decisions about your health?

   1) □ Not useful at all
   2) □ Not useful
   3) □ Unsure
2. How important is it for you to be able to access health resources on the Internet?

   1) □ Not important at all
   2) □ Not important
   3) □ Unsure
   4) □ Important
   5) □ Very important

3. I know what health resources are available on the Internet

   1) □ Strongly Disagree
   2) □ Disagree
   3) □ Undecided
   4) □ Agree
   5) □ Strongly Agree

4. I know where to find helpful health resources on the Internet

   1) □ Strongly Disagree
   2) □ Disagree
   3) □ Undecided
4) □ Agree

5) □ Strongly Agree

5. I know how to find helpful health resources on the Internet

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

6. I know how to use the Internet to answer my questions about health

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

7. I know how to use the health information I find on the Internet to help me

1) □ Strongly Disagree
2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

8. I have the skills I need to evaluate the health resources I find on the Internet

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

9. I can tell high quality health resources from low quality health resources on the Internet

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree
10. I feel confident in using information from the Internet to make health decisions

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

A1.4: Trust in physician scale

Please check-mark the response that applies best to you within the circle:

1. I doubt that my doctor really cares about me as a person

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

2. My doctor is usually considerate of my needs and puts them first.

1) □ Strongly Disagree
2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

3. I **trust my doctor** so much that I always try to follow his/her advice.

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

4. If my doctor tells me that something is so, then it must be true.

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree
5. I sometimes distrust my doctor’s opinion and would like a second one.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

6. I trust my doctor’s judgement about my medical care.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

7. I feel my doctor does not do everything he/she should for my medical care.

1) □ Strongly Disagree
8. I trust my doctor to put my medical needs above all other considerations when treating my medical problems.

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree

5) □ Strongly Agree

9. My doctor is a real expert in taking care of medical problems like mine.

1) □ Strongly Disagree

2) □ Disagree

3) □ Undecided

4) □ Agree
5) □ Strongly Agree

10. I trust my doctor to tell me if a mistake was made about a treatment.

   1) □ Strongly Disagree
   2) □ Disagree
   3) □ Undecided
   4) □ Agree
   5) □ Strongly Agree

11. I sometimes worry that my doctor may not keep the information we discuss totally private.

   1) □ Strongly Disagree
   2) □ Disagree
   3) □ Undecided
   4) □ Agree
   5) □ Strongly Agree

Final question: Would you be interested in participating in a follow-up qualitative interview?

   Yes    No

If yes, when would be the best time for you?
A) Now

B) Follow-up phone call, Please list three times that would work best for you:

   a. ____________
   b. ____________
   c. ____________

What is the best method of contacting you? A) Telephone: _______________  B) Email: _______________
APPENDIX 2: QUALITATIVE INTERVIEWS

Thank-you very much for taking the time to participate in this interview. I would like to request your permission to audio-tape our conversation so that I may be able to listen to it later if I missed any notes. Would that be alright?

Ok great, thanks. The purpose of this interview is to help me better understand your experience as a patient at St. Michael’s Hospital. I will ask you some questions about your e-health literacy, ability to search the internet for information and preferred role in treatment decision-making. If a question is unclear, feel free to ask.

Theme 1- E-health Literacy

1. Could you describe the sources of information you use for your health care related decisions?
   a. Probes – online websites, health care providers, family/friends

2. Can you describe your process of finding health information online?

3. How often do you look for information online? What are the specific sources of electronic health information you use and why?
   a. Follow-up: why do you prefer certain sources of health information over others for a specific health condition?

4. How often do you use these sources?
5. Can you explain how these sources of information vary by the type of health care condition? (for example, glaucoma vs. hypertension)?

6. Can you describe how you judge the trust-worthiness of the information you read online?
   a. Probes – Credentials of author, credentials of host organization

**Theme 2- Preferred role in treatment decision-making**

1. When meeting with the physician there are many roles that people can play in their health care decisions: autonomous, shared-decision making, and passive.
   a. Follow-up: Why do you prefer to take a [insert role here] in your health care decisions?

2. Could you please describe your preferred role in decision-making?

3. What would be the most important factors that influence the role that you wish to play in health care decisions?

4. How would you describe your preferred role in analyzing the risks and benefits of health care treatment options?

5. How does knowledge impact your preferred role in your health care decisions?
Theme 3- Trust in Physician

1. Could you describe what are the factors that influence trust that you have in your health care provider?

2. What would increase your trust in your health care provider?

3. How does communication impact the level of trust you have in your health care provider?

Conclusion:

1. Is there anything else that you would like to share with us for this interview?

2. Do you have any questions for me or about the research study? If I have any further questions for you, may I contact you?

3. If I have any further questions for you, is it ok for me to give you a call back?

Thank you very much for taking the time to help me complete my PhD Dissertation project. Your responses are appreciated and will be valuable in better tailoring patient engagement activities to suit the needs of patients and families.
APPENDIX 3: INFORMED CONSENT FORM AND PRIMARY CARE SETTING

PATIENT RECRUITMENT POSTER

3.1 Informed Consent Form

LETTER OF INFORMATION AND CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: The relationships between perceived e-health literacy and primary care patients’ preferred role in treatment decision making.

Short Title: E-health Literacy and Patients’ Preferred Roles in Treatment for their current health condition

Research Study Staff at St. Michael’s Hospital:

1. Dr. Navindra Persaud, Principal Investigator

2. Vidhi Thakkar, Doctoral Candidate

3. Professor Raisa Deber, Professor at IHPME

4. Professor Aviv Shachak, Professor at IHPME

STUDY STAFF AVAILABILITY: Monday to Friday 9:00 am – 5:00 pm

CONFLICT OF INTEREST
The principal investigator, co-investigators, and research staff do not have any conflicts of interest, financial or otherwise, related to this study or its outcome.

**INTRODUCTION & PURPOSE OF THE RESEARCH**

You are being invited to consider participating in a research study. The focus of this research project is to better understand the way you prefer to interact with your physician for health care decisions. Understanding your preferred roles in health care decision-making is the focus of this research. We will also examine your comfort with the use of the internet (e-health literacy) to find information about your health condition. Your level of e-health literacy, which is your ability to use the internet to obtain information regarding your health condition, may also impact your preferred role.

**DESCRIPTION OF THE RESEARCH:**

This study begins with a survey looking at your preferred roles, e-health literacy, and trust in physician. The survey is followed directly by qualitative interviews that further examine your level of e-health literacy and preferred role in treatment decision-making.

A Research staff member will explain the research objectives, harms and benefits in this informed consent form. If you decide to participate you may provide informed consent. Then you will complete a 20-30-minute quantitative survey. The survey will be completed on paper in a private quiet clinical examination room. A staff member will be present to help answer any clarification questions about the survey. If you have difficulty with your vision, Vidhi Thakkar will read the questions to you. Family members may also assist you in completing the survey. The final question asks whether you are willing to assist with a brief 15-20-minute follow-up qualitative interview after the survey at a time at your convenience.

**ALTERNATIVES TO PARTICIPATION**
Because this study is not looking at ways to provide medical treatment to you, the alternative to taking part in this study is not to take part. Whether you choose to take part in this study or not, you will receive the same standard and level of care at St. Michael’s Hospital.

**POTENTIAL HARDS (INJURIES, RISKS, OR DISCOMFORTS)**

There are no medical risks if you take part in this study. You may feel uncomfortable answering some survey questions yet you may decline to answer questions or stop the interview at any time if there is any discomfort.

**BENEFITS TO BEING IN THE STUDY**

There are no direct benefits from participation in this study though you may gain some satisfaction from knowing your preferred role in decision-making and your level of e-health literacy. Participation may or may not help to design patient-centered initiatives for primary care patients.

**PARTICIPATION AND WITHDRAWAL**

Participation in this study is voluntary. You can choose to end participation at any time without having to provide a reason, although it would be helpful if you told us why you decided to withdraw from the study. You may decline to answer any question that you do not want to answer. If you withdraw, the study data collected up to that point may still be used. This will be discussed with you.

**CONFIDENTIALITY AND PRIVACY**

Your confidentiality will be respected and no information that discloses your identity will be released or published without your consent unless required by law. Your name and identifying information will not be used in any publications or presentations that come from this study. For our analysis, you will be identified with a study number and not by your name; the master list will be stored separately from the
study data and destroyed after study completion. If you agree to participate in interviews, the recordings or transcripts will not contain any identifiable information. If you do not wish to be recorded for this research study, you cannot participate in the research. Your answers to these survey questions will not be conveyed to your health care provider or be put in your medical record. Any recordings or transcripts made from your interview will not contain any identifying information. Your audiotapes and transcripts will be stored in a locked filing cabinet in a secure area and destroyed five years after study completion. Only the research team listed above will be allowed to look at your records. We are requesting your email address only if you are interested in receiving the overall findings of this research study. Researchers who wish to access the data from this study will only be able to do so with appropriate ethics review and approvals.

Your data will be collected, coded, and stored in accordance with the Personal Health Information Protection Act (PHIPA) in Ontario and St. Michael’s Hospital guidelines. Only those individuals involved in the conduct of this study will have access to the information collected as part of your involvement in the study. If you wish to withdraw from the study at any time, the investigators may still use study data that was collected up to the point of withdrawal if you consent to this option. No direct quotes from your interview/questionnaire responses will be published or used in reports of the results.

It is important to understand that despite these protections being in place, there continues to be the risk of unintentional release of information. The study investigators will protect participants’ records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will be accidentally released is small. The information collected will not include any personal health information.

**COMPENSATION FOR PARTICIPATION**
There will be no compensation provided for the purpose of this research study.

**FURTHER INFORMATION**

If you have any questions, concerns, or would like to speak to the study team for any reason, please call during regular business hours (Monday to Friday, 8:00 am to 5:00 pm).

**RESEARCH ETHICS BOARDS CONTACT**

This study protocol has been reviewed by the Research Ethics Board subcommittee at St. Michael’s Hospital. If you have any questions about your rights as a research participant you may contact the chair of the Research Ethics Board. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
PARTICIPANT CONSENT FORM

PROTOCOL TITLE: The relationships between perceived e-health literacy and primary care patients’ preferred role in treatment decision making

I acknowledge that the research study described above has been explained to me. I have read the statements in the informed consent form and confirm that the study information and procedures have been explained to me during the consent process. I have had the opportunity to ask questions about the study and any questions that I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising the quality of medical care at St. Michael’s Hospital for myself and for other members of my family. As well, the potential risks, harms, and discomforts have been explained to me and I also understand the benefits (if any) of participating in the research study.

I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law. I have been given sufficient time to read and understand the above information.

I understand that if I choose to disclose my email address it will not be shared and will only be used to communicate about an interview time and provide me with the final findings of this research.

I hereby consent to participate.
Name of Participant (Please print)  Date/Time

_______________________________________________  __________________________
Signature of Participant

_______________________________________________  __________________________
Name of Person Obtaining Consent (Please print)  Position

_______________________________________________  __________________________
Signature of Study Personnel Obtaining Consent  Date/Time

Note: Please retain a copy of this form for your records.

Declaration of Assistance – Witness to Consent Process

Study Participant’s Name (Print): ______________________________

ASSISTANCE DECLARATION AND SIGNATURE:

I have provided assistance during the consent discussion between the potential participant and the person obtaining consent by (please check one):

☐ Acted as a witness to the consent discussion

☐ Assisted in delivery of consent discussion (reading/oral)
☐ Other: ______________________________

I attest that the information was accurately explained and the participant has freely given consent to participate in the research study.

__________________________________  __________________________  __________
Name of Person Assisting  Signature of Person Assisting  Date
(printed)

Relationship to Study Participant: ________________________________

Contact Information of Person Assisting (phone): __________________________
3.2 Primary care setting patient recruitment poster

As a part of a doctoral thesis dissertation, there is a research project occurring on primary care patients’ preferred roles in health care decision-making.

**INTRODUCTION & PURPOSE OF THE RESEARCH**

Patient engagement and the design of patient centered initiatives are important features of a health care system. In order to design these initiatives, it is important to understand your preferred roles in treatment decisions.

This study helps us understand your preferred roles in health care treatment decision making. We will also ask about your ability to use the internet, your preferred role in treatment decisions, and the trust that you have in your health care provider. Your level of e-health literacy, which is your ability to use the internet to obtain information regarding your health condition, may also impact their preferred role in treatment decisions. The rationale of this study is to better understand patients preferred role in treatment decision-making, their self-reported level of e-health literacy, and patients’ trust in their physician. Are you interested in participating in this study? If so, please contact the following study coordinators for further information:

Your participation in this research is greatly appreciated.

**APPENDIX 4: DATA TRANSFER AGREEMENT**

This Agreement is made by and among:
with respect to data that the Disclosing Party will provide to the Receiving Party for the study entitled: **The relationships between perceived e-health literacy and primary care patients’ preferred role in treatment decision making** (the “Study”). As applicable herein, a Party hereto that discloses and sends data to another Party hereto is hereinafter individually referred to as a “Disclosing Party” and a Party hereto that receives data from another Party hereto is hereinafter individually referred to as a “Receiving Party”.

This Agreement is made in compliance with section 44(5) of the *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3 (“PHIPA”).

The parties hereby agree as follows:

1. **Definitions.** As used in this Agreement, the term:

   a) "Data” means all personal information (including without limitation medical data and information and other personal health information) that has been collected for the purpose of the Study at Disclosing Party and is provided to the Receiving Party for the purpose of carrying out the Study.

2. **Compliance.** In transferring the Data the parties shall comply with all applicable laws, regulations, guidelines and policies (“Applicable Law”). The Disclosing Party will prepare and furnish the Data in accordance with Applicable Law including without limitation
obtaining all appropriate consents. The Data will not be collected and/or transferred until the Disclosing Party’s research ethics board ("REB") and, if applicable the Receiving Party’s REB, have: a) approved the Study protocol; and b) approved the Study informed consent forms or waived the requirement to obtain consent. The Disclosing Party retains the right but not the obligation to conduct audits of Receiving Party’s compliance with this Agreement upon reasonable advance written notice to Receiving Party and at mutually acceptable times. If there is a breach of the Agreement by Receiving Party, Disclosing Party may require that all Data be returned promptly to Disclosing Party or destroyed in a secure manner at Disclosing Party’s option. The Disclosing Party retains the right, acting on reasonable grounds, to refuse the transfer of the Data requested hereunder.

3. **Non-Disclosure of Data.** The Receiving Party shall limit access to the Data only to its internal personnel and/or agents who need access for the purposes herein and who are bound by the same confidentiality obligations herein ("Study Staff"). Without limiting the obligation set out in s. 2, the Receiving Party agrees that it/he/she shall, and shall require its/his/her Study Staff, to:

a) maintain Data in confidence, and not disclose Data except as permitted by this Agreement;

b) use Data solely for the purposes of the Study or other expressly consented purposes, in compliance with:

   (i) the Study protocol as approved by the Disclosing Party’s REB and as amended from time to time, provided that amendments are approved by the Disclosing Party’s REB (the “Protocol”);
(ii) any written conditions imposed by the Disclosing Party’s or Receiving Party’s REB;

(iii) the Study subject’s consent consistent with the informed consent form approved by the Disclosing Party’s REB (the “Consent”) or, if the requirement to obtain consent has been waived, or otherwise determined to be unnecessary, by the Disclosing Party’s REB, the waiver of consent given by the Disclosing Party’s REB (the “Waiver”);

(iv) any other conditions or restrictions imposed by Disclosing Party relating to the use, security, disclosure, return or disposal of the Data as set out in this Agreement.

c) not use the Data to identify any individuals.

d) not transfer the Data to any third parties without the prior written consent of the Disclosing Party and without obligating such third parties to comply with the terms and conditions hereof. Notwithstanding the forgoing, the Receiving Party may transfer the Data:

(i) to regulatory authorities, provided that the Receiving Party gives prior written notice of such intended disclosure to the Disclosing Party;

(ii) as otherwise permitted by the Consent or Waiver; or

(iii) in order to comply with Applicable Law or judicial process, or with a court or regulatory order, provided that the Receiving Party gives prior written notice of such intended disclosure to the Disclosing Party and takes all lawful
actions that are reasonable in the circumstances to minimize the extent of such
disclosure and obtain confidential treatment for such disclosure.

e) securely destroy the Data as required by the Protocol or instructed by the Disclosing
Party and provide a written confirmation of the manner of destruction in a form
acceptable to Disclosing Party.

4. **Safeguards and Notification.** The Receiving Party shall use appropriate safeguards
(including without limitation with respect to encrypting identifying numbers, linking files,
storing and retrieving files from secured locations) to prevent any unauthorized use or
disclosure of the Data and shall promptly report to Disclosing Party any unauthorized use or
disclosure of which Receiving Party becomes aware.

5. **Contact with Subjects/Individuals.** The Receiving Party shall not make contact or attempt
to make contact with an individual unless the Disclosing Party first obtains the individual’s
consent to be contacted, except to the extent that the Receiving Party is otherwise the
individual’s health information custodian.

6. **Financial Matters and Intellectual Property.** Except as expressly provided herein, no
right, title or interest in and to the Data is granted to the Receiving Party or implied hereunder.
SMH and U of T shall own the analyzed Data that has been stripped of personally-identifying
information and incorporated into its Study database. All other applicable financial matters
and intellectual property terms are attached as Schedule “D” hereto.
7. **Publication.** SMH and U of T shall have the right to use a) the analyzed, de-identified data derived from the use of the Data; and b) information and results arising out of analysis of the Data, as part of a publication or presentation of the results of the Study. SMH and U of T shall not include any personally identifying information in any publication or presentation. SMH and U of T’s investigators’ contribution to the Study shall be acknowledged appropriately in any such publication or presentation in accordance with academic standards.

8. **Study Documents.** The following Study documents are attached hereto and/or incorporated by reference:

| Schedule A – Study Protocol |  □ Attached  |  ☒ Incorporated by Reference |
| Schedule B – Written Conditions of REB |  □ Not Applicable  |  □ Attached  |  □ Incorporated by Reference |
| Schedule C – Consent or Waiver |  □ Attached  |  □ Incorporated by Reference |

9. **General Terms and Conditions.**

   (a) No party shall be entitled to assign or transfer this Agreement or the rights and obligations hereunder to any third party without the prior written approval of the other parties.
(b) This Agreement including the attached Schedules represents the entire understanding between or among the parties related to the Study and supersedes all previously or contemporaneously executed agreements related to the Study.

(c) This Agreement shall not be amended, modified, varied or supplemented except in writing signed by each of the parties.

(d) No failure or delay on the part of any party hereto to exercise any right or remedy under this Agreement shall be construed or operate as a waiver thereof.

(e) The parties hereto are independent contractors. Nothing contained herein shall be deemed or construed to create between or among the parties hereto a partnership or joint venture or employment or principal-agent relationship. No party shall have the authority to act on behalf of any other party or to bind another party in any manner.

(f) Each party to this Agreement assumes responsibility for its own obligations under this Agreement.

(g) No party shall use, or authorize others to use, the name, symbols, or marks of another party hereto or its staff for any endorsement purposes without prior written approval from the party whose name, symbols or marks are to be used.

(h) This Agreement shall be governed by and construed in accordance with the laws of the Province of Ontario and the federal laws of Canada applicable therein.
SCHEDULE “A”

Study protocol as approved by the Disclosing Party’s REB

Incorporated by reference: St. Michael’s Hospital REB 17-140

SCHEDULE “B” – (if applicable)

Written conditions, if any, imposed by the Disclosing Party’s or Receiving Party’s REB

Incorporated by reference: St. Michael’s Hospital REB 17-140

SCHEDULE “C”
Informed Consent or Waiver of Consent

Informed consent form approved by the Disclosing Party’s REB  □ Applicable  □ Not Applicable

OR:

The requirement to obtain consent has been waived, or has otherwise been determined to be unnecessary, by the Disclosing Party’s REB for the purposes of the Agreement. □ Applicable  □ Not Applicable

SCHEDULE “D” – (if applicable)

Financial Matters and Intellectual Property Terms
Financial Matters: N/A

Intellectual Property Terms: N/A
Re: REB # 17-1407 - The relationships between perceived e-health literacy and primary care patients' preferred role in treatment decision making

REB APPROVAL: Original Approval Date: June 08, 2017
Annual/Interval Review Date: June 08, 2018

Thank you for your application submitted on 01 May, 2017. The above noted study has been reviewed through a delegated process (not by Full Board review). The views of the St. Michael’s Hospital (SMH) Research Ethics Board (REB) have been documented and resolved. Please note that no member of the St. Michael’s Hospital Research Ethics Board associated with this study was involved in its review or approval.

The REB approves the study as it is found to comply with relevant research ethics guidelines, as well as the Ontario Personal Health Information Protection Act (PHIPA), 2004. The REB hereby issues approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review of REB approval. In addition, the following documents have been reviewed and are hereby approved:

1. Protocol ver: 06/05/2017
2. Consent Form - ICF ver: 05/26/2017

Furthermore, the following documents have been received and are acknowledged:

1. Survey Questions and Interview guide (received 06/01/2017)

During the course of this investigation, any significant deviations from the approved protocol and/or unanticipated developments or significant adverse events should immediately be brought to the attention of the REB. Please note that shared electronic health systems such as ConnectingOntario, cGTA, PRO, RIMAR, OLIS, HDES, eCHN and IAR do not permit access for research purposes.

All institutional approvals must be coordinated and approved through the Office of Research Administration (ORA) prior to initiation of this research.

If a Clinical Trial Agreement is required, it must be reviewed and approved by the ORA prior to commencing any study related activities.

All investigational drug product dispensing must be coordinated through the Research Pharmacy at 416-864-5413.

The St. Michael’s Hospital (SMH) Research Ethics Board (REB) operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans, the Ontario Personal Health Information Protection Act, 2004, and ICH Good Clinical Practice Consolidated Guideline E6, Health Canada Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Product Regulations, and the Medical Devices regulations. Furthermore, all investigational drug trials at SMH are conducted by Qualified Investigators (as defined in the latter document).
APPENDIX 6: SCATTER PLOTS BETWEEN THE DEPENDENT AND INDEPENDENT VARIABLES

Problem-Solving (chest pain) score and problem-solving (current condition) score
A one-way Spearman’s correlation was computed between the two variables: problem-solving (chest pain) and problem-solving for the current condition. There was a moderate and statistically significant correlation (r=0.706 p=0.000*). It was hypothesized that there would be a positive correlation between participants’ problem-solving (chest pain) score and problem-solving (current condition) score. Results of this research showed that this hypothesis was correct. This positive moderate relationship is expected as both problem-solving questions are the same except the clinical condition is different (chest pain vs. the participants’ current health condition). As seen in Figure A6.1 there is a positive and moderate correlation between these two variables.

Figure A6.1: Scatter Plot between problem-solving chest pain score and problem-solving current condition score

Decision-making score (chest pain) score and decision-making score (current condition) score
A one-way Pearson’s correlation was computed between the two variables: decision-making score (chest pain) and decision-making score (current condition). Results of this correlation showed a very strong but statistically significant correlation ($r=0.935$, $p=0.000^{***}$). It was hypothesized that there would be a strong and positive correlation between participants’ decision-making scores (current condition) and their decision-making scores (chest pain). Results of this research show that the original hypothesis was acceptable. Of note, most participants preferred a shared decision-making role for decision-making in both the chest pain and current condition clinical condition. As seen in Figure A6-2, there is a strong positive correlation between these two variables.

Figure A6.2 Scatter plot of decision-making (chest pain) score and decision-making (current condition) score

This section presents the findings of correlations between dependent and independent variables that were statistically insignificant. It is important to note that this same of participants
did not have much variability in terms of their trust in physician, perceived e-health literacy s, and preferred roles, which may, in part, explain these insignificant findings.

**Age and trust in physician score**

A one-way Pearson’s correlation of trust in physician score and age was not statistically significant ($r=0.056$, $p=0.519$). It was hypothesized that there would be no relationship between the age of participants and their trust in physician scores. Results of this thesis project show that this is an acceptable hypothesis.

![Figure A6.3: Scatter plot between age and the trust in physician score](image)

As can be seen by the scatter plot in Figure A6.3, there is no relationship between participants’ age and the trust that they have in the physician. Most participants had high levels
of trust in physician and scores centered around the 30-40 criteria. This sample showed overall high levels of trust in physician.

**Age and perceived e-health literacy**

A one-way Pearson’s correlation of age and the perceived e-health literacy was not statistically significant (r= -0.144 p =0.094). It was hypothesized that there is an inverse relationship between participants’ age and their perceived e-health literacy. This entails that younger participants would have a higher perceived e-health literacy. However, this hypothesis was incorrect. Results of this research showed that there is no statistically significant correlation between age and the perceived e-health literacy in this sample of primary care patients.

![Figure A6.4: Scatter plot between age and perceived e-health literacy](image)

Figure A6.4: Scatter plot between age and perceived e-health literacy
As can be seen by Figure 4 in the scatter plot between age and participants’ e-health literacy, there is no correlation between these two variables. Most participants fell within the range of 20-60, with one outlier having a high e-health literacy of 70.

**Age and problem-solving (current condition score)**

A one-way Pearson’s correlation of age and problem-solving (current condition score) was not statistically significant ($r = 0.109, p = 0.200$). It was hypothesized that there would be no relationship between participants’ age and their problem-solving (current condition) score. Results of this analysis showed that this hypothesis was correct.

![Figure A6.5: Scatter plot between age and the PSCC score.](image)

As can be seen by the scatter plot, there is no correlation between age and participants’ PSCC Score. Most participants problem-solving scores for the current condition fell between 2-3 for the problem-solving current condition score.
Age and decision-making (current condition score)

A one-way Pearson’s correlation of age and decision-making (current condition score) was not statistically significant ($r = -0.029$ $p=0.733$). It was hypothesized that there would be no correlation between participants’ age and their decision-making (current condition score). Results of this research showed that this hypothesis was correct. Participants had a very weak, negative and statistically insignificant correlation between their age and decision-making score.

Figure A6.6: Age and decision-making (current condition score)

When considering age and participants’ decision-making scores, there is no correlation between these two variables as seen in the scatter plot in Figure A6.6.

Perceived e-health literacy and the problem-solving current condition score
A one-way Spearman’s correlation between the variables of e-HEALS and problem-solving for the current condition score was not statistically significant. It was hypothesized that there would be no correlation between participants’ perceived e-health literacy and their problem-solving current condition score. Results from this thesis dissertation showed that this hypothesis was correct. Results of this correlation were as follows: $r=0.161$, $p=0.061$. This indicates a very weak and statistically insignificant correlation. Therefore, in this sample of primary care participants, there is no relationship between participants’ e-health literacy score and their problem-solving current condition score. This finding may be because there was not much variability in participants’ problem-solving current condition score and their perceived e-health literacy.

Figure A6.7: Scatter plot between participants’ perceived e-health literacy and problem-solving current condition score.
As can be seen by this scatter plot of perceived e-health literacy and their problem-solving current condition score, there is no relationship between these two variables. Most of participants’ scores for e-HEALS gathered around the mean of 30 and most problem-solving current condition scores were centered around the values of 2 and 3.

**Perceived e-health literacy and problem-solving for the chest pain clinical condition**

A one-way Spearman’s correlation between the variables of perceived e-health literacy and the problem-solving score for the chest pain clinical condition was computed. It was hypothesized that there would be no correlation between these two variables. This hypothesis was correct. It was not significant (r=0.029, p=0.735). Therefore, in high acuity condition such as chest pain, there is no correlation between participants’ perceived e-health literacy and their problem-solving score for the chest pain clinical condition. This finding is aligned with our original hypothesis that despite the increasing availability of health information online, participants would still prefer a shared decision-making role.
Figure A6.8: Participants’ perceived e-health literacy and problem-solving chest pain score

It was hypothesized that there would be a very weak correlation and statistically insignificant correlation between these two variables. Results of this thesis dissertation showed that this hypothesis is acceptable. A one-way Spearman’s correlation between the variables of participants perceived e-health literacy and their preferred role in decision-making for the chest pain clinical resulted in a weak but statistically significant correlation (r = 0.150, p=0.082). This is aligned with our hypothesis that participants’ e-health literacy scores would not be related to their problem-solving chest pain scores.
Figure A6.9: Scatter plot between participants perceived e-health literacy and problem-solving chest pain score

As can be seen by Figure 9 above, there is no relationship between participants perceived e-health literacy score and their chest pain score. This finding may be because there is not much variance in participants’ perceived e-health literacy and their problem-solving chest pain scores.

**Trust in physician score and decision-making current condition score**

A one-way Spearman’s correlation between the variables of trust in physician and decision-making current condition resulted in a weak and statistically insignificant correlation \( (r = -0.203, p = 0.019) \). It was hypothesized that there would no relationship between these two variables. Results from this analysis do not support this hypothesis. The inverse relationship between participants’ trust in physician score and their decision-making current condition score
is plausible. For example, if participants had a higher level of trust in their physician, they would prefer a shared or passive role as opposed to an autonomous role, which is indicated by a higher decision-making score.

Figure A6.10: Scatter Plot between participants trust score and decision-making current condition score

Trust in physician score and problem-solving chest pain vignette score

A one-way Spearman’s correlation of trust in physician and problem-solving for the chest pain vignette was not statistically significant (r=0.023, p=0.791). It was hypothesized that there would be no relationship between these two variables. Results of this research project proved that this hypothesis is acceptable. The acuity of the chest pain clinical condition may explain the inverse relationship between these two variables. For example, in high acuity clinical situations like chest pain, participants would prefer a shared or passive role as opposed to an autonomous role, which would be indicated by higher problem-solving scores.
Figure A6.11: Scatter plot between participants trust score and problem-solving chest pain scores

Trust in physician and decision-making chest pain vignette

A one-way Spearman’s correlation of trust in physician and decision-making for the chest pain vignette resulted in a very weak and statistically insignificant correlation (r=0.151, p=0.082). It was hypothesized that there would be no relationship between these two variables. Results of this thesis project showed that this hypothesis is acceptable.
Figure A6.12: Scatter plot between participants trust score and decision-making chest pain scores

Figure A6.13: Scatter Plot of trust score and perceived e-health literacy
Perceived E-Health literacy Score and Decision-Making Score for Participants’ Current Condition Score.

A one-way Spearman’s correlation was computed between the variables of perceived e-health literacy and participant’s decision-making on the PSDM scale, indicating a very weak but statistically significant correlation ($r=0.185$, $p=0.031^{**}$).

Figure A6.14: Scatter plot of participants’ perceived e-health literacy and decision-making score for current condition

Trust in physician score and problem-solving current condition score
A one-way Spearman’s correlation between the variables of trust in physician and problem-solving current condition resulted in a negative weak but statistically significant relationship ($r = -0.202$, $p = 0.020^*$). A higher trust in physician score meant that patients were more likely to hand over responsibility for the problem-solving tasks to their physician.

Figure A6.15: Scatter plot between participants trust in physician score and their problem-solving current condition scores

The correlation between the problem-solving current condition and chest pain situation and the decision-making (current condition) vs. decision-making (chest pain) are presented with the Factor Analysis in Appendix 1.
APPENDIX 7- BINARY LOGISTIC REGRESSION TABLES

For the current condition situation:

After testing all of the assumptions of a binary logistic regression, this test was conducted. A binary logistic regression was conducted to predict patients’ preferred roles in health care decision making for the current condition using patients’ perceived health information literacy and trust in physician scores as predictors. As seen in Table A7.1, a test of the full model against a constant only model indicated that this model was statistically significant and was able to reliably distinguish between patients preferred roles ($\chi^2 (2) =10.60, p =0.005$).

Table A7.1 Block 1: Method = Enter

<table>
<thead>
<tr>
<th>Omnibus Tests of Model Coefficients</th>
<th></th>
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<tr>
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<td>df</td>
<td>Sig.</td>
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<td>Step 1</td>
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<td>.005</td>
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<tr>
<td>Step</td>
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Table A7.2 Variables in the Equation

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<td>.081</td>
<td>.126</td>
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</table>

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.

As can be seen in Table A-7.2, the Nagelkerke R Square is 0.126, indicating a weak effect size of the predictors in the equation. Nagelkerke $R^2$ is a modification of Cox & Snell $R^2$, the
latter of which cannot achieve a value of 1. For this reason, it is preferable to report the Nagelkerke $R^2$ value.

**Table A7.3 Beginning Block Classification Table**

| Block 0: Beginning Block Classification Table$^{a,b}$ |  
|---|---|---|---|---|---|---|---|
| | Observed | | | | | | 
| | Preferred role CC | 1 | 2 | Percentage Correct | 
| Step 0 | Preferred role CC | 1 | 100 | 0 | 100.0% | 
| Overall Percentage | 2 | 26 | 0 | .0% | 
| | | | | | 79.4% | 

a. Constant is included in the model.
b. The cut value is .500

**Table A7.4 Block 1: Enter Method Classification Table$^a$**

| Observed | Predicted |  
|---|---|---|---|---|---|---|---|
| | Preferred Role Current Condition | 1 | 2 | Percentage Correct | 
| Step 1 | Preferred Role Current Condition | 1 | 99 | 1 | 99.0% | 
| Overall Percentage | 2 | 26 | 0 | 78.6% | 

a. The cut value is .500

*Tables A7.3 and A7.4* shows how many patients preferred a shared (1) or passive role (2). Table A7.2 is with the beginning method, with no predictor variables and Table A-7.3 is with the enter method with both predictor variables (perceived health information literacy and
trust in physician score). Of note, most participants preferred a shared role. The set of predictors correctly classifies 78.6% of cases in the sample, which is no different from the percentage of cases correctly classified in the model without predictors (79%).

**Table A7.5 Variables in the Binary Logistic Equation**

<table>
<thead>
<tr>
<th>Variables in the Equation</th>
<th>B</th>
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<th>Sig.</th>
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<tr>
<td>Trust in Physician</td>
<td>.114</td>
<td>.042</td>
<td>7.304</td>
<td>1</td>
<td>.007</td>
<td>1.121</td>
</tr>
<tr>
<td>Perceived Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Information</td>
<td>-0.054</td>
<td>.036</td>
<td>2.266</td>
<td>1</td>
<td>.132</td>
<td>.947</td>
</tr>
<tr>
<td>Information Literacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-4.992</td>
<td>2.024</td>
<td>6.080</td>
<td>1</td>
<td>.014</td>
<td>.007</td>
</tr>
</tbody>
</table>

<sup>a</sup> Variable(s) entered on step 1: trustscore, ehealsscorenew.

As can be seen by Table A7.5, the Exp (B) for the trust score is a significant predictor of patients’ preferred roles B=1.121, p=0.007. Exp(B) value indicates that a patient with a one-point higher score on the trust scale is 12% more likely to have a shared role. The perceived e-health literacy Exp (B) was statistically insignificant B=0.947, p=0.132. Therefore, patients’ perceived health information literacy was not a significant predictor of patients’ preferred roles. A Nagelkerke’s $R^2$ of .126 indicated a weak relationship. This means that although the model is statistically significant, only trust in physician is a significant predictor of patients’ preferred roles. The Wald criterion demonstrated that only the trust score made a significant contribution to prediction (p = 0.007).
For the chest pain situation:

A binary logistic regression was conducted to predict patients’ preferred roles in health care decision making for the chest pain situation using patients’ perceived health information literacy score and trust in physician scores as predictors. As seen in Table 5.6, a test of the full model against a constant only model indicated that this model was statistically significant and was able to distinguish between patients’ preferred roles ($\chi^2(2) = 9.39, p = 0.009$).

Table A7.6 Omnibus Test of Model Coefficient

<table>
<thead>
<tr>
<th>Omnibus Tests of Model Coefficients</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Chi-square</td>
<td>df</td>
</tr>
<tr>
<td>Step 1</td>
<td>9.394</td>
<td>2</td>
</tr>
<tr>
<td>Block</td>
<td>9.394</td>
<td>2</td>
</tr>
<tr>
<td>Model</td>
<td>9.394</td>
<td>2</td>
</tr>
</tbody>
</table>

As can be seen in Table A7.6, the Omnibus Test of Model Coefficients is statistically significant for Step 1. The Omnibus Test of Model Coefficient is significant (p<0.05) indicating that there is a relationship between the predictors and outcome in this model.

Table A7.7 Model Summary

<table>
<thead>
<tr>
<th>Model Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.
As can be seen in Table A7.7, the Cox & Snell and Nagelkerke R Square value of 0.100, which means that there is a very weak relationship between predictors and the outcome.

**Table A7.8: Block 0: Beginning Block**

<table>
<thead>
<tr>
<th>Classification Table&lt;sup&gt;a,b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicted</td>
</tr>
<tr>
<td>PrefroleCP</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Observed</td>
</tr>
<tr>
<td>Step 0</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Overall Percentage</td>
</tr>
</tbody>
</table>

a. Constant is included in the model.
b. The cut value is .500

**Table A7.9 Block 1 Enter Method Classification Table**

<table>
<thead>
<tr>
<th>Classification Table&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicted</td>
</tr>
<tr>
<td>Preferred role Chest Pain</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Observed</td>
</tr>
<tr>
<td>Step 1</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Overall Percentage</td>
</tr>
</tbody>
</table>
a. The cut value is .500

Table A7.9 above shows that the model will predict participant’s preferred scores correctly in 70% of cases. As seen in Tables 5.8 and 5.9, the classification tables shows that there is an improvement in prediction of 5% comparing to the model with no predictors (65% vs. 70%).

Table A7.10 Variables in the Equation

<table>
<thead>
<tr>
<th>Variables in the Equation</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1(^a)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust score</td>
<td>.084</td>
<td>.033</td>
<td>6.517</td>
<td>1</td>
<td>.011</td>
<td>1.088</td>
</tr>
<tr>
<td>Ehealth score new</td>
<td>-.050</td>
<td>.031</td>
<td>2.646</td>
<td>1</td>
<td>.104</td>
<td>.951</td>
</tr>
<tr>
<td>Constant</td>
<td>-3.111</td>
<td>1.584</td>
<td>3.855</td>
<td>1</td>
<td>.050</td>
<td>.045</td>
</tr>
</tbody>
</table>

\(^a\) Variable(s) entered on step 1: Trustscore, Ehealsscorenew.

As seen in Table A7.10, the trust score is a significant variable within the equation (Exp (B)) = 1.088, p=0.011, p<0.05. However, the perceived e-health literacy is not significant Exp (B) =0.951, p=0.104. A Nagelkerke’s $R^2$ of .100 indicated a weak relationship between the prediction and grouping. The predictive power of the model was weak with a correct classification of the observed cases going up from 68% in the null model to 70% (refer to Appendix 7 for the tables). The Wald criterion demonstrated that only the trust score made a significant contribution to prediction (p = 0.011). Patients’ perceived health information literacy was not a significant predictor (p=0.104). Exp(B) value indicated that a patient with one point higher score on the trust scale was 9% more likely to have a shared role. The findings of this regression were as we had predicted because there was little variance in the sample in that most
people had a high trust in physician and preferred a shared role. These findings are important to those planning patient engagement.
APPENDIX 8: POST-HOC POWER CALCULATIONS

Appendix 8 provides the G*Power 3.19.2 output of the post-hoc calculation for the four t-tests for the shared and passive group of patients for the trust in physician and perceived health information literacy variables. The post-hoc results are described in the Results section 4.12.

Figure A8-1: G*Power 3.19.2 output for post-hoc power of the test for differences in the trust in physician scores (current condition)
Figure A8-2: G*Power 3.19.2 output for post-hoc power of the test for differences in the perceived health information literacy scores (current conditions)
Figure A8-3: G*Power 3.19.2 output for post-hoc power of the test for differences in the trust in physician scores (chest pain vignette)
Figure A8-4: G*Power 3.19.2 output for post-hoc power of the test for differences in the perceived health information literacy scores (chest pain)
APPENDIX 9: QUALITATIVE INTERVIEW CODEBOOK

Patient Engagement, Trust in Physician, E-Health Literacy Qualitative Interviews

Coding instructions: Coding can be done at the lower and/or higher level. For example, if something falls under “source of health information” and it is not a website or the physician, you can still code it as “source of health information”. Feel free to add codes if you discover any new ones as you are reading the transcript.

Thematic Analysis Coding Scheme (Codes & Sub-Codes):

1. Sources of Health Information
   a. Website Source
      i. MayoClinic
      ii. Youtube
      iii. WebMD
      iv. Google
      v. Peer-reviewed Journal Articles
      vi. Wikipedia
      vii. Medicine.net/ Medicine.org
      viii. Healthy baby healthy parent e-book
      ix. Drugs.com website
x. Sick Kids children’s health website

xi. Toronto Public Health

xii. About My Kids Website

xiii. CADRE

xiv. Learning Disorders Website of Ontario

xv. Portico at CAMH

xvi. Kids Mental Health Matters

xvii. Their own electronic health record (through portal)

b. Physicians

c. Frequency of website access:
   
   i. Monthly

   ii. Weekly

   iii. As needed Basis

   iv. Rarely

   v. Daily

d. Family and Friends

e. Other patients

f. Books
2. Process of finding Health Information:

a. Searching Symptoms

3. Trust Worthiness of Health Information: (Please provide example quote):

a. Assessment criteria for credibility of health information:
   i. Authorship and credentials
   ii. Organization’s credentials
   iii. Validation across several websites.
   iv. Not discussed in interview

b. Attitudes towards online health information
   i. Skeptical
   ii. Optimistic

c. Confirm credibility and reliability of sources with family doctor
   i. Yes
   ii. No
d. Confirm credibility and reliability of sources with:
   
i. Other websites

   ii. Family doctor

4. Patients’ preferred role when communicating with their doctor

   a. Prefer to let doctors make the decision

   b. Prefer to take the decision themselves

   c. Prefer to partner with the doctor in making the health care decision (e.g. weighing risks and benefits).

5. Factors that influence selection of people’s preferred role:

   a. In weighing the risks and benefits:

      i. Prefer to do it myself

      ii. Prefer to converse with physician

      iii. Prefer to let the physician make the decision.

   b. Knowledge of health condition

6. Factors that affect the trust in health care provider:

   a. Appropriate prescriptions

   b. Phone call communication and follow-up

   c. Clear coherent and timely communication in the clinical appointment
d. Empathy and Communication:
   i. Medical history and physical exam.
   ii. Time for conversation
   iii. Discussing choices/ options
   iv. Knowledge sharing between the patient and health care provider

e. Knowledge and experience of physicians.

f. Referral to colleagues or other specialists.

7. Factors that affect the source of health information consulted
   a. Nature of health condition
      i. Emergency
      ii. Acute Non-Emergency
      iii. Chronic Condition
   b. Worries/ concerns
   c. Visits clinician regardless of health condition.

8. Factors that influence participants’ preferred roles:
   a. Patient’s knowledge of their condition
   b. Provider knowledge and experience
   c. Access to health care
d. Knowledge sharing between the patient and health care provider

e. Patient Doctor Relationship.

9. Thoughts about communication mode:

a. In person

b. Phone

c. Email

d. Access to patient portal
References


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109. Kraetschmer N. Preferences of patients undergoing angiogram for participation in treatment decisions: Coping style and the problem solving-decision making scale. Toronto, Ontario: Graduate Department of Community Health, University of Toronto; 1994.


111. van der Vaart R, van Deursen AJAM, Drossaert CHC, Taal E, van Dijk JAMG, van de Laar MAFJ. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *Journal of Medical Internet Research*. 2011;13(4):e86.


