NOTE TO USERS

The original document received by UMI contains pages with slanted print. Pages were microfilmed as received.

This reproduction is the best copy available

UMI
THE IMPACT OF TRUST ON ROLES PATIENTS WISH TO PLAY IN MAKING MEDICAL DECISIONS.

by

Natasha Ann Sharpe

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy, Graduate Department of Community Health and Epidemiology, in the University of Toronto

©Copyright by Natasha Ann Sharpe 1997
The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author’s permission.

L’auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L’auteur conserve la propriété du droit d’auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.
To my husband David,

for the love and partnership that made this work a pleasure.
The Impact of Trust on Roles Patients Wish to Play in Making Medical Decisions.

Natasha Ann Sharpe

Department of Health Administration, University of Toronto

Doctor of Philosophy 1997

ABSTRACT

Background: Current medical and bioethical literature calls for active patient participation in making decisions about their own treatment. However, the literature also suggests that many patients do not want to participate. This study examines the following questions: To what extent do patients want to participate in problem solving (where preferences are irrelevant, e.g. diagnosis) and decision making (e.g. what is to be done) about their own treatment? To what extent do they want to be informed? What is the impact of respondents’ trust in their physician, personal characteristics (age, level of education) and disease characteristics (diagnosis of cancer, chronicity, availability of support groups) on their desire for participation? What is the impact of respondents’ desire for participation and trust in the physician on use of alternative therapies and preference of label (‘patients’, ‘clients’, ‘partners’, ‘consumers’, ‘survivors’, or ‘customers’)?

Methods: In this cross-sectional survey, questionnaires including the PSDM scale and the Trust in Physician scale were completed by 202 respondents from each of 3 teaching hospital clinics (breast cancer, prostate cancer, fractures).
**Results:** We found that most respondents (52%) wanted a *shared* participation role, where problem solving (PS) is handed over to the physician but not decision making (DM); 43.7% of respondents desired a *passive* role, where both PS and DM are handed over; and only 4.3% desired an *autonomous* role. Trust in the physician was inversely related to desire for participation: as trust levels rose, the respondent was more likely to be passive. Age, education, and support group use were found to be predictive of desire for participation, although other disease characteristics were not. Low trust levels were associated with alternative therapy use. Preference of label was influenced by both trust and desire for participation: respondents with high trust levels and desire for a passive role were more likely to indicate they strongly liked being referred to as a patient.

**Conclusions:** The impact of trust on the desire for participation is our most important finding. The links between trust, use of alternative therapies, and preference of a consumerist label suggest that trust in physicians is an integral element of satisfying patient-physician relationships.
ACKNOWLEDGEMENTS

I would like to thank my supervisor Professor Raisa Deber for her enthusiasm for the research, insight and guidance. Dr. Deber’s mentorship has made the completion of this dissertation a challenging and rewarding experience.

I would also like to thank my advisory committee members, Drs. Peter Singer and Donna Stewart for their time and meticulous attention to detail. Their suggestions were extremely valuable for the preparation of the thesis. I extend my deep appreciation to my father Dr. Paul Morris --for the inspiration to begin the doctorate-- and to my friend Dr. Mark Higgins for the incentive to meet its ambitious deadline. In particular, I would like to acknowledge Ann Pendleton’s contribution to the data management.

I would like to acknowledge the support of SSHRC grant 410970299 Preferences for participation in medical treatment decisions. Finally, I extend my sincere appreciation to Drs. Trachtenberg and Toi from the prostate centre; Dr. Lieberman from the fracture clinic; Dr. Ambus from the breast cancer clinic, and to the other clinicians, staff and patients of the study sites, who made possible the completion of this research.
# Table of Contents

Chapter 1 (Introduction) ................................................................. 1

Chapter 2 (Literature Review) ...................................................... 7

Chapter 3 (Methods) ................................................................. 49

Chapter 4 (Characteristics of Respondents) ............................... 72

Chapter 5 (Results) ................................................................. 90

Chapter 6 (Discussion and Conclusions) .................................. 136

References ................................................................................... 161

Appendix (Questionnaire and Scales) ......................................... 173
LIST OF TABLES

Correlations between selected variables .......................................................... 55
Patient Category ................................................................................................. 59
Age by Clinic ....................................................................................................... 74
Ethnic Background by Clinic ............................................................................... 75
Marital Status by Clinic ....................................................................................... 75
Level of Education by Clinic ............................................................................... 76
Employment Status by Clinic .............................................................................. 77
Overall Health by Clinic ..................................................................................... 78
Health Care Professionals by Clinic ................................................................... 89
Mortality Vignette: Problem Solving Scores ....................................................... 91
Mortality Vignette: Decision Making Scores ...................................................... 92
Current Health Condition: Problem Solving Questions ..................................... 92
Current Health Condition: Decision Making Questions ..................................... 94
Patient Category by Age .................................................................................... 107
PSDM Score ........................................................................................................ 109
Patient Category by Sex, controlling for education level .................................. 111

LIST OF FIGURES

Clinic by Sex ....................................................................................................... 73
Preference for “patient” ....................................................................................... 78
Preference for “client” ......................................................................................... 79
Preference for “customer” ................................................................................... 80
Preference for “survivor” ..................................................................................... 80
Preference for “consumer” .................................................................................. 81
Preference for “partner” ...................................................................................... 82
Perceived Knowledge by Clinic ......................................................................... 84
Perceived Knowledge by Information Seeking Score ......................................... 85
Attitude Towards Medical Care .......................................................................... 87

vii
CHAPTER I

INTRODUCTION

This research will examine issues related to patient participation in medical decision-making, with a specific focus on the question of what drives specific patient populations to participate in decision making and the effect of trust on their desire for participation. This is an important topic for a number of reasons. First, it has been suggested that increased patient participation increases patient satisfaction and adherence to therapy. Second, many medical decisions require knowledge of the patient’s preferences in order to choose the optimal treatment for the specific patient. Finally, current standards in bioethics and law call for active patient participation for purposes of empowerment and recognition of the patient’s right to self-determination and autonomy.

What is the appropriate role for a recipient of medical care? Current medical and bioethical literature calls for active patient participation in making decisions about their own treatment. The literature also suggests that patients wish to be informed, but not involved (Biley, 1992; Lerner et al, 1990; Brody, 1992). The shift from the historical patient-provider relationship where the physician was expected to direct care and decide treatment, to a relationship where the patient is expected to be much more autonomous, has placed both parties in new roles—where it would seem that neither is yet fully comfortable (Kassirer, 1994; Pellegrino, 1994). Is there a gap between the demands of this new relationship on patients and what patients actually want? Could differences be resolved through a more grounded and rigorous definition of participation?
This research tests a number of hypotheses related to two key concepts: choice of role in decision making; and trust. As will be further discussed in the literature review, trust is one of the most important elements of the patient-physician relationship. However, the impact of the recipient’s trust in their provider on their choice of role in decision making has not been previously studied. This thesis further examines which recipients are likely to prefer a role where they rely on clinicians for expertise but keep control of decision making.

The dependent variable in this research is the role that patients wish to play in terms of participation in their medical decisions. Identification of some of the factors required for active patient participation in decision making will be a useful tool for health professionals searching for ways to guide their patients to exercise their autonomy, for patients searching for empowerment, and for policymakers who desire to enable all the parties to be involved in ethical and health-promoting relationships.

The choice of role that patients wish to play in making treatment decisions was an outgrowth of a previous SSHRC-funded study, Medical Decision Making: Who and How? Patient Empowerment and Decision Rules, which postulated that one reason for the discrepancy between the emphasis on patient participation in the literature and the reports from clinicians that their patients do not wish to participate is that “participation” had not properly been defined. The Problem Solving Decision Making (PSDM) scale used in this thesis research was developed for the Decision Rules study. The PSDM scale makes the distinction between
“problem solving” (PS) tasks, which involve expertise and for which preferences are irrelevant (e.g., what is the diagnosis? what are the likely outcomes of the available treatment alternatives?) and “decision making” (DM) tasks, which incorporate both knowledge and preferences (e.g., how important are various outcomes to me?)

Based on the results of the Decision Rules study, we hypothesise that:

I i) most patients will want to hand over problem solving; and
   ii) some patients will want involvement in decision making.

Since the literature appears to support the view that recipients of care wish to be informed, but not involved, we accordingly hypothesise that

II Most patients will want to be informed.

The literature review will show that other research suggests that there is likely to be considerable variation in the desire for participation as a function of such factors as age, education, and whether the disease is chronic (since patients more experienced with their illness would obviously have more time to become well informed) or involves a diagnosis of cancer (since the stakes are higher). We accordingly hypothesise that

III Respondent and disease characteristics will be correlated to the person’s desire for PS and DM participation:
   i) people experienced with their chronic illnesses will be more participative; but
   ii) people with life-threatening illnesses (in this study, those with diagnoses of
cancer) will be less participative; and

iii) less educated and older people will be less participative.

Although trust is widely considered to be an integral part of the medical interaction, there has been a paucity of empirical research in this area. This study examines the influence of trust on the recipient’s doctor on desire for information and participation, and desire for a participative role in decisions about medical treatment. We hypothesize that:

IV Trust will be correlated with the desire for participation, such that:

i) people with high levels of trust will hand over control of PS and DM to the provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.

Some of the models proposed for the doctor-patient relationship where the recipient of care is expected to be a full participant in medical decision-making have been called ‘consumerist’ in orientation (Relman, 1994). Such participative recipients of care are often referred to as clients, consumers, customers, and the like. We investigate the relationship between trust level and preferred label: “patient,” “client,” “consumer,” “survivor,” “customer,” or “partner.” The term “patient” has come under attack for being too paternalistic, but very little research has been done on what recipients wish to be called. We hypothesize that:

V Trust will be correlated with preference of label: respondents who mistrust their providers will be less satisfied with the label ‘patient’ and will prefer labels with a
more consumerist orientation.

One suggestion has been that the lack of trust in mainstream physicians can lead to increased use of alternative therapies (Pietroni, 1994). We accordingly investigate this possible relationship, hypothesizing that:

**VI Respondents with a low level of trust in their physician will report a higher use of alternative therapies.**

Political science literature suggests that people who are politically participative tend to enjoy greater access to information (Lupia, 1992). Further, increased information leads to different political choices. The medical literature suggests that those people with more information tend to be more participative in their medical treatment decisions, yet less satisfied with the interaction with their provider (Brody et al, 1989a). We accordingly hypothesize that the greater availability of information for people with a "politically" ailment such as breast or prostate cancer will have an impact on their trust levels, their desire for participation, and their preferred label:

**VII Respondents with breast or prostate cancer, especially those who are involved in support groups, will be less likely to hand over control, less likely to have high levels of trust, and more likely to prefer a label with a more consumerist orientation.**

The preceding hypotheses were tested using a total of 606 respondents; 202 respondents
from each of three out-patient clinics at a tertiary care Toronto hospital: a breast cancer clinic, a prostate cancer centre, and a fracture clinic.

This thesis will be presented as follows. Chapter one has provided an introduction and overview of the thesis and its hypotheses. Chapter two provides a review of the relevant literature. Chapter three describes how the study was carried out, including the methodology, the research subjects, questionnaire construction, coding, testing the quality of the data and analysis of the data. Chapter four presents data on characteristics of the respondent sample. Chapter five describes the results. The final chapter summarizes and interprets the results and suggests future research.
CHAPTER II

LITERATURE REVIEW

This chapter is divided into two parts. The first part uses the hypotheses as the organizing taxonomy for a review of the relevant literature. The second part moves beyond the hypotheses to discuss the bioethics literature on models of the patient-physician relationship, and also examines political science literature related to democratic participation. The second part was included for two reasons. First, in order to briefly examine how the recipient of care’s desire for participation may influence the patient-physician relationship, since the extent to which a patient participates is an important and defining characteristic of models of the relationship. Second, in order to provide an overview of political science participation theory, where participation has enjoyed a deeper and more sustained analysis than it has in the medical literature. The chapter is structured as follows:

PART I:

HYPOTHESIS I
HYPOTHESIS II
HYPOTHESIS III
HYPOTHESIS IV
HYPOTHESIS V
HYPOTHESIS VI
HYPOTHESIS VII

PART II:

MODELS OF THE PATIENT-PHYSICIAN RELATIONSHIP
POLITICAL SCIENCE MODELS OF PARTICIPATION
PART I:

**HYPOTHESIS I:**  

i) most patients will want to hand over problem solving; and  

ii) some patients will want involvement in decision making.

Our first hypothesis is grounded in current medical and bioethical literature, which calls for active patient participation in making decisions about their own treatment. This shift away from the historical patient-provider relationship where the physician was expected to direct care and decide treatment, towards a relationship where the autonomy of the patient is emphasized, has placed both the parties in a new role where it would seem that neither is yet fully comfortable. Respect for the autonomy of the patient and the right of the patient to self-determination are accepted by the health care professions, who agree that the paternalistic model of patient care is no longer appropriate, nor legal. Patient autonomy is said to require the patient to actively participate in health care decision-making. Since the ethical practice of medicine and health care requires the provider to respect the autonomy of the patient, and the medical literature calls for the patient to participate in order to be autonomous, patient participation is not simply an important factor in the patient-provider relationship, but a necessary condition for an ethical relationship to exist (Saunders, 1995; Kassirer, 1994; Veatch, 1991). The importance of patient participation is largely unquestioned in the body of literature, but there is much less consensus surrounding what it is, whether it is a realistic goal, or how it can be achieved.

Patient participation in medical decision-making has not enjoyed a particularly long history in the medical literature. The definition of terms tends to be spotty and vague, with the
overarching ideas that patient participation is inherently desirable, necessary for an ethical relationship with the provider, and might lead to improved outcomes for the patient through increased levels of adherence to treatment recommendations. Embedded in these concepts are implicit definitions of participation as wide ranging as a pre-condition for adherence, or as condition for patient autonomy. What is largely unanswered is the question of operationalizing participation: for example, does a patient have to be compliant in order to be participatory? We shall first explore relevant nursing and medical literature.

Serious problems with implementing patient decision-making and patient participation have been encountered by the health professions. Much current research shows that not only do many patients not participate in medical decision-making, but also that they do not want to participate (Degner & Sloan, 1992; Waterworth & Luker, 1990). This apparent lack of desire for participation has posed difficult questions for providers, who on the one hand are in professions whose code of ethics requires them to seek patient participation, and on the other hand are faced with distressed, ill, possibly dying patients who seem to find decision-making to be an unwanted additional burden.

Nursing and medical literature tend to be very similar in scope and results in their examination of patient participation. According to the nursing literature, participation means that “taken-for-granted presuppositions about the health care setting are all ready to hand for the individual.” (Ashworth, 1992). The ideal that patients should be participants in their own care has found wide acceptance amongst nurses, whose literature states a number of
requirements for participation to take place: the attunement to a mutual stock of knowledge at hand, emotional and motivational attunement to the other’s concerns, taking it for granted and implicitly assuming that the other takes it for granted that one can contribute worthily, and feeling that one’s identity is not under threat (Ashworth, 1992). Much nursing literature points out that although patient participation is difficult to attain, participation appears to embody many of the ideals central to current thinking in nursing, and the attempt to build participatory relationships with patients is ethically required of members of a ‘caring’ profession (Ramos, 1992; Saunders, 1995).

Some of the problems identified in the nursing literature included the point that patients did not want to be collaborators in medical decision-making (Avis, 1994). Biley (1992) points out that although nurses are now being actively encouraged to promote the inclusion of patients in decision making, there is very little empirical evidence to support the contention that patients are demanding or welcoming a more active role. Although the need for a fully informed individual (patient) to control medical decision making is explicitly stated in medical literature, (Katz, 1984; Williams, 1994) anecdotal reports as well as a body of empirical literature seem to confirm that they may not wish to take an active participatory role. This point is expanded in the medical literature, where clinicians question why patients allow critical decisions to be made for them, and whether physicians might avoid usurping patients’ decision-making prerogatives (Kassirer, 1983).

Physicians are calling for improved methods by which they can assess patient attitudes, so
that these results can be incorporated into the decision-making process and increase patient participation (Kassirer, 1994). It is evident from the literature that doctor facilitation of patient involvement is a key element in patient participation: doctor facilitation and information exchange relates consistently to patient perceptions of post-visit changes in their understanding, perceived control over illness, and desire for involvement in decision-making (Lerner et al. 1990; Brody, 1992). Successful interventions developed to increase patient involvement in care and active involvement in decision making include standard educational sessions, help in reading their own medical record, and coaching to ask questions and negotiate medical decisions (Greenfield et al. 1985; Roter, 1984). Results of such interventions include increased interactions with physicians, and increased preference for active involvement in medical decision making.

The call for greater patient participation suggests a shift in political philosophy about who should be allowed or expected to make health care decisions for whom. The medical literature calls for physicians to change their behaviour to allow increased patient participation, even though they might perceive patient participation as threatening their sense of competence or autonomy (Wofford & Moran, 1994). It is interesting to note that clinicians are suggesting practice guidelines that shift control away from the physician, and advise educating the patient through pre-encounter information sessions so that during the medical encounter they can state their preferences plainly (Kaplan et al, 1989).

Many believe that the implicit respect physicians had for patients’ preferences about
outcomes is no longer enough, and that in the era of formal guidelines such assessments need to be explicit. At this micro level, how can one reconcile the insistence by the health professions for greater attention to active participation by the recipient of care with empirical suggestions that this is not what most such recipients desire?

There are two probable, though contentious answers to the above question. One is that the increasing social emphasis on the concept of personal responsibility is producing a climate where it is unacceptable for the recipient of care not to exercise their right to autonomy. In the field of medical ethics the driving force behind patient autonomy has been the legal concept of informed consent--in order to let the individual decide what she or he wishes to do with respect to their health care. As bioethicist Arthur Caplan has pointed out, “It may be true, that as most physicians believe, you can get people to sign anything you want. It may be true that most people don’t want to be autonomous. But the driving force throughout health care ethics for the past two decades has been to make people respect individual autonomy, empower patients, allow them to exercise individual choice.”(Caplan, 1992). In the United States, the social changes that are taking place regarding personal responsibility as a method of curbing costs of social programs such as welfare and health care is creating an environment which increasingly emphasizes the concept of autonomy (Mechanic, 1996).

Autonomy not only creates rights (e.g. the right of an autonomous individual to deny a physician permission to use life-saving treatment) but also responsibilities (in the Canadian case of Malette v. Shulman it was held that the patient was responsible for the content of the
written directive she was carrying refusing treatment—physicians could not be held liable for non-treatment of such a patient, even if this resulted in the death of the patient). Thus, an autonomous individual is held to be accountable for his or her actions, to have a duty to be prudent, to have an obligation to be responsible for reasonably foreseeable circumstances. The more an individual is held to be personally responsible for things that occur to them, the more emphasis is being placed on the concept of autonomy. This is a concept which now permeates health policy—most transplant programs exclude alcoholics, many insurance companies have incentives for lifestyle choices, some heart valve replacements will not be performed on smokers or drug abusers. Even though many patients may want the provider to make medical decisions for them, a wide-spread social emphasis on personal responsibility may be making that decision less acceptable.

A second answer to the question of why the health professions are keenly interested in emphasizing patient participation might be that there is another agenda on the part of the providers that does not simply involve the desire to respect the autonomy of the patient through ensuring their participation in decision-making. Patients who participate are more likely to adhere to treatment recommendations (Cassileth, 1980). Medical nonadherence is commonplace and a serious public health problem, with health care systems burdened with “preventable cost” and patients at risk for unabated disease. The consistent finding is that between one half and one third of patients do not adhere to medical recommendations. As noted in one review, providers may seek participation on the instrumental grounds that satisfaction increases adherence (Williams, 1994). Golin et al (1996) proposed an adherence
model that suggests that participation not only improves adherence directly, but also indirectly improves adherence by positively affecting patients' satisfaction with the doctor-patient interaction. However, as Saltman noted, emphasis on patient satisfaction views patients as consumers (the object of service delivery), whereas emphasis on patient empowerment views them as the active subject of the service system (Saltman 1994).

The traditional concept of adherence as the ability of the patient to carry out the doctor's orders has prevailed within adherence research, even when the model of shared decision making has been advocated for the doctor-patient relationship. With such high numbers of patients being nonadherent, it is evident that many patients are making their own decisions about their health care regardless of what they tell the providers. Participation is being identified not only as a method for enhancing patient autonomy, but also as a possible method through which the providers can work with the patient towards improving outcomes.

According to some researchers, a shift in emphasis away from attempting to persuade the patient to adhere towards learning how health professionals can contribute to the decision-making of the patient could have the following benefits: health professionals would be able to "participate in real shared decision-making and understand the context within which patients reach their decisions" (Donovan, 1995).

Patient participation is widely recognized by medicine and the allied health professions to be an inherent principle of ethical health care and linked to benefits in treatment outcomes (Greco and Eisenberg, 1993). Given that the health care and policy literatures stress the
point that patients who participate show greater satisfaction and better treatment outcomes, it seems all the more surprising that front line nurses and clinicians report that most patients do not wish to participate. Previous work by Baumann and Deber suggests that one reason for this apparent discrepancy is that patient participation in medical decision-making needs to be broken down into two theoretically distinct dimensions of patient decision making about treatment options (1989). “Problem solving” tasks, which involve expertise in order to identify diagnosis, treatment modalities, and probability of different outcomes, were compared with “decision making” tasks which involve placing a value on particular outcomes and weighing treatment alternatives and trade-offs based on individual need and preferences. The results showed that in the population studied most patients wanted to hand over control of problem-solving tasks, but many wanted to participate in decision making tasks.

In that study, 300 patients with cardiac disease who were scheduled to receive angiograms (a diagnostic test) were surveyed at The Toronto Hospital. One portion of the questionnaire was a new instrument, which was termed the Problem Solving Decision Making (PSDM) scale; the scale was validated on a sample of nursing students. The PSDM gave three brief vignettes; for example, “Suppose you had mild chest pain for three days and decided that you should visit your doctor about this”. Respondents were asked “who should decide” for each of a series of tasks, written to encompass both PS and DM activities. To enhance compatibility with previous studies, response categories used the same 5-point scale employed by Ende et al.: “1=the doctor alone”; “2=mostly the doctor”; “3=both equally”; “4=mostly me”; and “5=me alone” (Ende et al 1989).
The four problem-solving tasks on the PSDM were referred to as:

*Diagnosis:* "Who should determine (diagnose) what the likely cause of your symptoms are?"

*Treatment Options:* "Who should determine what the treatment options are?"

*Risks/benefits:* "Who should determine what the risks and benefits for each treatment option are?"

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

The two decision-making tasks were referred to as:

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

*What is done:* "Given all the information about risks and benefits of the possible treatments, who should decide what treatment option should be selected?"

The descriptions, but not the labels, appear on the questionnaire. Factor analysis confirmed the existence of these two dimensions. The study confirmed the hypothesis for this patient group: 98.4% of the 12 PS scores were between 1 and 3 (i.e., from physician to shared control, with a score of 3 indicating a desire for shared control), whereas 78% of the 6 DM scores were between 3 and 5, indicating the respondent's desire to participate.

The results confirmed the hypothesis that few individuals would wish to control PS, for which expertise would be required, but that given the necessary information, many would indeed wish to be involved with DM. This thesis will further explore the PS/DM distinction,
and will focus on trust as it relates to desire for a participative role. Based on this literature, we hypothesized that trust would be correlated with preference for participation such that very high trust levels would be linked with desire to hand over control of both problem solving (PS) and decision making (DM), moderate trust levels would be linked with desire for shared DM, and low trust levels would be correlated with a desire to share or take over PS and to take over DM.

It seems likely that restrictions based on cost will increasingly influence providers' decisions about patients. An editorial in the New England Journal of Medicine states that it will therefore be essential to identify decisions in which it is especially important to consider patients' values and to protect such decisions from external decision making. To do so, precisely which decisions (or perhaps which kinds of decisions) that require the most patient participation and reliable ways of assessing patients' preferences need to be identified (Kassirer, 1994).

Physicians have already identified some of the circumstances that should alert them that they may be dealing with a 'utility sensitive' decision. Though the list is undoubtedly incomplete, they are 1. when there are major differences in the kinds of possible outcomes (for example death vs. disability); 2. when there are major differences between treatments in the likelihood and impact of complications; 3. when choices involve trade-offs between near-term and long-term outcomes; 4. when one of the choices can result in a small chance of a grave outcome; 5. when the apparent difference between options is marginal; 6. when the patient is
particularly averse to taking risks; and 7. when a patient attaches unusual importance to certain possible outcomes (Kassirer, 1994).

These categories were supported by the results of the Decision Rules cardiac study, which found that high fear situations may make individuals more risk averse; there was a significantly greater willingness to hand off PS in the condition involving possible mortality (cardiac) than in those involving morbidity (urinary problems) and quality of life (fertility), probably because the consequences of error were seen to be too high for respondents to wish to keep control (Deber & Kraetschmer, 1995). Ende found that physicians as patients preferred that the principal role in decision making for their own illnesses be handled by their providers rather than by themselves, a tendency that increased with the severity of their illness (1990).

Whether the recipient of care should participate is partly a normative question, and this aspect was more fully discussed in the section on models of the physician-patient relationship. However, there are clear and compelling health reasons why recipients of care should consider a participative approach to their care. Greenfield et al (1988) have suggested that patients who perceive that they have choices in their treatment and thus some control over their health status indirectly achieve better outcomes through “enhanced or protected immune functioning”. Other studies have also found that participation leads to better outcomes and higher levels of satisfaction amongst recipients of care (Speedling & Rose, 1985; Brody et al 1989). As Katz has pointed out, medicine is an art rather than a science, and is as such
uncertain (1984). The optimal treatment for many afflicted individuals will be ambiguous—unless the physician knows the recipient’s wishes, he or she will be unable to recommend a course of treatment that takes into account the recipient’s values. For instance, the value assigned by the decision maker to specific outcomes can in some cases determine the optimal treatment (Barry et al 1995; Fowler et al 1994; Williams, 1994). Studies have also consistently shown that physicians are poorly able to predict what their patients actually want (Gray et al 1990; Brody et al 1989; Lidz et al, 1985; Brock & Wartman, 1990).

The difficulties that efforts to increase patient participation in medical decision making have encountered in the clinical setting are problematic for a number of reasons. As noted, patient participation has been empirically associated with improved outcome measures such as better health status (Kaplan, Greenfield & Ware, 1989) and improved patient recall, satisfaction, and adherence to therapy (Hall & Roter, 1986). Second, there is strong evidence that given the opportunity, most people want to participate to some degree in their medical choices (Beisecker et al, 1996). Finally, in a recent study of prostate patients, it was found that those who did participate in their treatment decisions subsequently had more trust in their physician (trust article). The link of participation to a propensity for a trust is a clue that trust plays a significant role in the recipient of care’s relationship with the provider.

**HYPOTHESIS II: Most patients will want to be informed.**

As noted by Etchells et al (1996), obtaining informed consent is a process with three components: disclosure, capacity, and voluntariness. Capacity refers to the ability of the
recipient to understand the information and the foreseeable consequences of his or her
decision. Voluntariness refers to the right of the recipient to make his or her decision without
duress or manipulation. The physician is responsible for disclosing the purpose, risks,
benefits, alternatives and nature of the proposed treatment and ensuring that the patient
comprehends all information 'material' to making a decision whether to undergo or forgo a
proposed treatment or diagnostic procedure. In this thesis the discussion of informed consent
is limited to an overview of how the legal requirements have influenced the context in which
the physician-patient relationship occurs.

Most partnership models are conceptualized using the doctrine of informed consent as a
necessary, though not sufficient condition to transform the theory of patient autonomy into a
clinical reality. In any discussion of informed consent as it relates to the patient-physician
interaction it is important to recall that although this doctrine has undoubtedly been
responsible for changing the nature of the interaction between recipient and provider of care,
it is a legal doctrine which was neither intended nor designed to serve as a blueprint for the
provider-patient encounter. As Katz (1984) points out, the medical profession is responsible
for creating its own ‘doctrine’ that is responsive to law and to the current needs of
practitioners and patients. The vision of the ideal physician-patient interaction and of
physician-patient communication is one which medicine must build within the parameters of
law; however, the resulting construct should stem from the medical profession rather than
borrow this ideal from the legal discipline.
In a preemptive response to those who would argue that informed consent has become an ethical ideal in the medical interaction, it should be affirmed that indeed it has, but that this is not the doctrine of informed consent. The ethical idea of informed consent was and continues to be developed by bioethicists, philosophers, and legal theorists (Etchells et al, 1996; Keyes, 1995; Kaufmann, 1983; Beauchamp & Faden, 1995). This conception imbues the ethical normative ideals of the medical interaction within a partnership model: the provider should/ought to empower the patient; the patient should seek such empowerment; the two ought to be partners of equal standing; this should be something both parties strive for and desire.

Among the evident differences between the ideal and some practical applications is that genuine patient participation is neither required nor specifically encouraged by the discrete event of obtaining a signature on a consent form. Further muddying the waters, it is often said that informed consent in effect requires patient participation. The process of informed consent does. However, The President’s Commission for the Study of Ethical Problems in Medicine found that the practical implementation of informed consent often gives rise to an empty ritual which has led to few positive changes in the patient-physician relationship, where the patients are presented with complex information that they cannot understand and that has little impact on their decision making (1982). As Bunn & O’Connor (1996) noted, recent health legislation and health care position papers emphasize the need for informed choice, rather than informed consent, on the part of the recipient of care.
Physicians write that increased participation by patients in making decisions about their medical care requires that patients be informed about alternatives and options and given an opportunity to express their wishes. This implicitly endorses a view that the technical expertise of providers should be used to break down the traditional knowledge gap between them and the patient, empowering the patient to assess the merits of various treatment alternatives (Wennberg, 1990). A number of studies have suggested that most patients do wish to be informed (Lerman et al, 1990; Weiss 1986), but that the desire for information does not translate into a desire for decision-making.

**HYPOTHESIS III:** Respondent and disease characteristics will be correlated to the person’s desire for PS and DM participation:

i) people experienced with their chronic illnesses will be more participative; but

ii) people with life-threatening illnesses (in this study, those with diagnoses of cancer) will be less participative; and

iii) the less educated, and older people will be less participative.

The experience a respondent has with their chronic disease is expected to have a significant impact on desire for participation: if one has been living with an affliction for an extended period, it seems likely that one will have the motivation and incentive to be interested in higher levels of participation—and participation in the long term treatment choices. A study of patients with chronic diseases has also found that such individuals are less willing to hand over control to physicians (Lidz, 1985). In studies of cancer patients, it has been found that
although newly diagnosed cancer patients preferred to leave treatment decisions to their physician (Degner & Sloan, 1992), those living with the disease for an extended period desired a higher level of participation (Cassileth et al, 1980).

The diagnosis of cancer can be anticipated to have an impact on decision-making. In some cancer research (Cassileth et al, 1988) the diagnosis of cancer has been taken to mean that the recipient of care is facing a severe and life-threatening illness. The fact that most people fear death makes health care decisions that carry death as a risk rather salient issues for them—as Kassirer (1994) found, even a small risk of death associated with a procedure will tend to skew patient’s decisions away from that particular course of treatment. It is not surprising that ordinary people can figure out what they want done or not done in issues of health care, even though many of them can be lost when it comes to the medical procedures involved. It suffices that since people want to avoid death—it follows immediately that they should desire treatments that do not involve that risk. This form of reasoning is driven primarily by emotion, rather than employing a rational decision-making calculus. According to Sniderman (1991), people become much more analytic and complex in their thinking when they care a lot about an issue as opposed to a more erratic, visceral, and simplistic response when they are indifferent.

There is also empirical evidence that better educated persons may prefer greater involvement in decision-making (Cassileth et al 1980; Strull et al 1984; Weeks 1994; Siminoff & Fetting, 1991; Wartman et al 1983). Education is a variable which is strongly related to
socioeconomic status (SES), and is often used as a proxy for measuring social class (Leslie & Brinkman, 1988). Some political science researchers suggest that if education is used in a regression, "controlling for SES or occupation is unnecessary and shortsighted" (p. 50). In a study of diabetics with low socio-economic status, Pendleton & House found that they expressed significantly less desire to be actively involved with their medical treatment decisions or to seek information than did college students (1984). Education in general, not specific to the current health condition, is also positively related to the desire for participation. In a meta-analysis of the role of patient education in the doctor-patient encounter, Haug (1993) found that patients with university degrees and/or graduate degrees were the most willing to challenge the physician, actively seek information, and desire a more egalitarian relationship. Studies of patient satisfaction concluded that the highly acquiescent respondents were older, less well-educated, and in poorer health (Ross, Steward, & Sinacore 1995). A recent study by Degner et al (1997) found that education was a significant predictor of the amount of control women wanted in breast cancer decision making.

As several studies have concluded, age appears to be an important predictor of preferences for participation in decision-making (Cassileth et al 1988; Strull et al, 1984; Weeks, 1994) - thus it is hypothesized that older people will desire less involvement. Ende et al. (1989) found that younger people were more inclined to participate, whereas older patients were less likely to make decisions or to desire to be informed.

There is limited agreement as to whether sex differences have an impact on participation. In
a 1993 study of 459 janitors and maintenance personnel in a health care facility, it was found that younger and better-educated individuals reported a higher desire for involvement, but that there were no sex differences in preferences (Thompson, Pitts & Schwankovsky). In a study of seniors’ participation in a fitness program it was found that among beginners women were more likely to participate because “daytime meetings were offered” and “people I trust recommend it” but there were no sex differences among members who had participated for three or more years. The motivation levels of men who were long-term participants increased to resemble those of women (Lee, 1992). However, Blanchard et al (1988) concluded that those who preferred to leave decisions to physicians were primarily older, sicker males, almost all of whom were married; they suggested that these patients had become more dependent on their wives and on their physicians.

**HYPOTHESIS IV:** Trust will be correlated with the desire for participation, such that:

i) people with high levels of trust will hand over control of PS and DM to the provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.

Baier (1986) defines trust as the cooperative behaviour that depends on one person’s expectation that the other person will voluntarily act to the first person’s benefit. Trust is widely held to be crucial to the physician-patient relationship (Horder, 1994). Indeed, trust has not only been called the basic building block of doctor-patient interactions, but also that it
is the issue that should receive an "intense and single-minded focus" from those in the current practice of medicine (Rogers, 1994). Patients are noted to be concerned about the technical competence of the physician, but it is at least of equal importance to them to feel that the doctor will put their interests before any other consideration. (Horder, 1994). This being so, it is appropriate to begin at this basic level, tracing the impact of trust on the medical encounter and the scope that it enjoys.

In the last twenty-five years autonomy has replaced beneficient paternalism as the dominant ethic of medical care. Much attention has been paid to levelling the doctor-patient relationship, based on the emerging consensus in the courts and in segments of the general population that the patient's autonomy is central to the clinical interaction (Englehardt, 1996; Bayertz, 1996; Keyes, 1995.) The shift in the locus of decision-making from the doctor to the patient was heavily reinforced by the legal requirement for informed consent (Silverman, 1996). The sea change in the socio-political framework has indeed produced a more informed, better educated, and more questioning recipient of care (Eisenberg et al, 1993). It is an important question to consider whether trust is possible in this setting, or whether it is as outdated and inappropriate an ethic as paternalism.

Some claim that trust is a barrier to the optimal relationship between provider and recipient: one where the recipient is an aggressive and engaged information seeker, who shops carefully amongst competing providers, who defines their own needs, takes an active role in their own treatment, and takes responsibility for their treatment decisions (Zola, 1990). There are a
number of reasons to be wary of this model. For instance, it is well documented that people with critical illnesses depend on their physicians strongly, and strong relationships benefit them by helping them to deal with fear and uncertainty (Cassell, 1995). One can also point out that the personal relationship between recipient and provider is the context in which medical care is given. This relationship is the one in which treatment is chosen and carried out; not only would distrust be yet another stress and drain of energy for the ill person, but also paralyzing for the ill person who depends on the physician as his or her source of information (Brody, 1992). In addition, taking responsibility for treatment decisions is frequently construed by recipients as meaning that any subsequent illness is evidence of their personal failure (Steinberg, 1990).

The metaphor of the consumer denies the emotional aspect of the relationship the recipient has with their provider, and also does not recognize that in acute illness the option of making a decision to be a buyer or not is significantly compromised. Being ill is inherently disempowering, and a conscious effort is needed to empower the recipient of care (Beauchamp & McCullough, 1984). A trusting relationship with the physician has been hailed as empowering to the recipient--if individuals trust that their doctor is working in their best interest, they not only feel more satisfied with the medical encounter but also gain the sense that the choices they make will influence what happens to them (Steinberg, 1990).

As recently as three years ago, it would seem that most Canadian recipients of hospital care trust their doctors. For instance, Charles et al suggested that over 90% of patients in their
survey of 4599 adults discharged from Canadian hospitals “reported that they had a relationship of confidence and trust in their physician and that they had been involved in decision making as much as they wanted to be” (1994). It is evident that current changes in the Canadian delivery of health care, most obviously those occurring under the rubric of cost control, have been noted as having the potential for profound effects on the recipient’s trust in his or her provider (Relman, 1994). The awareness amongst recipients that cost is a consideration leads to a breakdown in trust over whether it is the most appropriate—or the cheapest—treatment that is being provided (Neuberger, 1994). Recipients of care have responded by an increasing distrust in the medical profession (although this is often accompanied by considerable confidence in their own doctor) (Blendon et al, 1994). Research on trust levels is thus of particularly timely interest.

Trust is highly correlated with patient satisfaction (Anderson & Dedrick, 1990). Trusting people have a better adherence to treatment recommendations with the concomitant potential for improved health status, less anxiety, and an increased sense of being cared for which may improve their sense of well-being (Thom & Campbell, 1997). Although trust is held to be a necessary and extremely valuable component of the doctor-patient relationship in the medical literature, there have been relatively few studies of this topic. Thom and Campbell’s 1997 qualitative study of 29 subjects in focus groups found that the perception of a partnership with the physician was a dimension of trust. These researchers found that patients distinguish factors that are technical (e.g. diagnosis) from those that are interpersonal, and that both technical and interpersonal characteristics such as communication and caring were essential
for developing and maintaining trust.

Studies from psychology and psychiatry of the therapeutic relationship have found that better communication, shared goals, and sharing of power are an important predictor of outcome of therapy in these fields (Alexander & Luborsky, 1986; Hatcher et al 1995; Horvath, & Greenberg, 1986). Nursing has also explicitly valued trust as a dimension in the nurse-patient relationship, yet as in medicine there is a dearth of empirical research. In a 1994 review of the literature Lowenberg found only one study which even peripherally documented the degree of trust within the nurse-patient relationship.

The only quantitative measure we and others (Thom & Campbell, 1997) found in the literature for trust in physicians was developed by Anderson and Dedrick (1990) using a population of men with multiple chronic health conditions. The Trust in Physician scale was developed and validated using two studies of 160 and 106 participants respectively. This scale was used in this research and will be further discussed in the methods chapter. Defining trust as the belief that the physician will act in the patient’s best interest and will provide support and assistance concerning treatment and medical care, this 11-item scale was presented in a five-point Likert format with response options ranging from “strongly agree” to “strongly disagree”. Results showed that patients in this sample with high trust expressed lower desires for personal control in the medical interaction.

To date, no studies have been done that fully examine the relationship between the recipient
of care's trust in their physician and their choice of role in treatment decision making.

**HYPOTHESIS V:** Trust will be correlated with preference of label: respondents who mistrust their providers will be less satisfied with the label 'patient' and will prefer labels with a more consumerist orientation.

It is evident that patients want the confidence that their provider is acting in their best interest. In a climate where recipients of medical care are more aware that physicians may be balancing the benefits of medical treatment against the costs that it engenders, it is unsurprising that there has been a growing skepticism. An increase in managed care arrangements in the United States where the physician is financially rewarded for recommending less costly treatment options has led to a spate of publications on patient trust (La Puma & Scheidemayer, 1994; Swee, 1995). Providers are concerned that economic incentives to under-treat will lead to a deleterious influence of corporate financial goals on the patient-physician relationship, most notably on the aspect of trust (Relman, 1993a).

Recipients of care are not only encouraged to be skeptical and informed consumers, ready to question their medical treatments, but in some cases also to become their own utilization reviewers (Angell, 1993). The belief that an individual doctor may no longer have the interests of the individual patient at heart is not limited to the United States. British patients are also being encouraged to move to a consumerist model, and to question doctors and their recommendations in a manner similar to those of their American counterparts. One chairman of a London NHS Trust recommended a move towards a consumerist approach as being "long overdue" (Neuberger, 1994). But what does this mean for the recipient of care?
Haug and Levin (1983) report from a meta-analysis of health behaviours that consumerism in medicine is a reality, with younger, more knowledgeable people being skeptical of medicine’s efficacy and physicians’ dedication to their patients. Implicit in consumerism is that the customer is the sole arbiter of his or her needs, and that the role of the tradesman is to satisfy them. It is no part of a seller’s ethic to discourage a customer from buying on the basis that the item in question is not one which the customer needs. The ethics of trade are based on the premise that the buyer is always right, and also on the principle of *caveat emptor*. What is very clear from the literature is that recipients of care in a consumerist model are not patients (Lupton et al, 1991; Relman, 1994; Barondess, 1994). References to consumers, clients, purchasers, customers, and the like abound.

In previous work, Deber (1995) demonstrated that the connotations carried by these labels in the medical context are quite clear from their dictionary definitions. Patient is defined as "having or showing patience", and as "a person receiving or registered to receive medical treatment". Patience, in turn, derives from the Latin word meaning "to suffer", and is defined as "the ability to endure delay, hardship, provocation, etc.". "Client" comes from a Latin root meaning "dependent", and is variously defined as "a person under the protection of another", "a person using the services of a lawyer, architect, or other professional person", or "customer". "Customer", in turn, comes from the Middle English word for tax collector, and is defined as "a person who buys goods or services from a shop or business". "Consumer, from the Latin consumere ("to take completely") means "a person who consumes, esp. one who uses a product", or "one that uses economic goods (see commodity)," while "consume"
is variously described as "to destroy or do away with completely", "to spend wastefully, squander, use up", "to utilize an economic good in the satisfaction of wants".

Where trust interfaces with preferred label is quite clear in examining the current status of medicine as a profession. Eliot Friedson writes

"it is useful to think of a profession as an occupation which has assumed a dominant position in a division of labor, so that it gains control over the determination of the substance of its own work. Unlike most occupations, it is autonomous or self-directing. The occupation sustains this special status by its persuasive profession of the extraordinary trustworthiness of its members. The trustworthiness it professes naturally includes ethicality and also knowledgeable skill. In fact, the profession claims to be the most reliable authority on the nature of the reality it deals with."(1970)

Trust is essential if physicians are to remain professionals, and it is equally evident that low levels of trust will lead to a devolution of the role of the physician-as-professional into the role of the physician-as-technical-instrument. This research accordingly tested the hypothesis that low levels of trust will result in a propensity to prefer a consumerist label, or a label other than that of ‘patient’, such as ‘partner’ or ‘survivor’.

**HYPOTHESIS VI**: Respondents with a low level of trust in their physician will report a higher use of alternative therapies.

What effect do low levels of trust have on the medical interaction? One possible outcome is that individuals with low levels of trust in medicine will avoid traditional medicine altogether
and turn instead to alternative therapies. Alternative medicine may be defined as therapies not taught in medical schools, not found in most hospitals, and not subject to similar reimbursement strategies to those of mainstream healthcare providers (Schneidman, 1994). Despite the cost disincentives associated with the use of alternative therapies, in combination with or as an alternative to traditional therapy, Commonwealth countries have experienced a surge in the number of consultations with alternative providers (Furnham & Bhagrath, 1993).

An Australian study of the sociodemographic characteristics and motives of alternative therapy users found that users reported a high level of dissatisfaction with traditional medicine. One of the commonly cited reasons given for such dissatisfaction included perceived problems in the interpersonal features of the doctor-patient relationship (Lloyd et al, 1993). This study also found that the high level of interaction between clients and alternative therapists and a perception of more information-sharing was attractive for these individuals. Although the term trust was not explicitly used, several studies of the psychology of trust have found that trust is more likely where the relationship is viewed as long term, and where communication is greater (Gambetta, 1988).

There have been other suggestions that the growing use of alternative therapies is related to failures of communication and trust in organized medicine, combined with a greater consumer orientation (Mechanic, 1996; Lupton et al 1991). As Haug and Levin (1983) report, consumerist recipients of care are turning to providers outside of traditional medicine in part
because of a skepticism about the dedication and efficacy of their physicians. It should be noted that alternative medicine use is often not an "either-or" situation, with many recipients of care using alternative therapists in conjunction with traditional providers (Haug & Levin, 1983). Life-threatening diseases, notably cancer and AIDS, have been especially linked to increased use of alternative therapies as well as traditional medicine (Cassileth, 1990).

Turning to alternative therapies due to a lack of trust in organized medicine and in physicians is most explicit in the AIDS literature. The frustration with conventional medicine is apparent (Pietroni, 1994). People with AIDS state that “believing that doctors and orthodox medicine holds the answers can be an obstacle to the self-empowerment of people with HIV. The trust must come from within, not outside.” (Greenberg, 1993).

It has been argued that this disenchantment with traditional medicine results from a better informed population who are more sophisticated consumers (Lloyd et al, 1991; Buckle, 1993). Traditional health care faces mounting criticism for being overwhelmingly reliant on expensive, invasive treatments—often with damaging side-effects (Steinberg, 1990). Discontent with the system’s lack of emphasis on prevention and a corresponding focus on curing disease rather than promoting health has also been the subject of much media attention over the past several years (Greenberg, 1994; Furnham, 1994.) Alternative therapists are contrasted as embracing a holistic, client-centred approach to treatment, promoting the active participation of the client in his or her health decisions (Eisenberg et al, 1993; Wellman, 1995).
There are major health and ethical issues relating to the use of alternative medicines in life-threatening illnesses, especially if the patient refuses potentially curative surgical or medical options on the advice of an alternative practitioner (Cassileth, 1996b). The British Medical Association accordingly appointed a committee to study use and value of alternative therapies, which found that clients of alternative therapists reported a lack of satisfaction with the medical encounter and had thus turned to alternative practitioners with more “time, compassion, and charisma” than traditional providers (1986). The BMA acknowledged that alternative medicine was growing in popularity, but believed that the reason was due to a lack of trust in medical care resulting from “modern medicine failing to give patients something they wanted.”

**HYPOTHESIS VII:** Respondents with breast or prostate cancer, especially those who are involved in support groups, will be less likely to hand over control, less likely to have high levels of trust, and more likely to prefer a label with a more consumerist orientation.

The final hypothesis which this research shall test is that the degree to which a disease is ‘politicized,’ where information about the disease is widely available, will have a corresponding positive effect on the patient’s desire for participation in decisions about their own care. Being a member of a group with a very well-known ailment, such as breast cancer, would correspondingly give one access to resources and information not as readily available to others.
The literature is divided as to whether politicization of a disease would lead to greater participation. The political science literature does not speak to personal participation in situations that only affect the specific individual, but rather addresses policy level participation. Mancur Olson (1971), argues that rather than participating, the average member will be a free rider since it is not rational for recipients of public goods (products and services that, once provided, cannot be withheld from consumers who do not wish to pay for them) to make the effort if they do not have to. An example might be the majority of those suffering from breast cancer benefiting from the activism and efforts of a vocal few to gain funding for research, start support groups, and provide readily available literature. On the other hand, Olson’s point that the motivation to participate will be greatly influenced by the kinds of services the organization provides might be a reason to expect that those with access to support groups will tend to be much more participatory at all levels.

Given the medical literature on patient participation, it is reasonable to suspect that support group membership may lead to a greater desire for participation. If the support group not only provides information, but also gives members new skills for questioning their physician, membership may mirror the effects of the coaching interventions that resulted in higher levels of participation.

PART II:

The extent to which a recipient of care participates in making medical decisions is a key factor in the patient-physician relationship. Various models of the patient-physician
relationship have different emphases on the importance of patient participation, from models where the recipient of care is not expected or encouraged to participate, to models where active participation is considered necessary. In considering the roles that recipients of care may wish to take in making medical decisions, it is important to note that the choice of role will strongly influence the recipient’s preference of a model of the patient-physician relationship. We will accordingly examine the nature of and the tensions within various models of the patient-physician relationship. The following models will be discussed: the beneficience model; the autonomy model; and partnership models. Since the level of patient participation is such an important characteristic of models of the patient-physician relationship, it is illuminating to move beyond the medical literature into the political science literature on participation, where the nature and determinants of participation have been more deeply and fully examined. We will briefly discuss political science models of participation and their links to the models of the patient-physician relationship.

MODELS OF THE PATIENT-PHYSICIAN RELATIONSHIP

The shift away from the traditional paternalistic model where the physician is the decision maker has been well documented (Balint & Shelton, 1996; Pellegrino, 1994; Brock, 1991). The ethical community has reinforced the growing public challenges to medical authority through emphasizing the patient’s right to self-determination and autonomy.

The beneficience model

According to Beauchamp and McCullough (1984) the beneficience model has as its moral
end the promotion of the patient’s best interest, as understood from the perspective of medicine. For centuries, this model was the overarching rubric under which medical care was delivered. The principle of beneficience expresses the aims of medicine as an avoidance of harm, and an obligation to promote health through the elimination or control of disease and injury. This model is derived from ancient Greek medical ethics, where the moral responsibilities of the physician are identical to those of medicine as a whole, as evoked by the Hippocratic Oath: “I will apply dietetic measures to the benefit of the sick according to my ability and judgement; I will keep them from harm and injustice.”

In its Western application, the beneficence model adapted the principle of beneficence to patient care through providing a medically grounded account of how to balance benefits over harms. Although this model has been conceptually equated with paternalism, some, most notably Thomasma (1988) and Pellegrino (1994) have argued that this model is not exclusively paternalistic, since it allows for the patient’s perceptions and values to be taken into account insofar as these are part of the patient’s good or best interests. However, the beneficence model clearly relies on the physician’s perception of the patient’s preferences and values, and does not acknowledge the patient’s expertise in deciding what these are. Minimal emphasis is placed on encouraging active participation from patients.

The autonomy model

According to Beauchamp and McCullough (1984):

“the autonomy model takes the values and beliefs of the patient to be the primary moral
consideration in determining the physician's moral responsibilities in patient care: If the patient's values directly conflict with medicine's values, the fundamental responsibility of physicians is to respect and to facilitate a patient's self-determination in making decisions about his or her medical fate. The obligations and virtues of the physician thus flow from the principle of respect for autonomy.”(p.26)

Since the 1960s patient autonomy has become the dominant principle shaping medical ethics. The distinctive feature of this principle is its emphasis on the individual patient's perceptions and values and its insistence that the role of the physician is to assist in the implementation of the patient's wishes insofar as their expertise permits. Characterized as the theoretical framework for a growing consumerist orientation, the autonomy model expects patients to assert a desire for medical information and their right to make their own medical decisions.

The autonomy model has been attacked on a number of grounds: first, that the relationship between the recipient of care and the provider is inherently unequal. The provider is healthy, has the technological and knowledge-based expertise, and has more information. The recipient of care is unwell, generally has less expertise, and is at least to some degree dependent on the provider for information. Second, models which have patient autonomy as the overriding factor, such as the “informative” model by Emanuel and Emanuel (1992) or Veatch's (1980) “engineer” model, reduce the physician to the role of a technician; it has been argued that this results in an abdication of provider responsibility and a minimalism in care and caring (Pellegrino & Thomasma, 1988). Third, for patients to become truly autonomous in the sense that they can make genuine decisions they are dependent on the
provider to enable and empower them—in a significant way they are dependent on the
beneficence of the physician. In previous work on the voluntary nature of action (Sharpe,
1995) the researcher examined in depth the requirements for a decision to be autonomous,
which include the availability of sufficient information to make a genuine choice a reality. If
the provider cannot be trusted to be telling the truth to the patient—is not sufficiently
beneficent to have the ethic of truth-telling-- then the provider cannot be used as a credible
source of information by the recipient of care.

Partnership models

There are several models of the patient-physician relationship which address the difficulties
presented by the autonomy model, while still respecting the principle of autonomy as the
prima facie moral principle of medical ethics. In the late 1950s Szasz and Hollander
foreshadowed these models with their recognition that a possible level of interaction between
the patient and physician was one of partnership, where the physician helps the patient to
make his or her own decisions (1956). The accommodation model of Siegler describes the
development of a dynamic mutual understanding of the goals of care between patient and
physician, permitting the provider to respect patient autonomy while retaining features of
physician paternalism (1981). Veatch (1980) proposed the collegial model where the
physician and patient are colleagues who share the common goal of eliminating illness and
preserving health. Veatch’s contractual model describes a covenant based on trust between
the provider and recipient, where there is a sense of obligation and benefit on both sides.
Emanuel and Emanuel (1992) parallel these models with the deliberative model, which is
close to the collegial model, and the interpretive model, where the physician seeks to discover and reify the patient's values. Several feminist theories also seek to move away from the "theoretical-juridical" models and towards a cooperative approach between provider and recipient of health care (Wolf, 1996; Faden, 1991).

Pellegrino (1990) has suggested a partnership model where the provider is responsible for enhancing and protecting the patient's capacity for self-determination. Pellegrino argues that the most ethical relationship between provider and recipient is one where decisions are made between the two parties, with the provider making the decision in the interests of the patient, and with the patient. Pellegrino additionally discusses the integrity of the decision that patients can make to give up their autonomy to the physician when they do not wish to participate in their medical treatment decisions, and argues that in these cases the physician has a moral mandate to decide for the patients.

**POLITICAL SCIENCE MODELS OF PARTICIPATION**

This section discusses political science models of participation, and shows where this body of research parallels the bioethics literature. Since this thesis will be in part examining the recipient of care's desire for information, this section will also discuss the relevant political science literature related to the effect of information on the desire for participation.

Pateman (1970) distinguishes "full participation" (where citizens have equal power to decide the outcome of decisions) from "partial participation" (where citizens can only influence
decisions) and “pseudo participation” (where those who have power try to create the illusion that outsiders are participating in the making of decisions). Arnstein (1969) suggested a ladder of increasing citizen participation to describe different levels of citizen participation in American government programs. Building on Arnstein's work, Feingold (1977) developed a five rung ladder: informing, consultation, partnership, delegated power, and citizen control.

‘Informing’ mirrors the beneficence or Veatch’s “priestly” model, where the patient as participant is the recipient of a one-way flow of information from the provider, with no channel provided for feedback. ‘Consultation’ also reflects the beneficence model, insofar as it allows for the participant to express his or her views, without a guarantee that these will be taken into account. A combination of these two rungs is likely appropriate for “problem solving” tasks where the patients’ preferences are irrelevant (e.g. the diagnosis and possible medical treatments will be unchanged by the patient’s desire for alternatives).

‘Partnership’ mirrors the accommodation model of Siegler (1981), or Veatch’s (1980) collegial model. ‘Delegated power’ and ‘citizen control’ have similar characteristics to the “informative” model by Emanuel and Emanuel (1992) or Veatch’s “engineer” model, where the patient is in control of decision-making. These two later rungs, which involve the redistribution of power to the patient, with the highest rung affording the patient dominant decision-making authority, are well within the framework of autonomy models.

It is important to move beyond the medical and allied health literature into the social science
literature to further examine the questions of who is more likely to participate and what ‘participation’ means. There is an interesting body of literature in political science related to characteristics of political participants. According to Barnes & Kaase (1979) those who take either unconventional political action or conventional political action tend to share certain demographic characteristics that are strikingly similar to those found in the medical literature on patient participation: male, Caucasian, higher incomes, higher prestige occupations, and educated. Education is thought to provide “the cognitive skills necessary to find one’s way around the confused miasma that surrounds politics...the experience of higher forms of education will tend to break down people’s natural tendencies to oversimplify their view of the world (112)”.

Since patients can rarely be completely informed, insofar as in most cases they are unable to fully appreciate the breadth and range of experience and knowledge the doctor is using to select particular treatment options or diagnoses, they must then use some method of compensating for their limited information in order to make decisions. According to Sniderman (1991, p.19) citizens can frequently compensate for their limited information about politics by taking advantage of judgemental heuristics. Heuristics are judgmental shortcuts, efficient ways to organize and simplify political choices, efficient in the double sense of requiring relatively little information to execute, yet yielding dependable answers even to complex problems of choice. This may be an answer to the problem of how someone can figure out which course of treatment to take—in other words be knowledgeable about their reasoning about medical choices without necessarily possessing a large body of
knowledge about medicine.

According to Popkin (1991) one of the information shortcuts that is commonly used is the media and elite interpretations -- which saves the effort of constantly searching for relevant facts. If one may presume that the physician is seen as an elite, then it is sensible to assume that the experience of clinicians facing patients who seem to want them to make their treatment choices for them may be related to this type of information-seeking. Extension of this line of reasoning implies that patients will hand over PS authority to physicians only if they trust health care providers as a reliable elite with the best interests of the patient at heart.

Differences between people in their levels of political awareness and information seem to systematically affect their reasoning about political choices--the thesis is that people take advantage of heuristics to compensate for a lack of information; on the other hand, the particular heuristics they take advantage of depend on the amount of information they have.

Lupia (1992) demonstrates that information asymmetries (the fact that some electoral participants have more accurate information than others) have an effect on electoral outcomes. Lupia’s point is that voters are rarely completely informed, and that less informed voters cast a different vote than if they had possessed better information. This seems to have a high correspondence with what was seen in the medical literature relating to doctor facilitation of patient participation: more information leads to different behaviour and different choices.
The political science literature also suggests that even patients who have been very informed about their medical options and seem very sophisticated in their analysis may not make 'rational' decisions about their health care. According to Luskin (1987) political sophistication carries with it the connotation that a person knows how to make up his or her mind, as opposed to a person who is naive or ignorant. A person is politically sophisticated to the extent that their political belief system is large, wide-ranging, and the beliefs are internally consistent. Luskin states that political sophistication is just the political case of a more general variable--size and range are translated as expertise, and constraint translates as integration. In the case of health care decisions, it should be noted that sophistication is not the same as rationality (864). According to Luskin, someone who generally makes decisions using a rational procedure can be expected to apply that procedure to other kinds of analysis. Procedural rationality is thus a constant within decision-making, with sophistication a variable. More sophisticated people with greater knowledge should thus do better at maximizing their "objective" interests, and could be expected to make a rational choice in medical decisions.

The political science literature could also be used to inform the medical literature on how patients make their medical decisions. According to Popkin (1991) making complex calculations in order to "maximize expected value" is difficult for all of us--people are most

1 Political sophistication is defined as the size of the persons political belief system (a person's political cognitions, together with those with which they are constrained. A constraint is simply an association: a belief or an attitude) and its range--specialist or wide sampling-- and the extent to which the cognitions are interconnected.
confident in their calculations and choices when they are able to use calculation shortcuts.

One problem in making choices is resolving contradictions and inconsistencies. When all the evidence points in one direction, our confidence in our predictions increases. People become much less confident in areas where they must assess probabilities or implicitly compare the likelihood of various outcomes. When they can think of "always" or "never", the probabilities of one or zero, they overrate the accuracy of their predictions. The higher expected return of a mixed bet with both gains and losses is more difficult for people to find enticing than a lottery with only gains, and since most medical decisions are rife with probabilities, uncertainties, and the outcome including both gains and losses, it is unsurprising that we search for ways to compress the decision into one dimension.

Popkin found that people have an aversion to making trade-offs between several factors: when they are being pushed into weighing the benefits or risks of different choices they tend to make their choices one-dimensional. Some types of data and probabilities make it easier for people to calculate and choose--people value consistent information over inconsistent information, preferring to use data that is all negative rather than mixed. They are more confident in making predictions from the more reliable to the less, even though actual accuracy is the same in either direction of measure. Psuedocertainty effects result in easy and clear calculations, and the fact that we are consistently bad at using data from diverse and incomparable sources makes it all the more reasonable that patients might tend to simplify complicated choices involving many dimensions to a single dimension.
SUMMARY

This literature review shows that patient participation is an underdeveloped area of research with little empirical validation of the preferences and processes involved. The bioethical and medical literatures assume that all patients wish to be participative, or at least want to receive information on their condition or disease. However, research and anecdotal reports from front-line clinicians and nurses suggest that there may not be a universal desire for participation. For example, younger patients are consistently found to have greater desire for participation than older ones, and there are indications that level of education and sex may also be predictive of desire for participation (Blanchard et al, 1988; Strull et al, 1984; Kaplan et al, 1995). Differences have also been found between those patients with a diagnosis of cancer, and those without—with cancer patients displaying less desire for a participative role (Degner, 1992; Cassileth et al, 1980).

This literature review did not find a previous empirical study of the relationship between trust in the physician and the desire for participation, between trust in the physician and use of alternative medicine, or between trust and preference of label. This thesis was designed to address this gap. If the trust level of recipients of care is related to their desire for participation, then clinicians may find that a model of the doctor-patient relationship for their patients which incorporates trust as a crucial factor is most appropriate. If trust levels are related to use of alternative medicine, clinicians may be able to identify which of their patients are likely to be attracted to alternative therapies, and design a course of treatment which incorporates that information. Additionally, if the label preferred by the recipient of care
telegraphs their trust level, then clinicians may be able to more easily identify what role the recipient of care wants to play.
CHAPTER III

METHODOLOGY

This chapter discusses the rationale for the research design; research design; setting/sample; data limitations; outcome measures; data analysis; logistic and linear regression analyses; sample size; and research ethics.

RATIONALE

A quantitative cross-sectional survey was chosen as the most appropriate means to meet the goals of this research for the following reasons: first, this study was in part testing the generalizability of previous PSDM research done primarily with male respondents awaiting angiograms. This study thus used sites that included both males and females, of a range of ages and severity of disease conditions. Second, the hypotheses tested by this study were grounded in previous research, both qualitative and quantitative. Although further qualitative research would have been useful for developing an overarching grounded theory linking the studied hypotheses, the strengths of the associations between the variables of interest would have been impossible to determine. Some of the strengths of quantitative research include its ability to test established theory, and show the relationships and strengths of association between variables. This quantitative study was designed not only to explore these relationships, but to generate questions for further research, both qualitative and quantitative. Third, it was a goal of this research to determine statistical significance of the associations, with a view to further operationalizing what 'participation' means in a reliable and
replicatable manner. Limitations of the methods used will be further discussed in the limitations section.

RESEARCH DESIGN

The research design was a cross-sectional survey. Sites were accrued by contacting the clinic staff physicians by telephone and asking for permission to approach their patients. Subsequent follow-up by letter confirmed participation. (In the case of the fracture clinic, one of the staff physicians agreed to have his patients approached after recruitment on site had begun of another staff physician’s patients.) In each case copies of the questionnaire and an explanation of the research were sent to the clinic staff before recruitment took place.

Since the clinic waiting rooms were also used by patients of uninvolved clinics, cases were located through a daily patient caseload sheet provided by the clinic staff at each site.

Patients were approached by the researcher using the following script:

"My name is Natasha Sharpe. I'm a researcher for a study asking patients their opinions about their participation in medical decision-making. The study is about preferences patients have for involvement in medical decision-making and what information they would like. We will also be asking about your views of your doctor and of organized medicine (including views of alternative therapies)."

We have the permission of this clinic to do this study but we are not connected with this
Your participation is purely voluntary. If you are willing to participate, be assured that none of your caregivers will see your responses. Your decision about whether or not to participate will not have any effect on your care. All responses will be anonymous, and there will be no way of identifying you.

Participation will involve filling out this questionnaire. It should take at most twenty minutes. You can fill it out in the waiting room, or, if it is more convenient, take it home with you. Would you be willing to take part in this study?

If "No"

"Thank you very much."

Record - refusal (also, sex and clinic)

If "Yes"

"Thank you. Here is a copy of the questionnaire. Please give it to me when you've finished completing it. We appreciate your help."

If "I want more information"

"The first page of the questionnaire gives some more information about the study. Would you like to take a look at it and see if you would be interested in participating?"

[RESEARCHER STEPS AWAY TO ALLOW PATIENT TO READ INFORMATION SHEET. ]

If patients participate:

"If you would like to receive a summary of our findings, please fill in an address where we
can reach you. This information will be kept separate from your responses, and cannot be linked to it.”

“Thanks again for your help.”

Respondents who were unable to hold or fill out the questionnaire themselves (eg. in the case of fractured wrists) had the researcher read the questionnaire exactly as it is written to them and write down the indicated responses. No respondents chose to take the questionnaire home with them, although postage paid envelopes addressed to the principal investigator were available. In the few cases where there was not enough time to complete the questionnaire on site, the respondents returned the survey partially incomplete.

**SETTING/SAMPLE**

The study population was comprised of patients at outpatient clinics of a Toronto teaching hospital. The hospital was primarily selected for its size, proximity, and ease of access; it also treats a large number of patients from the Toronto and surrounding area. There were three groups of respondents: patients at a fracture clinic, patients at a prostate cancer clinic, and patients at a breast cancer clinic. The fracture clinic population not only included patients with fractures, but also patients with spina bifida and low back pain. Two hundred and two respondents were accrued from each site. The exclusion criteria that were used were: patients had to be over 18, speak English, agree to participate, and be attending a clinic that had agreed to participate.
The breast cancer clinic was selected for the following reasons. First, breast cancer is a highly politicized disease which as a major cause of cancer deaths (O'Connor & Perrault, 1995) is viscerally relevant to women in our society. As a result the availability of support groups is greater, with a higher potential for measuring the impact of this source of information among patients at this site. Second, women with breast cancer have created one of the most vocal consumer groups in North America (Degner et al, 1997). Third, this clinic serves both newly diagnosed patients and patients living with the disease for over six months, allowing us to measure the disparate impact of a long-term illness. Finally, cancer patients have been identified as a population more likely to use alternative therapies as well as mainstream medicine and will accordingly be a useful population within which to study patterns of use and satisfaction.

The prostate cancer clinic was selected for the following reasons. First, prostate cancer is also a politicized disease with available support groups. Second, this clinic serves both newly diagnosed patients and patients living with their condition for more than six months, allowing us to measure the impact of a long-term illness among this group as well. Third, as cancer patients these respondents were expected to be more likely to use alternative therapies as well as traditional medicine than patients without a diagnosis of cancer. Finally, since prostate conditions involve only males, the clinic was expected to accrue a group that would be appropriate for comparison with female breast cancer respondents to measure the impact of sex on responses.
The fracture clinic was selected for the following reasons. First, the fracture respondents were expected to be facing an acute rather than a chronic medical condition. Second, none of the conditions at this clinic were expected to include diagnoses of cancer. Third, there were expected to be a minimum of conditions presenting at this site for which support groups are available, with a corresponding lack of 'politicization'. Fourth, these respondents were expected to be of a wide range of ages, including very young adults. Fifth, there were no expected differences in the prevalence of one sex over another in this clinic.

**DATA LIMITATIONS**

Using data from a single cross-sectional survey also limited our ability to impute longitudinal inferences. Although a cross-sectional study was an appropriate tool to examine the hypotheses of this research, we recognize that it is likely that individuals captured by our survey were at different stages of an “illness trajectory” and hence may have been both at a different psychological stage (newly diagnosed disease, vs. well-managed disease, for example) as well as possibly being confronted with different decisions. It is thus possible that the responses of any given patient to the questionnaire items will change over time; without a time series element to the research design, we cannot make inferences about what the nature of those changes may be.

Additionally, several variables were potentially confounding; for instance, sex and clinic are confounded for two of the three sites: all respondents in the breast cancer clinic were female, and all respondents in the prostate centre were male. Thus, it was only in the fracture clinic,
where recipients of care could be either male or female, that the effects of sex could be
directly examined. Other issues (such as the relationship between education level and socio-
economic status) have been previously discussed in the literature review. A table of
correlations between selected variables follows:

**TABLE OF CORRELATIONS BETWEEN SELECTED VARIABLES**

<table>
<thead>
<tr>
<th></th>
<th>Sex</th>
<th>Breast</th>
<th>Prostate</th>
<th>Education</th>
<th>Experience</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>1.0</td>
<td>0.694</td>
<td>-0.727</td>
<td>-0.07</td>
<td>-0.160</td>
<td>0.222</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.0001</td>
<td>0.0001</td>
<td>0.0534</td>
<td>0.0001</td>
<td>0.0001</td>
</tr>
<tr>
<td>Breast</td>
<td>-0.50</td>
<td>1.0</td>
<td>-0.04</td>
<td>0.2978</td>
<td>0.099</td>
<td>0.012</td>
</tr>
<tr>
<td></td>
<td>0.0001</td>
<td></td>
<td>0.0001</td>
<td>0.0123</td>
<td>0.762</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>0.078</td>
<td>0.0530</td>
<td>1.0</td>
<td>0.336</td>
<td>-0.463</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.0001</td>
<td></td>
<td></td>
<td>0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>-0.005</td>
<td>1.0</td>
<td>-0.057</td>
<td>0.8884</td>
<td>0.219</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.8884</td>
<td></td>
<td></td>
<td>0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>0.219</td>
<td>0.8884</td>
<td>-0.314</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>0.0001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Outcome Measures*

The questionnaire consisted of six sections. The first section consisted of questions related to
the health condition for which the respondent was seeking care at that clinic, and also asked
about their perceived knowledge of that condition. The second section consisted of the
Problem Solving Decision Making scale (PSDM) applied to their current health condition and
to a subsequent standardized mortality vignette. The third section inquired about preferences
for label as a recipient of care (patient, consumer, etc.) The fourth section inquired about attitudes toward medical care and trust, using the Anderson and Dedrick Trust in Physician Scale (1990) together with some of our own questions. The fifth section was concerned with preferences for information and behavioural involvement and employed the Krantz (1980) Health Opinion Survey (HOS). The final section consisted of basic demographic and background information questions including age, employment status, marital status, education level, overall health, use of and satisfaction with alternative and traditional providers, use of and satisfaction with a support group, and status as a health professional.

Hypothesis I: i) most patients will want to hand over problem solving; and

ii) some patients will want involvement in decision making.

This hypothesis was tested using the PSDM scale.

The Problem Solving-Decision Making scale was developed by Deber and Kraetschmer (1993) to measure preferences for role in problem solving and decision making situations in medical treatment. The term “problem solving” (PS) refers to tasks with a “correct” answer, for which preferences were irrelevant. For example, diagnosis is not influenced by whether one would prefer a lump to be benign or malignant. In contrast, “decision making” (DM) tasks involve both prior information and a judgement about preferences for alternative outcomes, for example requiring the conceptualization by the patient of what a particular outcome might mean for her and her family (Deber & Baumann 1992, Baumann & Deber 1989). The scale uses six statements of which four are problem-solving, concerned with
patient attitudes toward active participation in the problem-solving component of medical care:

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

b) Who should determine what the treatment options are?

c) Who should determine what the risks and benefits for each treatment option are?

d) Who should determine how likely each of these risks and benefits are to happen?

The remaining two statements are decision-making tasks measuring patient attitude toward active involvement in the decision making component of medical care:

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

f) Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?

These questions were applied to the respondent’s current health condition and to the standardized mortality vignette used by Deber and Kraetschmer reading “Suppose you had mild chest pains for three days and decided that you should visit your doctor about this.”

The response categories are the same as those employed by Ende (1989) and read: “1=the doctor alone”; “2=mostly the doctor”; 3=doctor and you equally”; “4=mostly you”; and “5=you alone”. Cronbach’s alpha coefficient measuring reliability for the PSDM applied to the mortality vignette was 0.743, which is similar to those of established scales (Ende, Krantz).
Respondents were also asked a general question asking them about their attitude towards medical care: Please circle the letter which best describes your own attitude towards medical care.

a. The patient should take complete control.
b. The patient should have more control than the doctor.
c. The patient and doctor should share the control equally.
d. The doctor should have more control than the patient.
e. The doctor should take complete control.
f. Other, (please specify): ________________________________

These were coded as numeric data (a=1, b=2, c=3, d=4, e=5, f=6).

The purpose of asking the general question about attitude was in order to suggest that the validated PSDM scale can show more nuance in patient desire for participation than a question which does not distinguish between PS and DM.

For purposes of statistical analysis, the variable of ‘Patient Category’ was created in order to assess respondents’ answers to the PSDM. (For logistic regression, ‘Patient Category’ was used as the dependent variable; for multiple regression, the full PSDM score was used). This method had been used in previous work with the PSDM (Kraetschmer, 1995). If the respondent wished to keep control of both decision making and problem solving (DM scores of 3, 4 or 5; PS scores of 4 or 5) in the standardized vignette, they were categorized as ‘Autonomous’. If the respondent wished to hand over or share problem solving and keep or
share control of decision making (PS scores of 3, 4 or 5; DM scores of 1, 2 or 3) they were categorized as ‘Shared’. If they wished to hand over control of both PS and DM (scores of 4 or 5), they were categorized as ‘Passive.’

<table>
<thead>
<tr>
<th>Patient Category</th>
<th>Keep control PS</th>
<th>Share control PS</th>
<th>Hand over control PS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep control DM</td>
<td>Autonomous</td>
<td></td>
<td>Shared</td>
</tr>
<tr>
<td>Share control DM</td>
<td>Autonomous</td>
<td></td>
<td>Shared</td>
</tr>
<tr>
<td>Hand over control DM</td>
<td>Theoretically</td>
<td>Implausible</td>
<td>Passive</td>
</tr>
</tbody>
</table>

Responses to the standardized PSDM mortality vignette rather than to the current health condition were used for the following reasons: first, respondents were visiting the clinics for a wide range of conditions; accordingly, a great deal of variation would be expected for ‘current health condition’ responses. (However, as will be shown, if current health condition data is used instead of the standardized vignette, the same results are found.) Second, the standardized mortality vignette had been used with success in previous work (Kraetschmer, 1995).

In order to ascertain whether respondents were familiar with the symptoms described in the mortality vignette, respondents were also asked how much experience they had had with the clinical situation (chest pain) described in the PSDM mortality vignette by asking them to circle all letters that applied:

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.

This question was asked in order to better compare PSDM answers to the mortality vignette to PSDM answers to the current health condition (see Hypothesis 3).

**Hypothesis II: Most patients will want to be informed.**

This hypothesis was tested using the Health Opinion Survey.

The Health Opinion Survey was also selected so that the relationship between trust and information preference could be examined. The HOS was developed by Krantz (1980) to measure patient attitudes toward preference for information and desire for behavioural involvement. The two factors are divided into subscales: the first is composed of seven items measuring a patient’s desire to be informed, the second is composed of nine items measuring attitude toward self-treatment and active behavioural involvement in medical care. The combined scores of the two subscales provides an overall measure of attitude towards medical treatment. A high score indicates a positive attitude toward active participation in medical care, whereas a low score indicates a passive approach to treatment.

The HOS was selected because of its wide use and reliability. The total HOS has a reported Kuder-Richardson reliability of .77, with the Behavioral Involvement and Information subscales reporting scores of .74 and .76 respectively.

The HOS Information subscale was further divided into three categories: of a possible score
of 100, scores from 0-32 were classified as ‘low information-seeking’; scores from 33-66 were classified as ‘moderate information-seeking’; and scores from 67-100 were classified as ‘high information-seeking’. These divisions have been used by Krantz and also by Kraetschmer (1995).

**Hypothesis III:** Respondent and disease characteristics will be correlated to the person’s desire for PS and DM participation:

i) people experienced with their chronic illness will be more participative; but

ii) people with life-threatening illnesses (in this study, those with diagnoses of cancer) will be less participative; and

iii) less educated and older people will be less participative.

Desire for participation was measured using the PSDM scale. The experience a respondent had had with their chronic illness was measured by asking respondents how long they had had their current health condition, giving them the option of months and years. A binary variable (EXPERIENCE) was created—if the individual had had their illness for more than six months this was coded as 1.

Respondents who had been living with their illness for more than six months were also expected to be past the initial stages of an “illness trajectory.” For instance, people who are newly diagnosed with a chronic ailment are expected to be at a different psychological stage than those who have had more time post-diagnosis. Creating an ‘experience’ variable allowed us to control for those who had been newly diagnosed. The difficulties of imputing
longitudinal inferences from cross-sectional data will be further discussed in the limitations section.

Respondents who had been living with their chronic illness for more than six months were expected to have had more time to learn about their illness, and therefore were expected to know more about their current health condition than those without a chronic health condition. We tested this assumption by asking respondents about their knowledge of their current health condition. We asked respondents about their knowledge of four aspects of their current health condition on a 5-point Likert scale from 1=not at all knowledgeable to 5=very knowledgeable. We asked respondents to “Please circle the number which best indicates how knowledgeable you feel about:
Your current health condition; the available treatment options; the risks and benefits of these options; and which treatment you prefer.” These questions do not comprise a validated scale, but have been used exactly as they appear in our questionnaire (shown in the Appendix) in previous research (Deber, 1995).

Diagnoses of cancer were combined into a binary variable LIFETHR. If the individual’s current health condition involved a diagnosis of cancer then this was coded as 1.

Education was measured using eight options, where respondents were asked to circle the letter corresponding to the highest level of education they had achieved.

a) some elementary school
b) completed elementary school (Grade 8)

c) some high school

d) completed high school

e) some post high school (college/university/trade school)

f) completed college/university

g) some graduate/professional school

h) completed graduate/professional school

Age was measured by asking respondents to indicate the year of their birth.

Hypothesis IV: Trust will be correlated with the desire for participation, such that:

i) people with high levels of trust will hand over control of PS and DM to the provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.

This hypothesis was measured using the Trust in Physician Scale and the PSDM.

The Trust in Physician scale is unique in that it is the only scale that we or others have found in the literature (Thom & Campbell, 1997) that measures a patient’s interpersonal trust in his or her physician. Developed by Anderson and Dedrick (1990), the eleven item scale was constructed and tested using a group of male patients with multiple chronic illnesses. The authors state that their scale had construct validity, which they estimated by comparing the scores obtained on the Trust in Physician scale with those obtained on a number of
theoretically related constructs, including the Health Locus of Control scale. Cronbach alpha was reported as .85 in the authors’ replication study. The scale uses a five-point Likert format with response options ranging from “strongly agree” to “strongly disagree” to assess whether the patient has confidence in the dependability, knowledge, and reliability of information of the physician. A high score (after appropriate item reversal) indicates a high level of trust and was related to low desire for control, conversely a low score indicates low trust and was related to less satisfaction with care.

After appropriate item reversal, the scale is divided by Anderson & Dedrick into three categories (low, medium, high) where scores averaging to less than 3 (where 3= neither agree nor disagree) are categorized as ‘low’ trust; scores averaging from 3 to 3.99 are categorized as ‘moderate’ trust; scores averaging between 4 and 5 are categorized as ‘high’. Rather than using these three categories alone, we subdivided ‘high’ trust into two categories, where scores averaging between 4 and 4.99 were categorized as ‘high’, and responses of 5 to every question were categorized as ‘blind’ trust. This subdivision was done after preliminary analysis of the data showed that mean trust levels were high, and a substantial number of respondents seemed to be responding 5 to every question. It was felt that the nuance of these extreme responses were being lost by leaving them in the larger Anderson & Dedrick category of ‘high’ trust.

**Hypothesis V:** Trust will be correlated with preference of label: respondents who mistrust their providers will be less satisfied with the label ‘patient’ and will prefer
labels with a more consumerist orientation.

Trust was measured using the Trust in Physician Scale. Preference of label was measured using our own questions. Respondents were asked to indicate on a 5-point Likert scale (1=strongly dislike, 2=moderately dislike, 3=neither like/dislike, 4=moderately like, 5=strongly like) how much they liked the following labels: patient, client, customer, consumer, survivor, partner. These labels were drawn from the nursing, medical, and mental health literatures.

Hypothesis VI: Respondents with a low level of trust in their physician will report a higher use of alternative therapies.

Respondents were asked in the demographic information section whether they had used an alternative provider in the previous year. They were asked to specify the type of provider, and given room to indicate two. These variables were manually checked, and recoded as two binary variables (ALT1, ALT2). It should be noted that use of alternative medicine by these respondents was not an "either-or" situation, since these respondents were also recipients of care at a traditional clinic.

Hypothesis VII: Respondents with breast or prostate cancer, especially those who are involved in support groups, will be less likely to hand over control, less likely to have high levels of trust, and more likely to prefer a label with a more consumerist orientation.

Labels were measured as discussed, and trust and desire to hand over control were measured
using the PSDM and the Trust in Physician scales. Support group use was coded as a binary variable (SUPPORT=1), with the respondent given room to specify one such group.

**DATA ANALYSIS**

The questionnaire was coded and each item was checked for errors before data was entered into the statistics program. Questions in which the respondent indicated two answers were averaged if numeric, or if a number range was indicated (e.g. a circle between 4 and 5). No respondents indicated two answers for a categorical variable. Raw data was entered into the SAS-PC statistical program as it was accrued on a weekly basis.

Questionnaires were identified by a unique identification number, against which the SAS raw data was manually checked to detect data entry errors. Errors were also detected using frequency tables for each item. One response per questionnaire per variable was ensured, and any incorrect codes were eliminated. Subsequent data analysis was performed using SAS-INSIGHT as well as the SAS-PC statistics package.

**Hypothesis I:** i) most patients will want to hand over problem solving; and

   ii) some patients will want involvement in decision making.

For this hypothesis, PSDM data was analysed using frequency tables. Factor analysis was performed on the PSDM for the standardized mortality vignette and the current health condition items in order to confirm the existence of two factors. The purpose of factor analysis is to explain the correlations or covariances among a set of variables in terms of a
limited number of latent, unobservable variables. “In common factor analysis it is assumed that the variables would be linearly related if not for random error or unique variation in each variable.” (SAS, 1990, p.40)

**Hypothesis II: Most patients will want to be informed.**

Factor analysis was also performed on the HOS scale in order to confirm the existence of the two subscales. The information-seeking subscale was then analysed using frequency tables.

**Hypothesis III: Respondent and disease characteristics will be correlated to the person’s desire for PS and DM participation:**

i) people experienced with their chronic illness will be more participative; but

ii) people with life-threatening illnesses (in this study, those with diagnoses of cancer) will be less participative; and

iii) less educated and older people will be less participative.

Chi-square tests of homogeneity or independence of each level were used to compute measures of association based on chi-square. The Pearson chi-square was used for these variables for detecting a linear association in 2x2 tables. Linear regression was also employed to predict desires for participation as a function of experience with chronic illness, diagnosis of cancer, age and education level of the respondents.

**Hypothesis IV: Trust will be correlated with the desire for participation, such that:**

i) people with high levels of trust will hand over control of PS and DM to the
provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.

This hypothesis was measured using the Trust in Physician Scale and the PSDM. The Pearson chi-square was used for these variables for detecting a linear association in 2x2 tables. Linear and logistic regression was also employed to predict desire for participation as a function of trust.

Hypothesis V: Trust will be correlated with preference of label: respondents who mistrust their providers will be less satisfied with the label ‘patient’ and will prefer labels with a more consumerist orientation.

Trust and preference of label were analysed using chi-square tests on 2x2 tables as well as with logistic regression.

Hypothesis VI: Respondents with a low level of trust in their physician will report a higher use of alternative therapies.

Trust and use of an alternative therapy were analysed using chi-square tests on 2x2 tables.

Hypothesis VII: Respondents with breast or prostate cancer, especially those who are involved in support groups, will be less likely to hand over control, less likely to have high levels of trust, and more likely to prefer a label with a more consumerist orientation.
This hypothesis was tested using chi-square tests on 2x2 tables as well as with linear and logistic regression.

Linear and logistic regression were also employed to predict desires for information and involvement as a function of other disease and patient-related factors; other univariate and multivariate analyses were performed which will be further discussed in the results chapters.

**LOGISTIC AND LINEAR REGRESSION ANALYSIS**

Logistic regressions were done to model the extent to which patient category can be explained by sets of independent variables. Logistic regression was performed because patient category is a categorical variable, rather than a continuous variable. Multiple regression analysis was then performed on the same sets of independent variables by replacing the categorical variable of patient category with the continuous variable of PSDM score. The models that will appear in the results chapter will show the following terms (SAS, 1990):

*Degrees of Freedom (DF)*: refers to the number of items whose values are free to vary.

*Sum of Squares*: The sum of squares column illustrates the basic identity in regression analysis which says that variation among the observed values of patient category (the dependent variable) can be attributed to two sources: 1) variation due to changes in the independent variable, and 2) random variation that is not due to changes in the independent variable. The MODEL term refers to the regression sum of squares; ERROR refers to the residual sum of squares, and C TOTAL refers to the sum of these two—the corrected total.
sum of squares.

*Mean Square:* The Mean Square column contains mean squares—which are computed by dividing the sums of squares by their respective degrees of freedom. The mean square for error is an estimate of the variance of the error term.

*F Statistic:* The value of the F statistic is the ratio of the model mean square divided by the error mean square. This is used to test the composite hypothesis that all coefficients except for the intercept are zero.

*R-square:* The R-square value tells us what portion of the variation of patient category is explained by variation in the independent variables in the model. The adjusted R-square is an alternative to R-square that is adjusted for the number of parameters in the model. When the ratio of regression parameters in the model (excluding the intercept) to the number of observations in the data set is small, the adjustment almost vanishes.

*Standardized Estimate:* standardized regression coefficients labeled Standardized Estimate are the estimates that would be obtained if all the variables in the model were standardized to zero mean and unit variance prior to performing the regression computation. Each coefficient indicates the number of standard deviation changes in the dependent variable associated with a standard deviation change in the independent variable, holding constant all other variables. The magnitudes of the standardized coefficients are thus useful in determining the relative importance of the effects of independent variables.

**SAMPLE SIZE**

We aimed to recruit 200 responses per site in order to ensure adequacy of sample size for statistical comparisons. The rule of thumb for cross-tabulations of categorical data is that the
expected value in each cell must exceed 5; for regressions, there should be at least 20 observations per independent variable (SAS, 1990). With a view toward the performance of sub-analyses (e.g., by sex, age, chronicity), 200 responses per clinic were judged to be more than adequate for our needs.

**ETHICAL REVIEW**

Since this research examined respondents views about their desired role in their medical treatment, the risks associated with this study were thought to be minimal. The questionnaire and research protocol was submitted to and approved by the Human Subject Review Committee of the University of Toronto. The Ethical Review Committee of the Toronto Hospital also reviewed and approved the questionnaire. The script in the discussion of sampling procedures informed each patient that participation was purely voluntary and that it did not have any impact on patient care. Completion of the questionnaire was taken to indicate consent.

Respondents were guaranteed confidentiality and were not asked for their names. Any names or addresses that patients chose to write on the questionnaire were securely maintained by the researchers--no names were solicited by the questionnaire, and no patients were identified. A summary of results was available to any interested participant.
CHAPTER IV

CHARACTERISTICS OF RESPONDENTS

This chapter presents data on response rates and selected demographic characteristics of the participants, including: sex, age, ethnicity, marital status, education level, employment status, health status, preference of label, and status as a health care professional.

RESPONSE RATES

Two hundred and two prostate cancer centre patients were approached. Of those, all were recruited into the study. One patient was not approached due to the clinic staff identifying him as unable to sufficiently understand English. Two hundred and six fracture clinic patients were approached. Of those, two hundred and two (98%) were recruited, three were excluded for language difficulties, and one destroyed the questionnaire after having begun. (Clinic staff subsequently identified this potential respondent as being mentally unstable.)

Two hundred and three breast cancer clinic patients were approached. Of those, two hundred and two (99.5%) were recruited, with one refusal. Total response rate was 606 of 611 (>99%). The high response rate was most likely due to a combination of several factors: the long waiting time at the clinic, lack of distraction, very few patients bringing children, and the approachability of the researcher. Respondents who were recruited were given a questionnaire to complete and return to the researcher. Data collection began in January 1997 and was completed in April 1997. On average, recruitment of respondents took place five hours a day, three and a half days per week.
RESPONDENT CHARACTERISTICS: SEX

The overall sample of 606 respondents was 51.2% female and 48.8% male; 4 people did not answer this question.

All breast cancer clinic respondents were female, all prostate centre respondents were male, and the fracture clinic was divided as follows: 48.8% male, 51.2% female.

(For all charts, boxed numbers refer to raw numbers of respondents unless followed by a percentage sign.)

N=198

AGE

Age ranged from 18 to 90 years, with the mean age being 56. Standard deviation was 15.49 years. Approximately 10% of the sample was under 35, with an additional 10% between 35 and 44. Approximately 25% were between 45 and 54. Around 22% were between 55 and 64, with approximately the same proportion between 65 and 74. Around 11% were 75 or
older. By clinic the breakdown was quite different: 45.5% of the fracture clinic respondents were under 45, as compared to 21% of the prostate patients and 14% of breast cancer patients. 61.4% of breast clinic respondents were between 45 and 64. 60.4% of prostate clinic respondents were 65 or over.

<table>
<thead>
<tr>
<th>Clinic</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;34</td>
<td>10.7%</td>
<td>4.0%</td>
<td>28.3%</td>
<td>0.5%</td>
</tr>
<tr>
<td>35-44</td>
<td>9.9%</td>
<td>9.9%</td>
<td>17.2%</td>
<td>3.0%</td>
</tr>
<tr>
<td>45-54</td>
<td>24.3%</td>
<td>36.1%</td>
<td>25.3%</td>
<td>11.9%</td>
</tr>
<tr>
<td>55-64</td>
<td>21.9%</td>
<td>25.3%</td>
<td>16.7%</td>
<td>24.3%</td>
</tr>
<tr>
<td>65-74</td>
<td>21.7%</td>
<td>17.8%</td>
<td>7.9%</td>
<td>39.6%</td>
</tr>
<tr>
<td>75+</td>
<td>11.5%</td>
<td>6.9%</td>
<td>4.6%</td>
<td>20.7%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=602

**ETHNIC BACKGROUND**

For the question "What is your ethnic background?" 41.4% of the sample self-identified as belonging to an Anglo Saxon ethnic category. 11.7% did not know or did not indicate their ethnicity. There was a sizeable population which indicated their ethnicity was ‘Jewish’, comprising 11.6% of the respondents. Those of Hispanic and Western European descent comprised 9.7% and 9.6% of the sample, respectively. 9.2% of the respondents indicated they were of Eastern European descent, with the remaining 6.8% indicating Asian or African ethnicity. Notable differences in clinic populations include: the large group which stated their ethnic background was Jewish (25%) in the prostate clinic, the proportion of those who did
not respond in the fracture clinic (20%), and the distribution of respondents of Hispanic background.

Self-identified Ethnic Background by Clinic

<table>
<thead>
<tr>
<th>Background</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anglo Saxon</td>
<td>41.4%</td>
<td>46.0%</td>
<td>41.6%</td>
<td>36.6%</td>
</tr>
<tr>
<td>Asian/African</td>
<td>6.8%</td>
<td>11.9%</td>
<td>4.5%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Eastern European</td>
<td>9.2%</td>
<td>5.9%</td>
<td>10.4%</td>
<td>11.4%</td>
</tr>
<tr>
<td>Western European</td>
<td>9.6%</td>
<td>7.4%</td>
<td>8.9%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.7%</td>
<td>12.9%</td>
<td>11.9%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Jewish</td>
<td>11.6%</td>
<td>6.9%</td>
<td>3.0%</td>
<td>24.8%</td>
</tr>
<tr>
<td>Did not answer</td>
<td>11.7%</td>
<td>8.9%</td>
<td>19.8%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=606

**MARITAL STATUS**

65.4% of the sample was currently married or in a common law relationship. 13.4% had never been married. 9.8% were widowed.

Marital Status by Clinic

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Married</td>
<td>13.4%</td>
<td>11.4%</td>
<td>24.6%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Married or CL</td>
<td>65.4%</td>
<td>62.9%</td>
<td>53.3%</td>
<td>79.7%</td>
</tr>
<tr>
<td>Separated</td>
<td>3.8%</td>
<td>4.5%</td>
<td>5.1%</td>
<td>2.0%</td>
</tr>
<tr>
<td>Divorced</td>
<td>7.5%</td>
<td>7.9%</td>
<td>10.8%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Widowed</td>
<td>9.8%</td>
<td>13.4%</td>
<td>6.2%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=599
There were eight categories of education level: some elementary school; completed elementary school; some high school; completed high school; some post-high school (university/college/trade school); completed university/college; some professional or graduate school; and completed professional or graduate school. The sample may be roughly divided into quarters: one quarter with some high school or less, one quarter with some post-high school, one quarter who had completed a university or college degree, and one quarter with a partial or completed professional or graduate degree. The prostate clinic had the largest proportion of well educated respondents, with 49.0% having a university degree or more.

Level of Education by Clinic

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some elementary school</td>
<td>5.3%</td>
<td>4.5%</td>
<td>4.6%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Completed elementary school</td>
<td>4.5%</td>
<td>4.0%</td>
<td>5.6%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Some high school</td>
<td>15.1%</td>
<td>17.8%</td>
<td>14.7%</td>
<td>12.9%</td>
</tr>
<tr>
<td>Completed high school</td>
<td>17.1%</td>
<td>18.8%</td>
<td>16.8%</td>
<td>15.8%</td>
</tr>
<tr>
<td>Some post-high school</td>
<td>15.8%</td>
<td>17.3%</td>
<td>18.9%</td>
<td>11.4%</td>
</tr>
<tr>
<td>Completed University/College</td>
<td>29.3%</td>
<td>26.7%</td>
<td>30.5%</td>
<td>30.7%</td>
</tr>
<tr>
<td>Some professional/graduate school</td>
<td>2.3%</td>
<td>3.0%</td>
<td>3.1%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Completed professional/graduate school</td>
<td>10.5%</td>
<td>7.9%</td>
<td>6.1%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=601

**EMPLOYMENT STATUS**

Employment status of the respondents can be roughly divided into thirds:
One third (36.6%) were employed full-time and one third (34.2%) were retired. The remaining third was comprised of those employed part-time (11.2%), homemakers (7.7%), and the not employed (7.9%). 9 respondents were disabled, and 4 were students (2.3%). 10 did not answer the question.

Employment Status by Clinic

<table>
<thead>
<tr>
<th>Employment</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time</td>
<td>36.6%</td>
<td>35.5%</td>
<td>43.8%</td>
<td>30.7%</td>
</tr>
<tr>
<td>Part time</td>
<td>11.2%</td>
<td>13.0%</td>
<td>12.4%</td>
<td>8.4%</td>
</tr>
<tr>
<td>Not Employed</td>
<td>7.9%</td>
<td>7.0%</td>
<td>11.3%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>7.7%</td>
<td>13.0%</td>
<td>10.3%</td>
<td>0%</td>
</tr>
<tr>
<td>Retired</td>
<td>34.2%</td>
<td>30.5%</td>
<td>17.0%</td>
<td>54.5%</td>
</tr>
<tr>
<td>Other</td>
<td>2.3%</td>
<td>1.0%</td>
<td>5.2%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=596

Differences by clinic are probably explained by differences in other variables: for instance, the lack of homemakers in the prostate clinic is likely explained by sex, and the higher proportion of unemployed to retired people in the fracture clinic is likely due to the age differences previously identified.

**OVERALL HEALTH**

Overall health was divided into five categories: excellent, very good, good, fair, and poor. Respondents were asked to indicate which best rated their overall health. Of all respondents, only 4.8% indicated that their health was excellent, 23.8% indicated that it was very good, 39.8% indicated that it was good, 24.6% indicated that it was fair, and 6.7% indicated that it
was poor. Five did not answer the question.

### Overall Health by Clinic

<table>
<thead>
<tr>
<th>Overall Health</th>
<th>All Clinics</th>
<th>Breast</th>
<th>Fracture</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>4.8%</td>
<td>2.5%</td>
<td>6.5%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Very Good</td>
<td>23.8%</td>
<td>19.0%</td>
<td>31.7%</td>
<td>20.8%</td>
</tr>
<tr>
<td>Good</td>
<td>39.8%</td>
<td>40.5%</td>
<td>38.7%</td>
<td>40.6%</td>
</tr>
<tr>
<td>Fair</td>
<td>24.6%</td>
<td>29.5%</td>
<td>18.6%</td>
<td>26.7%</td>
</tr>
<tr>
<td>Poor</td>
<td>6.7%</td>
<td>8.5%</td>
<td>4.5%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

N=601

**PREFERRED LABEL**

The univariate descriptive data on preference for label will be presented here. The association between trust and label (Hypothesis V) will be presented in the results chapter.

Most people liked or strongly liked being referred to as a patient (84.1%).

![Preference for "patient"

N=604

- strongly liked
- moderately liked
- neither like/dislike
- moderately dislike
- strongly dislike

N=604
Most people (75.1%) moderately disliked (44.7%) or strongly disliked (30.4%) being referred to as a client. Only one respondent indicated strongly liking the term.

The label 'customer' was moderately disliked (48.4%) or strongly disliked (45.7%). Of the remaining 5.9%, the breakdown was as follows: 5.2% neither liked nor disliked the term, three people (.5%) indicated moderately liking it, and only one person strongly liked it.
Most respondents indicated that they moderately disliked (46.2%) or strongly disliked (38.1%) being referred to as a survivor.
Most respondents indicated that they moderately disliked (53.4%) or strongly disliked (36.4%) being referred to as a consumer. No respondents indicated that they strongly liked the term.

Preference for "consumer"

- strongly liked
- moderately liked
- neither like/dislike
- moderately disliked
- strongly disliked

N=604
Most respondents indicated that they moderately disliked (48.1%) or strongly disliked (34.6%) being referred to as a partner. 7.8% indicated moderately liking the term, and 1.2% indicated strongly liking it, a higher proportion than for any other label other than that of patient.

![Preference for "partner" chart]

N=604

**PERCEIVED KNOWLEDGE**

Respondents were asked to rate their knowledge of four aspects of their current health condition on a Likert scale of one to five (1=not at all knowledgeable, 5=very knowledgeable.) They were asked to rate their knowledge of their current health condition, the available treatment options, the risks and benefits of these options, and which treatment they preferred. As discussed on pp. 55-56 in the methods chapter, these questions are not part of a validated scale, but have been used in previous research in tandem with the PSDM
Scores were divided into 'low knowledge' (score of 5-8), 'some knowledge' (score of 9-12), 'moderate knowledge' (score of 13-16) and 'high knowledge' (score of 17-20). 227 respondents (37.8%) indicated being highly knowledgeable, 161 respondents (26.8%) felt moderately knowledgeable, followed by 94 respondents (15.6%) feeling somewhat knowledgeable and 111 respondents (18.5%) indicating low knowledge.

The differences in current health condition knowledge between clinics was significant: the breast cancer respondents were less likely to feel knowledgeable than the fracture clinic respondents, who were in turn less likely to feel knowledgeable than the prostate clinic respondents (using Chi-square test, p<0.001). The fracture clinic contained the smallest percentage of those feeling low knowledge (9.2% as compared to 20% of prostate respondents and 27% of breast clinic respondents), which may in part be explained by the limited complexity of the conditions presenting at this clinic.
There is also a significant relationship (chi-square test; $p < 0.001$) between the HOS information seeking score and perceived knowledge (on the question which asked respondents to indicate how knowledgeable they felt about their current health condition, where 1 = not at all knowledgeable and 5 = very knowledgeable.) Of respondents who indicated that they were not at all knowledgeable about their current health condition, 69% also had low information seeking scores. As perceived knowledge increased, so did the proportion of respondents with high information seeking scores on the HOS.
In order to assess how familiar respondents were with the clinical situation presented in the standardized mortality (chest pain) vignette, we asked the following question:

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.

Most respondents (64.6%) indicated only that they did not know much about it, which is very similar to the previously mentioned proportion of those indicating low to moderate knowledge of their current health condition (61.8%). A direct comparison of the respondents’ knowledge of the mortality vignette to their knowledge of their current health
condition is not possible, since the mortality vignette questions measured familiarity rather than specific knowledge of options -- it did not seem legitimate to ask respondents to rate their knowledge of treatment preferences for chest pain they were not actually having. As was discussed in the methods chapter on p.55, the knowledge and familiarity questions were asked in order to explore whether the chronicity of the current health condition did in fact allow respondents to learn more about their illness and concomitantly have a greater desire for participation.

**ATTITUDE TOWARDS MEDICAL CARE**

Attitude was measured by a question asking respondents to indicate the statement which best described their attitude towards medical care.

Response categories were as follows: 

a) the patient should take complete control;

b) the patient should have more control than the doctor;

c) the patient and doctor should share control equally;

d) the doctor should have more control than the patient;

e) the doctor should take complete control; or

f) other (please specify).

Most respondents (63.4%) indicated that they felt the doctor and patient should share control equally. One of the two respondents (0.7%) who indicated 'other' wrote that he or she felt the family should share control, while the other indicated that 'prayer' best indicated his or her attitude towards medical care.
PROPORTION OF CANCER DIAGNOSES

Current health conditions were divided into two categories: diagnoses of cancer and other diagnoses. Diagnoses of cancer were considered to be more critical conditions with more severe consequences for the respondent than diagnoses that did not involve cancer. Each health condition was manually checked against the raw data before coding for cancer to ensure that no mistakes were made.

322 respondents or 53.4% of the sample had diagnoses of cancer. None of the patients in the fracture clinic had a diagnosis of cancer. Of respondents in the breast cancer clinic, 194 or 96% had a diagnosis of cancer. The remaining 4% were experiencing other conditions, such as benign lumps. Of respondents in the prostate cancer clinic, 128 or 64% of respondents
had a diagnosis of cancer, with the remaining 26% experiencing conditions such as prostatitis and benign prostatic hyperplasia.

![Diagnosis of cancer by Clinic](image)

N=606

**EXPERIENCE WITH CHRONIC CONDITION**

Respondents who indicated that they had been diagnosed with a chronic current health condition more than six months previously were coded as being experienced. Once again, each health condition was manually checked against the raw data before coding for experience to ensure that no mistakes were made. 381 respondents, or 65% of the sample had experience with their chronic illness.

Of the breast cancer population, 144 respondents, or 71.3% indicated that they were experienced with their chronic condition. 170 (87.6%) of prostate clinic respondents had experience. The fracture clinic was comprised of 126 (65.3%) respondents with acute
conditions and 67 (34.7%) experienced respondents with chronic conditions, which included spina bifida and back pain.

### Experience by Clinic

<table>
<thead>
<tr>
<th>Condition</th>
<th>Experienced</th>
<th>Acute/Inexperienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fracture</td>
<td>126</td>
<td>4</td>
</tr>
<tr>
<td>Breast</td>
<td>56</td>
<td>96</td>
</tr>
<tr>
<td>Prostate</td>
<td>32</td>
<td>138</td>
</tr>
</tbody>
</table>

**HEALTH CARE PROFESSIONALS**

9.3% of the sample self-identified as health care professionals. This involved a wide range of professions, including nurses, doctors, psychologists and alternative therapists, as well as some which are less widely considered to be health care professions, such as veterinarians, yoga instructors, and medical technology salespersons.

### Self-Identified Health Care Professionals by Clinic

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Health Care Professionals (N)</th>
<th>Total Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>25</td>
<td>4.2%</td>
</tr>
<tr>
<td>Fracture</td>
<td>11</td>
<td>1.7%</td>
</tr>
<tr>
<td>Prostate</td>
<td>20</td>
<td>3.4%</td>
</tr>
<tr>
<td>Total</td>
<td>56</td>
<td>9.3%</td>
</tr>
</tbody>
</table>

N=606
CHAPTER V

RESULTS

Hypothesis I: i) most patients will want to hand over problem solving; and
    ii) some patients will want involvement in decision making.

This section will first examine PSDM results for the standardized mortality vignette and then compare them with PSDM results for the respondents' current health conditions.

The respondents were asked to circle the number which best described how they felt about the six PSDM questions related to the standardized PSDM mortality vignette used in previous work (Kraetschmer, Deber). The mortality vignette read as follows:

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

The four problem solving questions were:

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

**Options**: "Who should determine what the treatment options are?"

**Risks and Benefits**: "Who should determine what the risks and benefits for each treatment option are?"

**Probability**: "Who should determine how likely each of these risks and benefits are to happen?"
The response categories were: ‘Doctor alone’; ‘mostly the doctor’; ‘doctor and you equally’; ‘mostly you’; or ‘you alone’.

About 90% of respondents indicated that the ‘doctor alone’ or ‘mostly the doctor’ should have control of the decision for every PS question. This mirrors the results of previous PSDM research, which also found that on the problem solving dimension, the vast majority of respondents would rather hand over to the provider (Kraetschmer, Deber).

Mortality Vignette: Problem Solving Scores

<table>
<thead>
<tr>
<th></th>
<th>Doctor Alone</th>
<th>Mostly Doctor</th>
<th>Both</th>
<th>Mostly You</th>
<th>You Alone</th>
<th>N Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>499 (84.0%)</td>
<td>69 (11.6%)</td>
<td>23 (3.9%)</td>
<td>1 (0.2%)</td>
<td>2 (0.3%)</td>
<td>594</td>
</tr>
<tr>
<td>Options</td>
<td>448 (75.4%)</td>
<td>85 (14.3%)</td>
<td>48 (8.1%)</td>
<td>10 (1.7%)</td>
<td>3 (0.5%)</td>
<td>594</td>
</tr>
<tr>
<td>Risks &amp; Benefits</td>
<td>433 (73.0%)</td>
<td>83 (14.0%)</td>
<td>56 (9.4%)</td>
<td>9 (1.5%)</td>
<td>12 (2.0%)</td>
<td>593</td>
</tr>
<tr>
<td>Probability</td>
<td>403 (68.0%)</td>
<td>99 (16.7%)</td>
<td>69 (11.6%)</td>
<td>8 (1.3%)</td>
<td>14 (2.4%)</td>
<td>593</td>
</tr>
</tbody>
</table>

The decision making questions were:

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

**Who should decide:** “Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?”
The same response categories were used as for the problem solving questions.

For the DM dimension, the results from the standardized vignette indicate that over half of the respondents did wish to be involved with decision making (responses of ‘both’, ‘mostly you’, or ‘you alone’).

**Mortality Vignette: Decision Making Questions**

<table>
<thead>
<tr>
<th>Item</th>
<th>Doctor Alone</th>
<th>Mostly Doctor</th>
<th>Both</th>
<th>Mostly You</th>
<th>You Alone</th>
<th>N Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utility</td>
<td>186 (31.4%)</td>
<td>66 (11.1%)</td>
<td>203 (34.2%)</td>
<td>31 (5.2%)</td>
<td>107 (18.0%)</td>
<td>603</td>
</tr>
<tr>
<td>Who decides</td>
<td>212 (35.8%)</td>
<td>70 (11.8%)</td>
<td>175 (29.5%)</td>
<td>38 (6.4%)</td>
<td>98 (16.5%)</td>
<td>603</td>
</tr>
</tbody>
</table>

The standardized vignette was used as the basis for comparison with the responses to the PSDM scale for the current health condition of respondents. For their current health condition, respondents still overwhelmingly wanted to give control to their doctor for the PS dimension.

**Current Health Condition: Problem Solving Questions**

<table>
<thead>
<tr>
<th>Item</th>
<th>Doctor Alone</th>
<th>Mostly Doctor</th>
<th>Both</th>
<th>Mostly You</th>
<th>You Alone</th>
<th>N Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>467 (77.7%)</td>
<td>71 (11.8%)</td>
<td>52 (8.7%)</td>
<td>5 (0.8%)</td>
<td>6 (1.0%)</td>
<td>601</td>
</tr>
<tr>
<td>Options</td>
<td>324 (53.6%)</td>
<td>85 (14.1%)</td>
<td>161 (26.7%)</td>
<td>21 (3.5%)</td>
<td>13 (2.2%)</td>
<td>604</td>
</tr>
<tr>
<td>Risks &amp; Benefits</td>
<td>341 (56.5%)</td>
<td>93 (15.4%)</td>
<td>124 (20.5%)</td>
<td>25 (4.1%)</td>
<td>21 (3.5%)</td>
<td>604</td>
</tr>
</tbody>
</table>
The following chart summarizes the data presented for problem solving in the standardized mortality vignette (chest pain) and current health condition scenarios:

<table>
<thead>
<tr>
<th>Probability</th>
<th>320 (53.6%)</th>
<th>112 (18.8%)</th>
<th>119 (19.9%)</th>
<th>22 (3.7%)</th>
<th>24 (4.0%)</th>
<th>597</th>
</tr>
</thead>
</table>

For the DM dimension, it is apparent that respondents are equally likely to want to share control of decision making related to their current health condition as they are for the standardized vignette. However, they are significantly more likely to want to take control of DM for their current health condition (chi-square test; p<0.001).
Current Health Condition: Decision Making Questions

<table>
<thead>
<tr>
<th>Item</th>
<th>Doctor Alone</th>
<th>Mostly Doctor</th>
<th>Both</th>
<th>Mostly You</th>
<th>You Alone</th>
<th>N Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utility</td>
<td>120 (19.9%)</td>
<td>32 (5.3%)</td>
<td>159 (26.4%)</td>
<td>66 (10.9%)</td>
<td>226 (37.5%)</td>
<td>603</td>
</tr>
<tr>
<td>Who decides</td>
<td>136 (22.6%)</td>
<td>41 (6.8%)</td>
<td>178 (29.5%)</td>
<td>50 (8.3%)</td>
<td>198 (32.8%)</td>
<td>603</td>
</tr>
</tbody>
</table>

The following chart summarizes the data presented for decision making in the standardized mortality vignette (chest pain) and current health condition scenarios:

**Desire for DM**

![Graph showing desire for decision making](image)

- Current Health Condition
- Standardized Vignette

*Patient Category*

The variable of 'Patient Category' was created in order to assess respondents' answers to the PSDM. If the respondent wished to keep control of both decision making and problem
solving in the standardized vignette, they were categorized as ‘Autonomous’. If the
respondent wished to hand over or share problem solving and keep or share control of
decision making they were categorized as ‘Shared’. If they wished to hand over control of
both PS and DM, they were categorized as ‘Passive.’

More than half of the respondents (52.0%) were classified as desiring shared control, 43.7%
of respondents were classified as passive, and the remaining 4.3% were considered
autonomous. No respondent was in the ‘theoretically implausible’ cell of ‘patient category’.

Patient category was highly related to attitude towards medical care (chi-square test; p
<0.001). Attitude was measured by our own item asking respondents to indicate the
statement which best described their attitude towards medical care, previously discussed in
methods, p.55. Response categories were as follows:

a) the patient should take complete control;
b) the patient should have more control than the doctor;

c) the patient and doctor should share control equally;

d) the doctor should have more control than the patient;

e) the doctor should take complete control; or

f) other (please specify).

Most (63.4%) indicated that they felt the doctor and patient should share the control equally.

The majority (88.2%) of those respondents who indicated that the patient should have more control than the doctor were autonomous. 92% of those indicating the patient should have more control than the doctor were autonomous (23%) or shared (58%). Of respondents indicating that the doctor and patient should share control equally, most (70.2%) were in the shared category. Of respondents who wished the doctor to take most of the control, 93% were passive. 100% of respondents who wished the doctor to take all of the control were classified as passive. The main use of this data is that it helps to confirm the construct validity of the patient categories.
Hypothesis II: Most patients will want to be informed.

The Krantz Health Opinion Survey (1980) provides information on preferences for self-care, active behavioral involvement in health care, and desire for health-related information. The results of the information-seeking subscale will be presented here.

The results showed that most respondents exhibited low information-seeking behaviour. 347 (59.2%) of respondents had low scores, 123 (21.2%) had medium scores, and 116 (19.6%) had high scores for the information subscale.
We went beyond the hypothesis that most patients will want to be informed to compare information-seeking behaviour to some other characteristics. This comparison was done in order to be able to discuss possible reasons why our hypothesis was not supported by the results (see discussion). We compared HOS information subscale scores to age, which showed that most respondents 55 or older (67%) have low information subscale HOS scores. In contrast, most (51%) of the respondents under 55 have moderate or high information subscale HOS scores. Although any cut point would be arbitrary, for consistency we chose the cut point of 55 years of age by referring to the Strull et al (1984) study which suggested that persons with cancer older than 54 were less likely to desire information than younger individuals with cancer.
There is also a significant relationship (chi-square test; p < 0.001) between information seeking score (low, medium, or high) and patient category. Over 80% of passive respondents exhibited low information seeking behaviour, as opposed to only 16% of autonomous patients. In contrast, most (60%) autonomous patients exhibited high information seeking behaviour, as opposed to only 2.7% of passive respondents.
There is also a significant relationship (chi-square test; $p < 0.001$) between information seeking score (low, medium, or high) and sex of the respondent. Over 70% of women exhibited low information seeking behaviour, as opposed to only 46% of men.
Hypothesis III: Respondent and disease characteristics will be correlated to the person's desire for PS and DM participation:

i) people more experienced with their chronic illness will have a greater desire to participate; but

ii) people with life-threatening illnesses (in this study, those with diagnoses of cancer) will be less participative; and

iii) less educated and older people will be less participative.

Hypothesis III.i Experience with chronic illness

We asked respondents to indicate (months, years) how long they had known about their current health condition. Respondents were said to be experienced with their chronic illnesses if they indicated they had received their diagnosis more than six months previously. This variable was created in order to study whether people with more time to learn about and live with their illness would wish to participate more. Each health condition was manually checked against the raw data before coding for experience with chronic illness (variable EXPERIENCE) to ensure that no mistakes were made (for instance, calling a fracture a chronic illness). 381 respondents, or 65% of the sample, had experience with their chronic illness. As hypothesised, people with such experience were more likely to be autonomous or shared (60%) as compared to those with acute illnesses, who were almost evenly split between passive (49.5%) and autonomous or shared (50.5%). The categories of autonomous and shared were collapsed for purposes of clarity in the text only; statistical tests were run using all three separate categories. (Chi-Square test; p <0.008)
Respondents experienced with their chronic condition were expected to have had more time to learn about their disease, thus knowledge of the current health condition was measured using the four knowledge questions that appear in the methods. Knowledge does not appear to have had an impact: 62% of those living with a chronic illness for more than six months indicated low or moderate knowledge of their condition, and 64% of those who had not indicated low or moderate knowledge of their condition.

**Hypothesis III.ii Diagnoses of cancer**

Current health conditions were similarly divided into two categories, diagnoses of cancer, and other health conditions. 322 respondents, or 53.4% of the sample had diagnoses of cancer. None of the patients in the fracture clinic had a diagnosis of cancer. Although people with diagnoses of cancer were more likely to be passive than were those respondents diagnosed with other health conditions, these associations were not found to be statistically significant.
(Chi-Square test; p>0.05).

Differences in desired level of participation: Current Health Condition and Standardized Mortality Vignette.

Recalling that diagnosis of cancer and chronicity were expected to have an effect on the desire for participation because of higher salience, greater motivation, and more time to learn more about the health condition, we decided to move beyond hypothesis III.i and ii to compare the desired level of participation for the standardized mortality vignette to the desired level of participation for the current health condition. Patient categories did not change for any of the respondents when comparing results of the PSDM for the standardized condition to the current health condition. Although respondents tended to have the same level of desired participation for their current health condition as they had for the standardized vignette, there were some marginal shifts, especially along the decision making dimension.
The problem solving dimension remained unchanged for over 98% of respondents. The decision making dimension showed more variation: Overall, 62.3% of passive respondents had no changes in score from the mortality vignette to their current health condition. 36.1% indicated a greater desire for participation (though not shifting patient categories), and only 4 indicated less desire for participation. Shared respondents had unchanged scores in 60.3% of the cases, with 38.1% indicating greater desire for participation and only 5 indicating less. Of the autonomous respondents, 92.3% had unchanged scores, with the remainder indicating a greater desire for participation.

Differences in desire for participation: respondents without diagnoses of cancer

For those without diagnoses of cancer, one (9.0%) autonomous respondent indicated a greater desire for participation for his or her current health condition, with the remaining 91% indicating the same level of desire as for the standardized vignette. For shared respondents without a diagnosis of cancer only 56.0% indicated the same level of desire, with 41.4%
indicating a greater desire for participation. 2.6% indicated they would prefer to be less participative for their current health condition. Passive respondents’ scores remained unchanged in 50.9% of cases, with 3.7% indicating less desire for participation for their own health condition and 45.3% indicating a greater desire for participation.

Differences in desire for participation: respondents with diagnoses of cancer

For respondents with diagnoses of cancer, one autonomous respondent indicated a greater desire for participation for his or her current health condition, with the remainder showing no difference in score. For shared respondents with diagnoses of cancer 65.0% showed no difference in score, with 34.4% indicating a greater desire for participation. One respondent indicated less desire for participation for his or her own condition. Passive respondents’ scores remained unchanged in 71.5% of cases, with no one indicating less desire for participation and 28.5% indicating a greater desire for participation.
Differences in desire for participation - cancer diagnoses

Hypothesis III.iii  Less educated and older people.

Patient category was strongly related to education (chi-square test; $p < 0.001$), with 66.5% of respondents with a professional or graduate degree classified as autonomous. In contrast, no respondents with an elementary level of education were classified as autonomous. 48% of those who had some or had completed college or university were classified as shared.
Patient category was also influenced by age (chi-square test; $p < 0.05$). As age increased, so did the likelihood of being classified as passive. As age decreased, so did the likelihood of being classified as shared. Age and classification into the autonomous category did not seem to follow a linear pattern, with the group of respondents between 55 and 64 containing the most respondents classified as autonomous.

<table>
<thead>
<tr>
<th>Patient category by age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Passive</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Shared</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Autonomous</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
Logistic regression was done to model the extent that patient category can be explained by the following set of independent variables: diagnosis of cancer, experience with chronic illness, age, and education level. Logistic regression was performed because patient category is not a continuous variable, but a categorical variable. Further multiple regression analysis was then performed using the continuous variable of PSDM score.

**LOGISTIC REGRESSION MODEL: Analysis of Variance — Patient Category**

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F Statistic</th>
<th>Prob&gt;F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>3</td>
<td>66.8143</td>
<td>22.2714</td>
<td>41.512</td>
<td>0.0001</td>
</tr>
<tr>
<td>Error</td>
<td>385</td>
<td>206.5539</td>
<td>0.5365</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C Total</td>
<td>388</td>
<td>132.30576</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Root MSE: 0.7325  
Resp Mean: 1.8770

| Parameter Estimates                                                                 |
|--------------------------------|-----|----------------|-------------|----------|
| Parameter                    | DF  | Estimate       | Standard Error | Prob > |T|  |
| Intercept                    | 1   | -16.4442       | 5.1022       | 0.0014  |
| Experience                   | 1   | 0.283388       | 0.0928       | 0.0001  |
| Diagnosis of Cancer          | 0   | 0              | .            | .        |
| Age                          | 1   | 6.0508         | 0.0026       | 0.0001  |
| Education                    | 1   | 48.6990        | 0.0198       | 0.0001  |

Both this regression analysis and the following multiple regression analysis show that the variable ‘diagnosis of cancer’ is collinear with other variables in the regression. More precisely, a linear dependency was found to exist between the diagnosis of cancer variable and several other independent variables. The SAS statistical package used for our data analysis is programmed to detect the existence of exact collinearity, and thus set the
parameter estimate for diagnosis of cancer to zero. When one variable is collinear with several others, the one variable is eliminated, rather than the several other variables it is collinear with. Running the regressions without the variable of 'diagnosis of cancer' would thus show the same results. Other potentially confounding variables were analysed for correlation: the table of correlations among these variables is included in the methods chapter.

**MULTIPLE REGRESSION MODEL: Dependent Variable — PSDM Score**

We repeated this analysis using multiple linear regression to model the extent that the dependent variable, PSDM score, can be explained by the same set of independent variables: diagnosis of cancer, experience with chronic illness, age, and education level.

The PSDM scores for the current health condition had the following range and mean for each of the three patient categories:

<table>
<thead>
<tr>
<th></th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive</td>
<td>1.0</td>
<td>2.83</td>
<td>1.31</td>
</tr>
<tr>
<td>Shared</td>
<td>1.666</td>
<td>3.666</td>
<td>2.71</td>
</tr>
<tr>
<td>Autonomous</td>
<td>3.166</td>
<td>5.0</td>
<td>4.102</td>
</tr>
</tbody>
</table>
In further exploratory univariate data analyses, we found that patient category was significantly related to sex (chi-square test; p<0.001). 6.9% of males were classified as autonomous, compared with 1.9% of females. 57.3% of males were classified as shared, compared with 47.5% of females. Half of the females (50.6%) were classified as passive, compared with 35.9% of males.
A further analysis shows that after controlling for education, patient category is only significantly related to sex (chi-square test; $p<0.001$) for the group of respondents that had graduated from high school, but not from college or university (N=208). The following table shows that at every other level of education, there is no statistically significant difference between women's desire for participation and men's desire for participation.

**Patient Category by Sex, controlling for education level.**

<table>
<thead>
<tr>
<th>Patient Category</th>
<th>Some High School</th>
<th>Some Post High School</th>
<th>University/College Degree</th>
<th>Graduate Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>Autonomous</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Shared</td>
<td>13</td>
<td>15</td>
<td>55</td>
<td>46</td>
</tr>
<tr>
<td>Passive</td>
<td>54</td>
<td>67</td>
<td>31</td>
<td>73</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>83</td>
<td>87</td>
<td>121</td>
</tr>
</tbody>
</table>

N=601
Further multivariate analysis showed that sex was only very weakly predictive of patient category (standardized estimate= -0.148). As pointed out by the SAS statistics manual, univariate analysis can show that a relationship is significant, but a multiple regression model is necessary to show the strength of the effects of individual variables (1990, p.24).

Patient category was also significantly related to clinic (chi-square test; p<0.001). 9.4% of the prostate clinic respondents were classified as autonomous, compared with less than 5% of fracture clinic respondents and less than 2% of breast cancer clinic respondents.

![Patient Category by Clinic](image)

N=606

Multivariate analysis using clinic as a variable will be presented under hypothesis VII.

**Hypothesis IV:** Trust will be correlated with the desire for participation, such that:

i) people with high levels of trust will hand over control of PS and DM to the
provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.

The results are striking: of the 38 respondents (6.3% of the sample) with blind trust, all but one are in the passive category. As trust decreases, the proportion of shared or autonomous respondents increases. For the 217 respondents (35.8%) with high trust levels, 59% were passive. Of the 292 (48.2%) with moderate trust levels only 31.7% were passive. Of the 59 respondents (9.7%) with low trust levels only 27.1% were passive. These associations were highly significant (chi-square test; p <0.001).

As hypothesised, most people with high levels of trust hand over control of PS and DM to the provider (98% of those with blind trust and 59% of those with high trust hand over PS and DM). Most people with moderate levels of trust hand over PS only. Sixty-six percent of respondents with moderate trust levels indicated they wished to keep or share control of
DM (while handing over or sharing control of PS), with 5.5% indicating they wished to take control of DM and PS. People with low levels of trust prefer to keep control of both PS and DM. Those with low trust levels are far more likely to be autonomous (13.6%) than any other trust group, keeping control of both DM and PS.


Question 10 M read as follows: “The medical profession has too much power.” (Response categories were from 1=strongly disagree to 5=strongly agree.) In examining the relationship between the trust categories from the Trust in Physician Scale and the responses to this item, we see that 81% of those who strongly agreed that the medical profession had too much power also were in the low trust category. No respondent with low trust strongly disagreed that the medical profession had too much power.

<table>
<thead>
<tr>
<th>Trust Category by Q10 M</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
</tr>
<tr>
<td>Blind Trust</td>
</tr>
</tbody>
</table>
Statistics for Trust Category by Q10 M

<table>
<thead>
<tr>
<th>Statistic</th>
<th>DF</th>
<th>Value</th>
<th>Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chi-Square</td>
<td>12</td>
<td>359.641</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Contingency Coefficient 0.625
Cramer's V 0.445
Frequency Missing = 5

Correlation analysis showed a 0.6004 correlation between Q10M and TRUST.

Question 10 N read as follows: “If you follow a physician’s advice, you will have less illness in your lifetime.” (Response categories were from 1=strongly disagree to 5=strongly agree.)

In examining the relationship between the trust categories from the trust in physician scale and the responses to the trust in medicine item, we see that 70% of those who strongly disagreed that following a physician’s advice would lead to less illness also were in the low trust category. No respondent with low trust strongly agreed that following a physician’s advice would lead to less illness.
Statistics for Trust Category by Q10 N

<table>
<thead>
<tr>
<th>Statistic</th>
<th>DF</th>
<th>Value</th>
<th>Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chi-Square</td>
<td>12</td>
<td>364.701</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Contingency Coefficient 0.615
Cramer's V 0.450
Frequency Missing = 5

A correlation analysis showed a correlation of 0.6193 between Q10N and TRUST.

Hypothesis V: Trust will be correlated with preference of label: people who mistrust their providers will be less satisfied with the label ‘patient’ and will prefer labels with a more consumerist orientation.

The univariate descriptive data about preference for label is presented on p.78.

84.1% of respondents moderately liked or strongly liked the term ‘patient’. Trust was highly
related to the affinity for the label of patient, with only those people with low trust strongly disliking the term. Those with blind trust only moderately liked (40.5%) or strongly liked (59.5%) being called patients. (Chi-square test; p < 0.001).

75.1% of respondents moderately disliked or strongly disliked being referred to as a client.

In examining the relationship of trust to the affinity for the label of client, we can see that people with blind trust did not like the term at all. People with medium or high trust tended to moderately dislike or strongly dislike the term. Of those with low trust levels, 14% moderately liked being referred to as clients, a higher proportion than in any other trust category.
'Customer' was a term moderately disliked or strongly disliked by 94.1% of the sample. In examining the relationship of trust to the affinity for the label of customer, we can see that people with high or blind trust did not like the term at all. People with medium trust moderately disliked the term. The low trust category contained the sole respondent who strongly liked the term.
84.3% moderately disliked or strongly disliked the term ‘survivor’. In examining the relationship of trust to the affinity for the label of survivor, we can see that people with blind trust did not like the term at all. People with medium or high trust tended to moderately dislike or strongly dislike the term. Of those with low trust levels, 19.3% moderately liked or strongly liked being referred to as survivors, a higher proportion than in any other trust category.
Trust by preference for "survivor"

'Consumer' was a label that no respondent, regardless of trust level, strongly liked. 89.8% of respondents moderately disliked or strongly disliked the term. In examining the table we can see that of those with low trust, over 20% were neutral or liked the term, a proportion not matched in any other trust category.
The term ‘partner’ was better received: 9.0% of respondents indicated moderately liking or strongly liking the label. It was most popular among those with low trust levels, 21% of whom moderately liked or strongly liked the term. Partner also appealed to 11% of those with medium trust levels. Of those with high trust levels, 3.3% moderately liked or strongly liked the term. Of the terms suggested other than that of patient, partner was the most popular, perhaps due to the high proportion of respondents who indicated that their attitude towards medical care was one where the patient and physician should share the control equally.
Hypothesis VI: Respondents with a low level of trust in their physician will report a higher use of alternative therapies.

The proportion of those using alternative therapies increases as trust decreases. (Chi-square test; p<0.001). Of those with blind trust, 1 had used an alternative therapy. Of respondents with high trust, 9.2% had used an alternative therapy. Of the moderate trust group, 29.9% had used alternative therapy. Of those in the lowest trust category, 50% had used an alternative therapy.

Hypothesis VII: Respondents with breast or prostate cancer, especially those who are involved in support groups, will be less likely to hand over control, less likely to have high levels of trust, and more likely to prefer a label with a more consumerist orientation.
In order to draw comparisons between ' politicized' illnesses and non-politicized conditions, we examined the fracture clinic and compared the other clinics to it when we explored the following variables: patient category, trust levels and preferred label.

**PATIENT CATEGORY**

Breast cancer respondents were most likely to be passive (52%), as compared to 41% of fracture respondents and 38% of prostate respondents. Fracture and prostate clinics contained a similar proportion of shared respondents (53.5% and 55.4% respectively) with the breast cancer clinic containing a lower proportion of shared respondents (47%) These differences were significant. (Chi-square test; p<0.001)

![Patient Category by Clinic](image)

**TRUST LEVELS**

Of the respondents in the fracture clinic, 11.9% had low trust, the highest proportion of all
clinics. 51% had moderate trust, 31.7% had high trust, and 5.4% had blind trust. Comparing these results with the prostate clinic shows the largest difference in the proportion of those with low trust (7.9% in the prostate clinic). The breast cancer clinic respondents had a lower proportion of respondents with moderate trust (42.5%) and the highest proportion of those with blind trust (10.4%). (Chi-square test; \( p < 0.001 \)).

![Bar chart showing trust level by clinic](image)

N=602

**PREFERENCE OF LABEL**

9.9% of breast cancer respondents moderately disliked the label ‘patient’, a higher proportion than in any other clinic. (Only 10 respondents—1.6% of total sample—strongly disliked the label ‘patient’.) Breast cancer respondents were also the least represented group in the category of strongly liking the label (only 12% of breast cancer respondents indicated strongly liking ‘patient’ as compared to 19.8% of prostate clinic respondents and 23% of fracture clinic respondents.)
The breast cancer clinic had the highest proportion of respondents who indicated moderately liking the label 'client'. 14.3% indicated moderately liking it, as compared to 9.9% of fracture clinic respondents, and only 3.5% of prostate respondents. Prostate clinic respondents were also more likely to strongly dislike the label (38.8%). (Chi-square test; p<0.001)
The distributions by clinic for preferences for the label 'customer' were fairly even, with over 90% of respondents in each clinic moderately or strongly disliking the term.

Distributions by clinic were also similar for the label 'consumer', with over 90% of all respondents moderately or strongly disliking the term.
21.7% of breast cancer respondents moderately or strongly liked the term 'survivor', as compared to 3.5% of fracture respondents and .5% of prostate respondents. (Chi-square test; p<0.001)
15.8% of breast cancer respondents moderately or strongly liked the term 'partner', as compared to 6% of fracture respondents, and 4% of prostate respondents. Prostate respondents were also more likely to strongly dislike the term (44%) as compared to 32% of fracture respondents and 26% of breast cancer respondents. (Chi-square test; p<0.001)

![Preference for "partner" by Clinic](image)

N=604

The results of patient categories, trust, and preference for label will now be displayed by support group use. 71 respondents of 606 (11.7%) indicated that they had used a support group within the previous year.

**PATIENT CATEGORY**

Only 17% of those who had used a support group were passive, as compared to 47% of those who had not. 77% of those who had used a support group were in the shared patient category, as compared to 49% of those who had not. (Chi-square test; p<0.001)
TRUST LEVELS

There is a striking difference in the pattern of trust levels between those who had used a support group, and those who had not. 19.8% of support group users were in the moderate or low trust categories, compared to 8.7% of those who did not use a support group. (Chi-square test; p<0.001)
PREFERENCE OF LABEL

Of those who had used support groups, over 30% strongly or moderately disliked the label ‘patient’, as opposed to under 5% for those who did not use a support group. (Chi-square test; p<0.001)

Almost 50% of support group users moderately or strongly liked the term ‘client’. By contrast, less than 10% of those who did not use a support group moderately liked the term, and none strongly liked it. (Chi-square test; p<0.001)
Patterns between groups were almost identical for the term ‘customer’.

38% of respondents who had not used a support group strongly disliked the term ‘consumer’.

Only 18% of support group users strongly disliked it. (Chi-square test; p<0.001).
48% of support group users moderately or strongly liked the term 'survivor'. In contrast, less than 10% of those who did not use a support group moderately liked the term, and none strongly liked it. (Chi-square test; p<0.001)
Patterns for the term 'partner' were also striking: over 40% of those who had used a support group moderately liked it, as compared to less than 5% of those who had not used a support group. (Chi-square test; p<0.001)

![Preference for "partner" by support group use](image)

N=604

**LOGISTIC REGRESSION MODEL: Analysis of variance - Patient Category**

In a regression model for patient category using the variables experience with condition, age, education, breast cancer clinic respondent, prostate cancer clinic respondent, trust level and preference of label, education is shown to have the greatest predictive value. Support group use could not be included with this method, due to the small number of support group users and the requirements of the statistical tests for sufficient numbers within variables in the regression. A logistic regression was used to model these variables, which resulted in an R-square of .3156 (Prob >F 0.0001).

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F Value</th>
<th>Prob&gt;F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analysis of Variance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parameter Estimates</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>DF</td>
<td>Parameter Estimate</td>
<td>Standard Error</td>
<td>Prob &gt;</td>
<td>T</td>
</tr>
<tr>
<td>Intercept</td>
<td>1</td>
<td>-19.2668</td>
<td>4.8264</td>
<td>0.0001</td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>1</td>
<td>0.239783</td>
<td>0.01797537</td>
<td>0.0001</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>-0.037950</td>
<td>0.01432825</td>
<td>0.0053</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td>1</td>
<td>0.118661</td>
<td>0.01180843</td>
<td>0.0001</td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>1</td>
<td>-0.652269</td>
<td>0.05245245</td>
<td>0.0001</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>1</td>
<td>-0.234484</td>
<td>0.05465272</td>
<td>0.0061</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>1</td>
<td>0.099225</td>
<td>0.06472264</td>
<td>0.0024</td>
<td></td>
</tr>
<tr>
<td>Preference of label</td>
<td>6</td>
<td>0.029643</td>
<td>0.05976421</td>
<td>0.0082</td>
<td></td>
</tr>
</tbody>
</table>

This regression model shows that all of these variables are independent predictors. The R-square of 0.3156 (Prob >F 0.0001) shows us that a significant portion of the variation of patient category is explained by variation in the independent variables in the model. In this model, level of education and trust have a relatively stronger effect on the dependent variable (patient category) than the other independent variables.

**MULTIVARIATE REGRESSION MODEL: Dependent Variable -- PSDM Score**

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F Value</th>
<th>Prob&gt;F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>12</td>
<td>120.5566</td>
<td>20.09283</td>
<td>44.113</td>
<td>0.0001</td>
</tr>
<tr>
<td>Error</td>
<td>566</td>
<td>257.80009</td>
<td>0.4555</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C Total</td>
<td>572</td>
<td>378.3575</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Root MSE 0.67902  R-square 0.3186  Dep Mean 1.79235  Adj R-sq 0.3114
Parameter Estimates

| Variable          | DF | Parameter Estimate | Standard Error | Prob > |T| Standardized Estimate |
|-------------------|----|--------------------|----------------|---------|-----------------------|
| Intercept         | 1  | 11.76463           | 4.16012511     | 0.00083 | 0.000000000          |
| Experience        | 1  | 0.130321           | 0.02567937     | 0.0004  | 0.10650060            |
| Age               | 1  | -0.037950          | 0.01432825     | 0.0034  | -0.12650879           |
| Education level   | 1  | 0.118661           | 0.01180843     | 0.0001  | 0.41273319            |
| Trust             | 1  | -0.652269          | 0.05236205     | 0.0001  | -0.23635319           |
| Breast            | 1  | -0.234484          | 0.05133912     | 0.0004  | -0.08714174           |
| Prostate          | 1  | 0.099225           | 0.05727264     | 0.0005  | 0.07792344            |
| Preference of label | 6  | 0.031881           | 0.06100212     | 0.0084  | 0.02457348            |

This regression model shows that all of these variables are independent predictors. The same results accrue from the use of either logistic or linear regression: in this model level of education and trust also have a relatively stronger effect on the dependent variable (patient category) than any of the other independent variables.
CHAPTER VI
DISCUSSION AND CONCLUSIONS

This final chapter will discuss each of the hypotheses in turn, the limitations of this study, and conclusions.

Hypothesis I: i) most patients will want to hand over problem solving; and

   ii) some patients will want involvement in decision making.

Summary   The results supported this hypothesis. Over 90% of respondents indicated that they would prefer to hand over control of the problem solving dimension of medical treatment decisions to their provider. Results were similar for both the standardized vignette and the recipient’s current health condition. In the case of the decision making dimension, over half of the respondents on the standardized vignette indicated that they would prefer to take or share control with the provider. This proportion increased to over two thirds of respondents on the current health condition vignette. Although respondents did tend to indicate a greater desire for participation for their current health condition than they had indicated for the standardized vignette, the shift towards more involvement was not large enough for a reclassification of any respondent from the passive category to the shared category, or from the shared category to the autonomous category.

The results of the question of what best described respondents’ attitude towards medical care, given a range of choices from ‘the doctor should have complete control’ to ‘the patient
should have complete control' were used to provide further evidence of construct validity of the PSDM. Interestingly, this general attitude question showed only 26.7% of respondents indicating that the doctor should have more control than the patient. Using the results of the PSDM, we see that 43.7% of respondents were classified as passive. Accordingly, a significant proportion of respondents who clearly wanted to hand over control of both problem solving and decision making dimensions for both the standardized vignette and their own health condition indicated on a more general question that they wanted to share control with the doctor. It may be the case that respondents felt that they were sharing control by allowing the doctor to take control. This interpretation is supported by the literature, which has suggested that patients are “involved in decision making as much as they wanted to be” (Charles et al, 1994).

*Previous research* The literature on the PSDM is limited to the previous work by Baumann, Deber, and Kraetschmer discussed in the literature review. The PSDM scale, as discussed in the Methods chapter, has been validated, and found to pick up distinctions between desire for problem solving participation and desire for decision making participation. The PSDM was used on 300 patients awaiting cardiograms, who indicated a similar desire to hand over problem solving (98.4% of the PS scores were between 1 and 3 (i.e., from physician to shared control), whereas 78% of the 6 DM scores were between 3 and 5, indicating the respondent’s desire to participate. The PSDM had not been used on a population including women, younger adults, or acute conditions before. The PSDM had been used to classify respondents into passive, shared or autonomous patient categories in
previous work (Deber). These categories may help to clarify the nuances of what respondents may mean when they answer general questions about their attitude towards control of medical treatment decisions.

**Discussion** The literature suggests that one possible reason why respondents were more likely to indicate desire for DM participation for their current health condition is that they may have known more about their current health condition than they did about the clinical situation described in the mortality vignette. Increased knowledge has been shown to increase desire for participation (Strull, Lo & Charles, 1984). However, our results indicated that most (approximately 62%) of the respondents felt that they had limited knowledge of their current health condition, and also ‘did not know much about’ the condition in the standardized vignette. Statistical analysis confirmed that knowledge as measured in this study did not have an impact on desire for participation. Another possible explanation may be that the impact of disease characteristics (e.g. diagnosis of cancer, chronicity of condition) or of other respondent characteristics, such as gender, which will later be discussed may be confounding the effect of knowledge. Since we used different items to measure respondents’ knowledge of their current health condition and respondents’ familiarity with the condition presented in the standardized vignette, we cannot make direct comparisons of their knowledge of one vis a vis the other. It is thus possible that respondents knew more about their current health condition than they did about the condition in the standardized vignette, yet answered in a way that would indicate low knowledge of both.
Although this is not a primary hypothesis, the differences in desire for DM participation between the standardized vignette and the current health condition deserve further exploration. One possible explanation why respondents were more likely to indicate desire for DM participation for their current health condition than for the standardized vignette is the higher salience that an illness they actually have would carry. As Sniderman (1991) pointed out, people can be motivated to be more thoughtful and analytic about issues that they care deeply about. A current illness would thus provide more incentive for desire for participation than a standardized illness that may not be salient for the respondent.

**Significance** The differences in desire for participation along the PSDM dimensions can perhaps shed some light on the question of what providers should do when the standard of ethical practice calls for active patient participation, and at the same time their perception is that their patients do not wish to participate. (Degner & Sloan, 1992; Waterworth & Luker, 1990) Distinguishing between problem solving (where the preferences of the patient are less relevant) and decision making (where preferences have an impact on the choice of treatment option) can allow physicians to provide their expertise to patients without infringing on areas where patients desire to share or take control of medical treatment decisions.

**Hypothesis II: Most patients will want to be informed.**

**Summary** This hypothesis was not supported by the results, which showed that 59.2% of respondents exhibited low information seeking behaviour on the Krantz Health Opinion
Survey. In moving beyond the hypothesis to further examine why our results did not support it, we found a significant relationship between patient category and information seeking score. 80% of passive respondents reported low information seeking behaviour. The low HOS information seeking subscale scores could be thus be anticipated for almost half of our respondents, since respondents categorized as passive comprised 44% of the total sample.

**Previous research** A number of studies have suggested that most patients do wish to be informed (Lerman et al, 1990; Weiss 1986), but that the desire for information does not translate into a desire for decision-making. Previous work with the PSDM (Kraetschmer, 1994) also used the HOS information seeking subscale, but did not analyse the relationship between desire for participation and information seeking.

**Discussion** Since older people are less likely to desire information (Ross et al, 1995), this may in part be explained by the high proportion of older people in the sample (53% over 55). Another influence may have been the relatively low levels of education attained by many respondents: 42% of the sample had a high school diploma or less. Cassileth et al (1980) found that education was a predictor of desire for information, which was supported by these results.

Another factor which may have influenced the scores is the characteristics of the clinics themselves: respondents were all patients of clinicians who were comfortable with having
their recipients participate in our survey. Since these clinics were thus not randomly selected, there may have been a bias towards clinicians who feel confident in their own abilities as providers of information. If clinicians were giving adequate information without the patients having to seek it out, this would in part explain the low information-seeking scores. An interesting question for future qualitative research would be to ask patients to explain how they are receiving information, and whether they are being given enough information by the clinician without having to seek it out.

**Significance**  Further qualitative research is necessary to ascertain why most of these patients had low information seeking scores. It is possible that the low mean levels of education posed a barrier for patients who may not have felt comfortable questioning their provider, or may have felt uncertain that they would understand their provider’s responses. Previous studies (Greenfield et al 1985; Roter, 1984) have shown that coaching patients to ask questions increases their desire for participation and their information seeking behaviour. Our results suggest that many patients could require some form of coaching intervention before being willing or able to actively seek information from their providers.

**Hypothesis III:** Respondent and disease characteristics will be correlated to the person’s desire for PS and DM participation:

i) people experienced with their chronic illness will be more participative; but

ii) people with life-threatening illnesses (in this study, those with diagnoses of cancer) will be less participative; and
iii) less educated and older people will be less participative.

**Summary**

i. Experience with chronic illnesses. This hypothesis was supported. Of the respondents experienced with chronic illnesses, 60% were classified as shared or autonomous, as opposed to 50% of those with acute illnesses or recently diagnosed illnesses, a difference which was found to be statistically significant (chi-square test; p<0.008).

ii. Diagnoses of cancer. The diagnosis of cancer was not found to be a significant predictor for participation (using Chi-square test, p=0.218). People with diagnoses of cancer were more likely to be passive (57%) than those with less severe conditions (43% passive). One respondent wrote in the margin of the questionnaire that he felt that his illness (which involved a diagnosis of cancer) made him afraid to make his own treatment decisions. However, those respondents with diagnoses of cancer were almost as likely as those without diagnoses of cancer to be classified as shared or autonomous.

iii. Age and education. This hypothesis was supported. Patient category was strongly related to education (chi-square test; p <0.001), with 66.5% of respondents with a professional or graduate degree classified as autonomous. In contrast, no respondents with an elementary level of education were classified as autonomous. 48% of those who had some or had completed college or university were classified as shared. Patient category was also influenced by age (chi-square test; p <0.005). As age increased, so did the likelihood of being classified as passive. As age decreased, so did the likelihood of being classified as
shared. Age and classification into the autonomous category did not seem to follow a linear pattern, with the group of respondents between 55 and 64 containing the most respondents classified as autonomous.

Previous research  The literature had suggested that people with chronic illnesses are less likely to hand over control, partially due to the increased incentive to participate if one is living with an affliction for an extended period, and partially due to the increased opportunity for participation with more frequent physician encounters (Lidz, 1983). Previous studies had also suggested that those with diagnoses of cancer would be less inclined to participate (Cassileth, 1980). Several studies have suggested that age may be an important predictor of preferences for participation in decision-making (Cassileth et al 1988; Strull et al, 1984; Weeks, 1994). Ende et al. (1989) found that younger people were more inclined to participate, whereas older patients were less likely to make decisions or to desire to be informed. There have also been suggestions that better educated persons may prefer greater involvement in decision-making (Cassileth et al 1980; Strull et al 1984; Weeks 1994; Siminoff & Fetting, 1991; Wartman et al 1983).

Discussion  This hypothesis examined the effect of two of the characteristics of the respondents’ health condition (experience with chronic illness and diagnosis of cancer) and two of their personal characteristics (age and education) on their desire for participation. We were anticipating from the literature that all four of these associations would be strongly significant. Since the diagnosis of cancer was not found to be significant, we went beyond
our hypothesis to explore possible reasons for our results.

In revisiting the data for those with a diagnosis of cancer, we explored whether the pattern noted by one respondent of being too afraid of his cancer diagnosis to make his own treatment decisions would hold for other respondents with diagnoses of cancer. We found that the pattern did hold; respondents with diagnoses of cancer were less likely to indicate greater desire for participation for their own health condition than they had for the standardized vignette. For instance, in the case of passive respondents with a diagnosis of cancer, only 28.5% indicated a greater desire for participation for their current health condition than for the standardized vignette. Over 45% of respondents with a diagnosis other than cancer indicated a greater desire for participation for their current health condition than for the standardized vignette. This pattern was mirrored to a lesser extent for both shared and autonomous respondents.

Since the diagnosis of cancer evidently has some effect on desire for participation, its lack of significance could perhaps be partially explained by the higher levels of education among those with diagnoses of cancer in the prostate clinic. Since the prostate clinic was heavily skewed towards the highly educated, Caucasian, male respondent in a higher prestige occupation who is much more likely to be participative, the nature of the diagnosis of cancer may have been confounded as a predictive variable. This is supported by the political science literature, which suggests that those most likely to participate and desire political participation are educated Caucasian males in high prestige occupations (Barnes & Kaase,
1979). Results from the breast cancer clinic did show a more clear pattern of those with diagnoses of cancer being less inclined to participate, which was anticipated by the literature (Cassileth, 1980).

We additionally examined the effect of sex on desire for participation, and found it statistically significant in both univariate and multivariate analysis. In multivariate analysis it was shown to be much more weakly predictive (standardized coefficient= -0.148) than other variables, such as education level (standardized coefficient= 0.430).

**Significance**  One could surmise from these results that the characteristics of the individual (other than sex) are more highly predictive of their desire for participation than are characteristics of their disease. As pointed out in the political science literature, the salience of an issue is highly predictive of the desire to participate. Although fear of critical illness has been noted to increase desire to hand over control (Cassell, 1995), high levels of education and other personal characteristics leading to increased desire for participation may counteract the desire to hand over decisions to an expert.

**Hypothesis IV:** Trust will be correlated with the desire for participation, such that:

i) people with high levels of trust will hand over control of PS and DM to the provider;

ii) people with moderate levels of trust will hand over PS only; whereas

iii) people with low levels of trust will prefer to keep control of both PS and DM.
Summary This hypothesis was strongly supported by the results. The association of trust and patient category was highly significant (chi-square test; p <0.001). As trust increases, so does the likelihood that a respondent will be passive: in the lowest trust category only 27.1% were passive, whereas in the highest trust category all but one respondent were in the passive category. As hypothesised, respondents with moderate trust levels are more willing to keep control of decision making than those with higher trust levels. 66% of moderate respondents were in the shared category, with 5.5% being autonomous. Those with low trust levels were far more likely to be autonomous (13.6%) than any other trust group, keeping control of both DM and PS. Most respondents in the sample trusted their provider, with only 9.7% of the sample indicating low levels of trust.

Previous research The impact of trust on the roles recipients of care wish to play in making medical decisions has not previously been studied. This research is of particular interest because it begins to address this gap in the literature. Research on patient trust levels in their physicians has been noted to be sparse (Thom & Campbell, 1997) with the literature mostly focused on links between trust and satisfaction.

Discussion These results inform the debate over what roles are appropriate for patients to play in medical decision-making for a number of reasons. First, only 38 (6.3%) of 606 respondents exhibited blind trust. Even among this highly trusting group, there was still one respondent who wanted to share control of decision making. It is evident that trust is related
to, but should not be conflated with a desire for a passive approach to medical decisions. Second, most people have both a moderate or high level of trust, and a desire for shared decision-making. This supports the literature which suggests that a trusting relationship with the physician can be empowering—if the patient trusts that the physician is acting in their best interest, they not only feel satisfied in the medical encounter, but also gain the sense that the choices they make will influence what happens to them (Steinberg, 1990). Once again, the characteristics of the clinic may well have had an impact on this variable: respondents were all patients of clinicians who were comfortable with having their recipients be surveyed for their levels of trust in their provider.

**Significance** It has been suggested that trust is a barrier to the optimal relationship between provider and recipient, where the recipient is an informed consumer who defines his or her own needs and takes responsibility for their treatment decisions (Zola, 1990). These results would suggest that many recipients who have high levels of trust in their providers can concomitantly feel that a participative role is appropriate for them. Although trust has an impact on participation, it certainly cannot be said from these results that trust limits participation.

**Hypothesis V:** Trust will be correlated with preference of label: respondents who mistrust their providers will be less satisfied with the label ‘patient’ and will prefer labels with a more consumerist orientation.
**Summary**  This hypothesis was strongly supported by the data. Although few respondents had low trust levels, almost half of those who did were indifferent to or disliked the term ‘patient’. Respondents with low trust levels tended to like other labels, most notably that of ‘client.’ Interestingly, no respondent strongly liked the term ‘consumer’, though a sizeable proportion of people with low trust levels were either neutral towards or liked labels with consumerist overtones, such as ‘client’ or ‘customer’.

**Previous research**  We did not find any previous research which empirically examined associations between preferred label and levels of trust. There is some literature which suggests that consumerist labels do to some extent reflect that the recipient of care’s values and beliefs are not those of a trusting patient (Relman, 1994; Gray et al 1990).

**Discussion**  Interestingly, the term ‘partner’ was better liked by respondents than any other label other than ‘patient’, with 9.0% of the sample indicating that they liked or strongly liked the term. However, according to the literature, ‘partner’ should have appealed more to those with moderate levels of trust than to those with low levels of trust, which was not reflected in these results. A possible explanation might be that those respondents with low levels of trust would like to have a partnership with their physician, and are accordingly indicating that they like the label which reflects the ideal.

Another result which was not anticipated by the literature was the number of respondents who did not like labels which would seem to better evoke their desire for participation in
medical decisions than that of ‘patient’. Let us recall that most people (52%) were classified as being in the ‘shared’ patient category, and that most people (63%) indicated that the statement that best described their attitude towards medicine was “the doctor and patient should share control equally”. One would therefore expect that a similar proportion of respondents would indicate that they liked, or at least did not actively dislike a label such as ‘partner’, which would intuitively seem to better reflect a relationship where control was shared. Thom (1997) found that the perception of a partnership with the physician was an element of trust. This suggests a possible explanation for our results: if a perception of partnership is indeed an element of trust, it would make sense that a group of respondents who were quite trusting would concomitantly feel the desire to share control and participate in decision making. If these respondents feel that partnership is inherently part of a trusting relationship with their physician, than the label of ‘patient’ might seem more appropriate than a label which diverged from their sense of traditional norms.

**Significance** Our results would suggest that those with low trust levels are more likely to choose labels that reflect a relationship with the provider which is closer to that of a buyer, or where the physician’s role is more technical than one of trusted advisor. The ‘buyer beware’ overtones of the consumerist labels are a clear thread through these results: those who prefer this label are significantly more wary than those who do not. A very interesting issue for future research might be to qualitatively examine what drives a recipient of care to prefer one label over another.
Hypothesis VI: Respondents with a low level of trust in their physician will report a higher use of alternative therapies.

Summary This hypothesis was strongly supported by the data. The proportion of those using alternative therapies increases as trust decreases (chi-square test; p<0.001). Of the 38 respondents with blind trust, 1 had used an alternative therapy. Of respondents with high trust, 9.2% had used an alternative therapy. Of the moderate trust group, 29.9% had used alternative therapy. Of those in the lowest trust category, 50% had used an alternative therapy.

Previous research It has been argued that the growing popularity of alternative medicine is due to a lack of trust in traditional medical care (BMA, 1986). The AIDS literature is most explicit in suggesting that patients will turn to alternative therapies due to a lack of trust in organized medicine and in physicians (Pietroni, 1994) and also suggests that believing that doctors and orthodox medicine hold the answers can be an obstacle to the self-empowerment of people with HIV (Greenberg, 1993). However, as pointed out by Haug (1983), alternative medicine use is not an either-or option for many recipients of care, who use both alternative and mainstream practitioners in making treatment decisions. Associations between trust levels in respondents’ physicians and respondents’ use of alternative therapies have not been previously explored.

Discussion Our results suggest that lack of trust is linked to use of alternative therapies.
It should be noted that this research, which was carried out in hospital clinics where patients were being cared for by traditional providers, is unlikely to have captured people with very little trust in physicians. This will be further discussed in the section on limitations of this study. Although these results support the idea that lack of trust and alternative therapy use are linked, we have no way of interpreting what these results mean in terms of adherence to recommendations made by traditional providers, or in terms of how individual patients are using both alternative therapies and traditional medicine.

For future research, an interesting result which should be further explored with a larger sample size is the link between alternative therapy use and support groups. Although the numbers are too small to allow for significant analysis, in looking at the raw data it is evident that those who use support groups are also using alternative therapies. Of the 71 respondents indicating that they had used a support group, 56 (78.9%) were using alternative therapies. If we recall that the trust levels of those who used support groups were lower than those of the group as a whole, it suggests the question of whether the support groups themselves are having a deleterious effect on trust with the result of increased use of alternative therapies, or whether those with low trust levels who are already looking outside traditional medicine are more likely to also use support groups.

**Significance** Providers with patients who are also using alternative therapies may find it useful to note that alternative therapy use was significantly associated with a lack of trust in the physician for this study's respondents. Lack of trust has been linked to low satisfaction
with the physician-patient interaction (Anderson & Dedrick, 1990), reduced adherence to
treatment recommendations, and reduced patient involvement in their medical treatment
decisions (Donovan, 1995). Patients who are using alternative therapies might therefore need
interventions designed to increase involvement in traditional medical treatment programs,
such as a coaching intervention designed to improve provider-patient communication.
Successful interventions developed to increase patient involvement in care and active
involvement in decision making include standard educational sessions, help in reading their
own medical record, and coaching to ask questions and negotiate medical decisions
(Greenfield et al 1985; Roter, 1984).

Hypothesis VII: Respondents with breast or prostate cancer, especially those who are
involved in support groups, will be less likely to hand over control, less likely to have
high levels of trust, and more likely to prefer a label with a consumerist orientation.

Summary Parts of this hypothesis were strongly supported by the results. Respondents
who were involved in a support group were much more likely to desire shared decision-
making, much more likely to be in a low or moderate trust category, and more likely to prefer
a label other than 'patient' (chi-square test; p <0.001). However, as mentioned in the results
chapter, the prostate respondents were less likely to have used a support group than the
breast cancer or fracture populations. The results also showed that breast cancer respondents
who were not involved with support groups were less likely to want to take or share control
than fracture or prostate clinic respondents.
Previous research  Being a member of a group with a very well-known ailment, such as breast cancer, would correspondingly give one access to resources and information not as readily available to others (Cassileth, 1980). More information has been consistently related to increased desire for decision making, and an increase in patients’ perception of control over their illness. (Lerner et al. 1990; Brody, 1992). Support group users would also have access to an environment where their condition was of high salience; according to the political science literature, a highly salient issue leads to increased participation and desire for control (Sniderman, 1991). Since the literature on trust and preference of label is so limited, we could not find previous research on associations with these variables with support group use.

Discussion  Results showing a greater number of support group users in the fracture clinic than appeared in the prostate clinic prompted a review of the raw data entries for coding errors, since we did not expect to find support groups for fractures. It was found that support group users in the fracture clinic were in most cases those respondents with chronic illnesses such as *spina bifida*. *Spina bifida* support groups were considered to be highly politicized by the users approached by the researcher.

A possible explanation for why prostate clinic respondents may not have indicated high levels of support group use is the comparatively recent politicization of this disease: prostate support groups may not be as well established as breast cancer or other support groups. The numbers are far too small to make any determination of significance, but sex may be a
predictor of support group use. Of the 71 support group users, 54 were women. In the fracture clinic, whose population was almost evenly split between males and females, there were 18 support group users, of which 12 were female.

One explanation for the breast cancer respondents being less participative than other clinic respondents has already been posited: the higher level of diagnoses of cancer in this clinic without the confounding effect of the very high average education level that occurred in the prostate clinic may have shifted the respondents towards being less participative. The demographics of the breast cancer clinic in no way mirror those of people said to be most likely to participate by the political science literature (Barnes & Kaase, 1979)—rather than being highly educated Caucasian males with higher prestige jobs, this group was entirely female, with much lower education levels and lower status jobs. Almost one in four breast clinic respondents identified themselves as being of an ethnic background which is considered to be a visible minority (Asian, African, or Hispanic) which according to the political science literature is likely to coincide with reduced levels of participation (Sniderman, 1991).

**Significance** The results that support group use among the breast cancer population was associated with the same pattern of low trust, increased desire for control and participation, and increased likelihood of preferring a consumerist label that occurred in the other groups suggests that politicization of the disease insofar as it allows the individual access to a support group does have an impact. If the individual avails herself of the support group, the demographic differences between her and respondents from other clinics have a minimal
impact on her trust levels and desire for participation. Overall, it would appear that the mere availability of support groups has little impact, but the use of them certainly would seem to have a large effect.

LIMITATIONS:

There were four main limitations of this research. First, our respondents were not a random sample of the population, and their responses thus only represent the views of the subset of people who use the particular clinics where we conducted our survey. We could not capture individuals whose trust in physicians was so low that they would not be found in a hospital clinic where they would be cared for by a physician. It is evident that this limited our ability to discuss use of alternative therapies— the literature suggests that alternative therapy users have less trust in organized medicine, and may not use traditional clinics at all. Since our sites were not randomly chosen, the characteristics of the clinicians who agreed to have us survey their patients may have biased our results. These clinicians were comfortable with having their patients fill out questionnaires asking about patient trust in their physician and patient information seeking behaviour. It is possible that these clinicians were confident that their patients would be inclined to respond that they trusted their physician and were satisfied with the amount of information they were being given.

Second, this research was quantitative, which severely limited our ability to interpret our results. Much of the nuances may have been lost by not giving respondents the option to qualify their answers, or suggest avenues for exploration that were not tapped by the
questionnaire. The discussion of our hypotheses highlighted the need for qualitative research to further explore the results of this work. Using a single cross-sectional survey also limited our ability to impute longitudinal inferences from the data. Although a cross-sectional study was an appropriate tool to examine the hypotheses of this research, we recognize that it is likely that individuals captured by our survey were at different stages of an "illness trajectory" and hence may have been both at a different psychological stage (newly diagnosed disease, vs. well-managed disease, for example) as well as possibly being confronted with different decisions. It is thus possible that the responses of any given patient to the questionnaire items will change over time; without a time series element to the research design, we cannot make inferences about what the nature of those changes may be.

Third, several variables were potentially confounding; for instance, sex and clinic are confounded for two of the three sites: all respondents in the breast cancer clinic were female, and all respondents in the prostate centre were male. Thus, it was only in the fracture clinic, where recipients of care could be either male or female, that the effects of sex could be directly examined. Other issues (such as the relationship between education level and socio-economic status) have been previously discussed in the literature review. A table of correlations between selected variables appears in the methods chapter.

Finally, several items on the questionnaire proved to be problematic. The questions related to knowledge of the current health condition could not be directly compared with the questions related to familiarity with the clinical condition presented in the standardized mortality
vignette. We did not think it appropriate to ask respondents specific knowledge questions about a condition that they did not actually have, but the lack of ability to directly compare responses limited our ability to analyse and interpret our results. We additionally did not give respondents an option of writing in their own preferred label—several respondents wrote in the margin that their preferred label was “my name.” Several respondents also noted in the margins that the PSDM scale did not include an option where they could indicate that they felt people other than themselves or their physician should be participating in medical treatment decisions.

CONCLUSIONS:

The results of this research tell a fascinating, if exploratory, story about which respondents are more likely to want to participate and what characteristics these individuals are more likely to share. We have seen that trust is a very important element of the physician-patient relationship, and perhaps most importantly that most people in this study wanted to participate in decision-making for the illnesses that they were currently facing. How can these and our other results inform providers and recipients of care?

Models of the physician-patient relationship might benefit from this research. Our findings suggest that the traditional beneficience model, which relies on the physician's perception of the patient's preferences and values (Beauchamp and McCullough, 1984) might not be a good fit for most of our respondents, who clearly feel that they have the expertise when it comes to the decision-making dimension of medical treatment decisions. The autonomy
model which has been so dominant in medical ethics may be equally inappropriate; this theoretical framework has been hailed as the basis for a consumerist orientation which was met with singular distaste by the majority of our respondents. As Pellegrino and Thomasma have argued (1988), models which have patient autonomy as the overriding factor may reduce the role of the physician to that of a technician. The majority of our respondents would clearly prefer a partnership, or to allow the physician to take the lead: the minimal levels of trust that have been said to characterize the autonomy model were not present in this population.

Other arguments made against the autonomy model were supported by these results. The inequality between the provider and the recipient in terms of personal health, expertise, and information anticipate the result that most people would prefer to hand over decisions requiring technical and knowledge-based expertise, and would additionally prefer to hand over control when their illnesses are critical. Interestingly, the group least likely to wish to hand over control of their life-threatening illnesses was that comprised of highly educated males who were likely to be in high status professions. This lends support to the theory that correcting the imbalance between provider and recipient is necessary for implementation of the autonomy-based models (Wolfe, 1994). It is beyond the scope of this research to suggest that the autonomy based models are normatively inappropriate, but our results certainly anticipate difficulties in implementing autonomy models in populations that are not demographically very skewed towards a high socio-economic status.
The choice of a model for patient-physician interaction which is biased towards the highly educated Caucasian male to the extent that participation and desire for control are assumed rather than nurtured is not appropriate for most of the population in this study. Our results indicate that most respondents did not feel highly knowledgeable about their current health condition, and decidedly did not want to take control of the problem-solving dimension of medical decisions. The relatively high levels of trust in the physician and preference of the label ‘patient’ indicated by the majority of respondents also suggests that the autonomy model is not what these individuals would feel comfortable with. Emanuel and Emanuel’s “informative” model or Veatch’s “engineer” model would not reflect the needs of a population which has low information-seeking behaviour and a significant proportion of respondents who are facing life-threatening conditions. As anticipated from the medical literature (Kassirer, Ende) as severity of illness increases to include the possibility of death, patients are more likely to want to hand over the principal role in decision-making.

A move towards partnership models would appear to be supported by this research. Most respondents indicated that they felt the doctor should share control with the patient, and indicated that they wanted to take a role in decision-making. Several partnership models were discussed in the literature review, sharing the common characteristic of calling for a move away from the autonomy model, while preserving the patient’s right to self-determination as the basis for medical ethics. The results of this research appear to especially support the model proposed by Pellegrino (1990), who points out the deficiencies of the autonomy model, while suggesting that the physician should act to enhance and protect the
patient's capacity for self-determination. He writes:

The patient may on the moral strength of his/her own moral claim to autonomy yield up his/her claim to autonomy. Sometimes the physician has made a sincere effort to involve the competent patient yet the patient does not wish to participate as fully as others might. The patient might then ask that the physician should decide what is "best".

Pellegrino goes on to state that the physician has in these circumstances, and only in these circumstances a moral obligation to decide for the patient, acting in the patient's interests. Pellegrino holds that the morally optimal condition is where the decision arises between the provider and patient, where the provider is sensitive to his or her stewardship of the patient's trust. Such a model would appear to better meet the needs of this population, who largely indicate a desire to hand over problem solving, while sharing in the final decision about which treatment should be selected for their condition. Very few respondents (>7%) indicated blind trust in their provider, and a similarly low proportion indicated low trust or the desire to be autonomous. It would seem that the results support a trust based partnership model that recognizes the importance of trust in the patient-physician relationship, while keeping the right to self-determination as the *prima facie* element.
REFERENCES


Schuster Macmillan, 1240.


Coburn D. (1993) State authority, medical dominance, and trends in the regulation of the


APPENDIX 1: QUESTIONNAIRE AND SCALES

HEALTH CARE DECISIONS SURVEY

Today’s Date: ______/______/______  Clinic: ______

day  month  year

The purpose of this study is to look at the role patients wish to play in making decisions about their own medical treatment. There are no right or wrong answers. We are interested only in your opinion.

The survey should take less than 20 minutes to complete. All the information that you give us will be kept strictly confidential. This questionnaire will not be seen by your doctor or nurses, and all results will be reported in summary form only, so that there will be no way to identify you.

For most questions, simply answer by circling the number or letter that best indicates your answer or opinion.

Nothing is more important to this study than the confidence and cooperation of the respondents. May we ask you to take a few minutes now to complete and return the questionnaire. If it is more convenient, stamped envelopes are available for you to return the questionnaire at your leisure. You have the right to not respond to any individual question if you do not wish to. You also have the right to stop at any time.

Thank you for your participation in this study; your cooperation is greatly appreciated.

For more information, please contact:
Ann Pendleton (416) 978-8384

or any member of the study team:
At the University of Toronto:
Raisa B. Deber, PhD, Department of Health Administration
Donna Stewart, MD, Toronto Hospital
Natasha Sharpe, PhD candidate
Marta Meana, PhD

At McMaster Medical Centre
Andrea Baumann, PhD, Associate Dean, Faculty of Health Sciences (Nursing)
Sheryl Boblin-Cummings, PhD, Assistant Professor, Faculty of Health Sciences (Nursing)
1. On the line below, please write in the health condition for which you are seeking care at this visit (we will refer to this as "your current health condition"): ________________________________

2. How long have you known you had this condition? ____ years ____ months

3. Is this your first visit for this condition? ___ yes ___ no, but 1st visit to this clinic ___ no, repeat visit to this clinic

4. Please circle the number which best indicates how serious you think this condition is.

<table>
<thead>
<tr>
<th>Your current health condition is</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all serious</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very serious</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. Please circle the number which best indicates how knowledgable you feel about:

<table>
<thead>
<tr>
<th>Your current health condition</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The available treatment options</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The risks and benefits of these options</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Which treatment you prefer</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very knowledgable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Please circle the number which best describes how you feel about each of the following statements related to making decisions about your current health condition.

<table>
<thead>
<tr>
<th>Who should determine (diagnose) what the likely causes of your symptoms are?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who should determine what the treatment options are?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who should determine what the risks and benefits for each treatment option are?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who should determine how likely each of these risks and benefits are to happen?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doctor alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>doctor and you equally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mostly you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7. Now please circle the number which best indicates how you would feel about each statement if you actually had the medical condition which is described in the scenario below.

_Suppose you had mild chest pains for three days and decided that you should visit your doctor about this._ (Circle one number for each question.)

<table>
<thead>
<tr>
<th>Question</th>
<th>doctor alone</th>
<th>mostly the doctor</th>
<th>equally</th>
<th>mostly you</th>
<th>you alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who should determine (diagnose) what the likely causes of your symptoms are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine what the treatment options are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine what the risks and benefits for each treatment option are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine how likely each of these risks and benefits are to happen?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

8. 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.

9. There are a number of terms which people may use to refer to people who receive medical care. For each, please circle the number which best indicates your view about being referred to in this way.

<table>
<thead>
<tr>
<th>Term</th>
<th>Strongly Dislike</th>
<th>Moderately Dislike</th>
<th>Neither like nor dislike</th>
<th>Moderately Like</th>
<th>Strongly Like</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Client</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Consumer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Survivor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Customer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
10. Please circle the number which best expresses your opinion about each of the following statements.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My doctor is usually considerate of my needs and puts them first.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I doubt that my doctor really cares about me as a person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I trust my doctor so much I always try to follow his/her advice.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>If my doctor tells me something is so, then it must be true.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I sometimes distrust my doctor's opinion, and would like a second one.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I trust my doctor's judgments about my medical care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I feel my doctor does not do everything he/she should for my medical care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I trust my doctor to put my medical needs above all other considerations when treating my medical problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My doctor is a real expert in taking care of medical problems like mine.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I trust my doctor to tell me if a mistake was made about my treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I sometimes worry that my doctor may not keep the information we discuss totally private.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I got as much information as I wanted about my condition.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The medical profession has too much power.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>If you follow a physician's advice, you will have less illness in your lifetime.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

11. Please circle the letter which best describes your own attitude towards medical care.
   a. The patient should take complete control.
   b. The patient should have more control than the doctor.
   c. The patient and doctor should share the control equally.
   d. The doctor should have more control than the patient.
   e. The doctor should take complete control.
   f. Other, (please specify): _________________________________
12. Please read each statement and decide whether you AGREE or DISAGREE with it.
(Please circle either Agree or Disagree for each statement)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually don’t ask the doctor or nurse many questions about what they are doing during a medical exam.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Except for serious illness, it’s generally better to take care of your own health than to seek professional help.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>I’d rather have doctors and nurses make the decisions about what’s best than for them to give me a whole lot of choices.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>It is better to rely on the judgements of doctors (who are the experts) than to rely on &quot;common sense&quot; in taking care of your own body.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>Clinics and hospitals are good places to go for help since it’s best for medical experts to take responsibility for health care.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>Learning how to cure some of your own illness without contacting a physician is a good idea.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>I usually ask the doctor or nurse lots of questions about the procedures during a medical exam.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>It’s almost always better to seek professional help than to try to treat yourself.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>Learning how to cure some of your illness without contacting a physician may create more harm than good.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>If it costs the same, I’d rather have a doctor or nurse give me treatments than to do the same treatments myself.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>I’d rather be given many choices about what’s best for my health than to have the doctor make the decisions for me.</td>
<td>A</td>
<td>D</td>
</tr>
</tbody>
</table>
Finally, we would like to ask you some questions about your background.

13. Sex:  
   a. Male  
   b. Female

14. Year of birth: ____

15. What is your ethnic background? ______________________________

16. What is your current marital status? (Circle one letter)  
   a. Never married  
   b. Married or common-law relationship
   c. Separated
   d. Divorced
   e. Widowed

17. What is the highest level of education you have received? (Circle one letter)  
   a. Some elementary school (up to grade 8)  
   b. Completed elementary school
   c. Some high school
   d. Completed high school
   e. Some post-high school (university/college/trade school)
   f. Completed university/college
   g. Some professional or graduate school
   h. Completed professional or graduate school

18. What is your employment status at present? (Circle one letter)  
   a. Employed full-time (30 hours or more per week)  
   b. Employed part-time
   c. Not employed
   d. Retired
   e. Homemaker
   f. Other, (please specify): ______________________________

19. We are interested in your use of health care services, other than the clinic you are now attending. For each possible source of care listed, please check the one box which will tell us whether you have used that type of service for any condition (not just your current health problem), and if you have, how valuable you have found it. (For example, if you have gone to your family doctor and found him or her somewhat valuable, please check that box.)

<table>
<thead>
<tr>
<th>Type of provider</th>
<th>Did not use</th>
<th>Used, and found</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Not at all valuable</td>
</tr>
<tr>
<td>Your family doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other specialist doctor(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital (inpatient)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support group (specify ____________________________)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative medicine provider (specify ________)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative medicine provider (specify ________)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
20. Overall, how would you rate your health now? (Circle one number)

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

21. Are you a health care professional?  ____ No  ____ Yes (specify) ________________

22. We would be interested in any additional thoughts you have about participation in making medical decisions or the subjects in this questionnaire.

---

This is the end of the questionnaire. Thank you very much for your participation. We would be happy to share a summary of the results once the study is complete. If you would like to receive a copy, please fill in your name and address on the attached page and return it with your questionnaire to the research coordinator.
### Items and Statistics for the Krantz Health Opinion Survey

<table>
<thead>
<tr>
<th>Information Subscale</th>
<th>Item correlations (total)</th>
<th>Item correlations (subscale)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually don’t ask the doctor or nurse many questions about what they are doing during a medical exam. (1)*</td>
<td>.46</td>
<td>.59</td>
</tr>
<tr>
<td>I’d rather have doctors and nurses make the decisions about what’s best than for them to give me a whole lot of choices. (3)*</td>
<td>.36</td>
<td>.36</td>
</tr>
<tr>
<td>Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health. (4)</td>
<td>.30</td>
<td>.48</td>
</tr>
<tr>
<td>I usually ask the doctor or nurse lots of questions about the procedures during a medical exam. (8)</td>
<td>.47</td>
<td>.59</td>
</tr>
<tr>
<td>It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing. (10)*</td>
<td>.35</td>
<td>.36</td>
</tr>
<tr>
<td>I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately. (15)*</td>
<td>.35</td>
<td>.58</td>
</tr>
<tr>
<td>I’d rather be given many choices about what’s best for my health than to have the doctor make the decisions for me. (16)</td>
<td>.35</td>
<td>.37</td>
</tr>
</tbody>
</table>

### Behavioural Involvement Subscale

<table>
<thead>
<tr>
<th>Behavioural Involvement Subscale</th>
<th>Item correlations (total)</th>
<th>Item correlations (subscale)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Except for serious illness, it’s generally better to take care of your own health than to seek professional help. (2)</td>
<td>.16</td>
<td>.24</td>
</tr>
<tr>
<td>It is better to rely on the judgements of doctors (who are the experts) than to rely on “common sense” in taking care of your own body. (5)*</td>
<td>.44</td>
<td>.49</td>
</tr>
<tr>
<td>Clinics and hospitals are good places to go for help since it’s best for medical experts to take responsibility for health care. (6)*</td>
<td>.36</td>
<td>.36</td>
</tr>
<tr>
<td>Learning how to cure some of your own illness without contacting a physician is a good idea. (7)</td>
<td>.23</td>
<td>.32</td>
</tr>
<tr>
<td>It’s almost always better to seek professional help than to try to treat yourself. (9)*</td>
<td>.42</td>
<td>.50</td>
</tr>
<tr>
<td>Learning how to cure some of your own illness without contacting a physician may create more harm than good. (11)*</td>
<td>.38</td>
<td>.45</td>
</tr>
<tr>
<td>Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves. (12)*</td>
<td>.42</td>
<td>.49</td>
</tr>
</tbody>
</table>
If it costs the same, I’d rather have a doctor or nurse give me treatments than to do the same treatments myself. (13)*

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Item to total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is better to rely less on physicians and more on your own common sense when it comes to caring for your body. (14)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Correlations are point biserial item-remainder correlations based on 200 cases. These correlations are all positive because scoring is reversed for negatively worded items, which are denoted by asterixes. Numbers in parentheses indicate the sequence of items on the scale.

* Negatively worded item.

(Krantz, Baum & Wideman, 1980, p. 980)

THE TRUST IN PHYSICIAN SCALE

Items and Statistics for the Trust in Physician Scale.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Item to total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>My doctor is usually considerate of my needs and puts them first.</td>
<td>4.76</td>
<td>.54</td>
<td>.57</td>
</tr>
<tr>
<td>I doubt that my doctor really cares about me as a person.*</td>
<td>4.84</td>
<td>.44</td>
<td>.51</td>
</tr>
<tr>
<td>I trust my doctor so much I always try to follow his/her advice.</td>
<td>4.77</td>
<td>.50</td>
<td>.56</td>
</tr>
<tr>
<td>If my doctor tells me something is so, then it must be true.</td>
<td>4.48</td>
<td>.89</td>
<td>.56</td>
</tr>
<tr>
<td>I sometimes distrust my doctor's opinion, and would like a second one.*</td>
<td>4.51</td>
<td>.69</td>
<td>.66</td>
</tr>
<tr>
<td>I trust my doctor's judgments about my medical care.</td>
<td>4.79</td>
<td>.64</td>
<td>.52</td>
</tr>
<tr>
<td>I feel my doctor does not do everything he/she should for my medical care.*</td>
<td>4.42</td>
<td>1.03</td>
<td>.52</td>
</tr>
<tr>
<td>I trust my doctor to put my medical needs above all other considerations when treating my medical problems.</td>
<td>4.77</td>
<td>.57</td>
<td>.41</td>
</tr>
<tr>
<td>My doctor is a real expert in taking care of medical problems like mine.</td>
<td>4.68</td>
<td>.71</td>
<td>.72</td>
</tr>
<tr>
<td>I trust my doctor to tell me if a mistake was made about my treatment.</td>
<td>4.63</td>
<td>.81</td>
<td>.53</td>
</tr>
<tr>
<td>I sometimes worry that my doctor may not keep the information we discuss totally private.*</td>
<td>4.67</td>
<td>.60</td>
<td>.61</td>
</tr>
</tbody>
</table>

Note: Means and standard deviation are from Study 2. An asterix denotes a negatively worded item.

**THE PROBLEM SOLVING DECISION MAKING SCALE: “Mortality” Vignette**

Please circle the number which best indicates how you would feel about each statement if you actually had the medical condition which is described in the scenario below.

*Suppose you had mild chest pains for three days and decided that you should visit your doctor about this. (Circle one number for each question.)*

<table>
<thead>
<tr>
<th>Question</th>
<th>doctor alone</th>
<th>mostly the doctor</th>
<th>equally</th>
<th>mostly you</th>
<th>you alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who should determine (diagnose) what the likely causes of your symptoms are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine what the treatment options are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine what the risks and benefits for each treatment option are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Who should determine how likely each of these risks and benefits are to happen?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

(Deber, Kraetschmer & Irvine, 1996, p.1417.)