MEDICATION ADHERENCE AMONG ADULT ASTHMA PATIENTS:

INVESTIGATING THE ROLE FOR SHARED DECISION-MAKING

by

Samantha Pollard

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Abstract

Background: Shared decision-making (SDM) has been suggested as a means to improve communication between patients and their healthcare providers, with the purposes of improving multiple asthma-related health outcomes. Despite mounting evidence that suggests potential benefits attributable to SDM, clinical uptake has been slow.

Objectives: The purpose of this dissertation is to ascertain the role of SDM in asthma management, to determine the extent to which SDM is currently being implemented into regular asthma care, and to suggest clinical implementation strategies that may facilitate SDM implementation in BC.

Methods: This project consists of a) a systematic review of physician attitudes toward SDM, b) a comprehensive narrative literature review to describe the proposed role of SDM in asthma, c) a population level analysis to explore variation in adherence to controller medication, as well as d) an online survey of 117 adult asthma patients living in BC.

Results: Results of this work show that in general a) physicians support the use of SDM in various clinical practice scenarios, b) there is a clear role for SDM in treating asthma patients with the goal of reducing the burden of controller medication non-adherence, and c) adherence to controller medications is sub-optimal, with little variation being explained at the population level. The patient survey (d) provided

additional insight into this research agenda by showing that while patients prefer to be actively involved in treatment decision-making, there is substantial variation in the extent to which asthma patients are being engaged in their care. Furthermore, multiple predictors of adherence that can be addressed during the clinical encounter (e.g. medication-related concerns) were shown to impact self-reported treatment adherence.

Conclusions: The results of this project provide further support for the use of SDM in regular care of asthma patients. I conclude by highlighting the importance of addressing issues related to adherence in an individual and ongoing basis, the value of increasing awareness about the use of SDM, and the potentially valuable role of engaging non-physician caregivers in future SDM implementation efforts. These findings may guide future research investigations regarding SDM uptake and efforts to reduce the disease burden of asthma.

Lay summary

Background: Asthma is a common chronic disease that affects 21 million North Americans. When asthma patients with moderate to severe asthma do not take their medication regularly, the risk of poor health outcomes increases. Engaging patients in decisions about their medication through shared decision-making (SDM) may encourage patients to follow their medication plan.

Objectives: To determine the potential role for SDM in asthma.

Methods: This thesis consists of two literature reviews, an analysis of pharmacy records, and an online survey of adult asthma patients in BC.

Results: Both doctors and asthma patients support SDM, but there is no common way to involve asthma patients in their care. Survey results show that more communication between doctors and their patients may support patients to follow their treatment plan.

Conclusions: Results of this project provide support for the use of SDM in clinical care of asthma patients, and suggest recommendations for implementation plans.

Preface

Chapters 1 and 7 are based on work conducted at The Centre of Clinical Epidemiology and Evaluation. I was responsible for writing the chapters.

Chapter 2 is based on the work conducted at The Centre of Clinical Epidemiology and Evaluation. I was responsible for identifying the research question, developing and piloting the search strategy, running the search, analysis, and drafting of the manuscript. Stirling Bryan (SB) and Nick Bansback (NB) were involved in the title/abstract and full text review phase, as well as synthesizing the results. A version of chapter 2 is published in Patient Education and Counseling.(1)

Chapter 3 is based on work conducted at The Centre of Clinical Epidemiology and Evaluation. I developed the research questions and drafted the chapter. SB, NB and J Mark Fitzgerald reviewed and provided initial comments for revision of each draft of the manuscript. A version of chapter 3 is published in Allergy.(2)

Chapter 4 is based on the work conducted at the Centre for Outcomes Research and Evaluation. I developed the research question, wrote and ran all analytic SAS code, interpreted the results and drafted the chapter. The data table used for analysis was built by Dr. Zafar Zafari and Dr. Wenjia Chen. University of BC Human Ethics Certificate: H08-01287.

All research was conducted at The Centre of Clinical Epidemiology and Evaluation and VGH's Gordon and Leslie Diamond Healthcare Centre. I developed the study documents. I wrote all R code and conducted all of the data analysis. Statistical consultation was provided by Dr. Penny Brasher and Shannon Erdelyi. Ethical approval for chapters 5 and 6 were provided by The University of British Columbia Clinical Research Ethics Board and Vancouver Coastal Health Research Institute Ethics Board: H10-01542.

Table of contents

List of tables

List of figures

List of abbreviations

AAAQ: Adult Asthma Adherence Questionnaire

ACT: asthma control test

AOR: Adjusted odds ratio

BC: British Columbia

CCI: Charleston comorbidity index

CDM: Clinical decision making

CoC: Continuity of Care

COPD: Chronic obstructive pulmonary disease

DM: decision-making

FDA: Food and Drug Administration

GP: general practitioner

ICS: inhaled corticosteroid

KT: Knowledge translation

LABA: long acting beta agonists

LTRA: Leukotriene receptor antagonist

MI: multiple imputation

MPR: medication possession ratio

NS: non-significant

OR: Odds ratio

PCC: patient-centered care

PDA: Patient decision aid

PDC: proportion of days covered

PS: Problem solving

PSDM: Problem solving decision-making (scale)

RCT: randomized controlled trial

SDM: shared decision making

SE: standard error

SES: socio-economic status

SNS: Subjective numeracy scale

SP: specialist

95% CI: 95% confidence interval

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Roxanne Rousseau, Dr. Nitya Suparakash, Suzanne Richardson, Pia Ganz, Dr. Penny Brasher and Shannon Erdelyi for their assistance with chapters 5 and 6.

Dedication

For my mother and my husband. Thank you for your endless support and encouragement.

Chapter 1: Introduction

1.1 Introduction

Support for the prevailing model of the clinical encounter is experiencing a shift from paternalism – wherein physicians play an authoritative role in the clinical encounter - to a patient-centered care (PCC) model where patients play an active role in the decision-making processes. Multiple healthcare systems have reported support for more active involvement of patients in the care process.(3–5) The Institute of Medicine defines PCC as "providing care that is respectful of, and responsive to, individual patient preference, needs, and values, and ensuring that patient values guide all clinical decisions"[(4) p. 3]. While first calling for increased communication and partnership between patients and their physicians, PCC recognizes the value of incorporating what matters most to patients, in making decisions about their care.(6)

1.1.2 What is shared decision-making?

One process for implementing a component of PCC is shared decision-making (SDM). Shared decision-making requires the active participation of both patients and their physicians at multiple stages of the healthcare encounter. Specifically, patients and physicians must acknowledge that there is a decision to be made, exchange information, weigh the risks and benefits of treatment options, and agree on the final treatment decision.(7,8) While physicians bring expert content

knowledge to the encounter, patients bring information about their personal values and preferences. What a patient views as important in determining the best treatment option may differ from what the physician assumes is important to the patient.(9) When both parties are able to communicate about these issues, patients and their physicians can then discuss various treatment options in light of the accompanying risks and benefits.

The concept of SDM was formally introduced by Charles et al. in 1997 and again in 1999.(7,10) However, throughout the 1980s and early 1990's, the value of engaging the individual patient in decisions about his or her healthcare was increasingly acknowledged.(11,12)

Shared decision-making frequently garners support in "preference-sensitive" clinical scenarios where multiple acceptable treatment options exist, and professional opinion may vary with regard to the optimal choice.(13,14)As such, the patient's personal values and preferences play an important role in determining the treatment plan.(8)Decision topics may include but are not limited to advance care planning for dementia patients,(15) delayed versus immediate breast reconstruction following mastectomy,(16) controller treatment options for patients with moderate to severe asthma,(17) prostate cancer screening,(18) breast conserving surgery versus mastectomy,(19) mental health,(20) as well as the decision to prescribe antibiotics for acute respiratory infection.(21)

Current evidence links SDM and decision support techniques with broadly positive patient-reported outcomes such as increased satisfaction, knowledge and trust in healthcare providers, and decreased decisional conflict. (17,22–26)

Although high-quality evidence suggests that SDM may improve various outcomes, clinical uptake has been sparse.(27) Furthermore, additional research is required to determine which SDM interventions are the most highly effective and in which settings.(8)

1.1.3 Rationale for the current research

With increased attention being paid to patient engagement in healthcare, but a corresponding lack of implementation into clinical practice, further attention is required to recommend strategies to promote clinical uptake. Here I seek to determine the state of SDM within asthma care and to determine potential avenues for future implementation efforts, specifically focused on reducing the burden of asthma through a reduction in treatment non-adherence.

The primary research questions answered by this thesis are informed by comprehensive reviews of the literature that appear in chapters 2 and 3. These background chapters ascertain the extent to which physicians support the use of SDM, determine what clinical scenarios garner the most support for SDM by physicians, and finally illustrate the proposed role for SDM in asthma management.

The following will briefly describe the methods and results of chapters 2 and 3, and to describe how those chapters inform the work reported in chapters 4 to 6.

1.1.3.1 Identifying variation in support for SDM

Physician support is a necessary requirement for the successful implementation of SDM; however, uncertainty exists as to the extent to which physicians endorse the use of SDM in their current practices and the variability of such support. Furthermore, several barriers have been suggested to explain why SDM uptake has been so sparse. Barriers include but are not limited to concerns about the length of time required for an SDM encounter, physicians' perceptions of appropriateness given patient characteristics, and the clinical context.(27) Chapter 2 consists of a systematic review that provides comprehensive groundwork for this research program, by exploring the extent to which physicians support the use of SDM.

The results of the systematic review (chapter 2) show that physicians most frequently support SDM in "preference-sensitive" scenarios such as chronic disease management, and where patients are both willing and able to participate in the decision-making process. Lack of support is identified when clinical practice guidelines clearly recommended a specific treatment option, and when the patient is deemed to be unable or unwilling to engage in the decision-making process, although considerable variation was found across clinical scenarios, physician specialties, and patient characteristics.

1.1.3.2 Establishing the role for SDM in asthma

As further background review, chapter 3 provides a description of the burden of asthma and the proposed role of SDM in reducing some of the negative health outcomes associated with asthma controller non-adherence. I propose an adapted theoretical framework that illustrates the pathways that link SDM with intentional and non-intentional asthma treatment non-adherence.(28) The framework describes various predisposing factors related to adherence motivation, as well as the modifiable and non-modifiable factors that both prevent or promote a given patient from adhering to his or her treatment plan. The framework recognizes that SDM functions within a much larger set of predisposing and motivating factors that impact adherence, while acknowledging that individual and structural barriers can impede an individual's ability to adhere, despite personal motivation to adhere.

1.1.3.3 Asthma as an appropriate clinical context for this research

Following the results of the systematic review (chapter 2) as well as the review on the nature of asthma management (chapter 3), asthma was selected as a case study for this thesis, for multiple reasons.

First, asthma is a preference-sensitive clinical scenario where several treatment options are available to patients with varying modes of administration, dosage, and

risks of adverse events, making asthma an ideal clinical context within which to explore a role for SDM.

Second, adherence to asthma medication is poor and linked to multiple health outcomes such as exacerbations, decreased quality of life, and in some cases death. Therefore, measureable outcomes exist wherein the impact of SDM can be investigated. A number of previous and ongoing investigations have addressed patient-reported and clinical outcomes associated with decision aids and SDM interventions, specifically within the context of asthma.(17,29–31)

Third, evidence suggests the presence of inaccurate disease and medication-related beliefs, decisional-conflict, and concerns that are inconsistent with those of their physicians, among asthma patients.(9,32–34) This suggests the need for increased communication between patients and physicians to reduce the misdiagnosis of patient preferences.(9) Therefore, there is a clear role for increased communication and exchange on information between patients and their physicians.

Finally, given the preference-sensitive nature of asthma management, asthma is a clinical scenario wherein physicians are likely to support the implementation of SDM (chapter 2). Therefore, asthma is a prime clinical context to explore the current state of SDM. Moreover, if we see limited adoption of SDM in a clinical context such

as asthma, it is unlikely that SDM or components of SDM are being utilized in other clinical contexts where there is likely less support from physicians.

1.2 Research objectives

The overarching objectives for this dissertation are:

1. To describe the extent to which physicians support the implementation of SDM, and in which specific clinical contexts (chapter 2);
2. To identify the role for SDM within the context of asthma (chapters 3 and 4);
3. To determine the extent to which asthma patients desire to participate in their decision making (chapters 5 and 6);
4. To explore the extent to which SDM and specific components of SDM are currently being implemented in asthma clinical care in BC, and the characteristics of those patients who are more likely to report being engaged (chapters 5 and 6)
5. To determine whether current self-reported adherence may be associated with perceived previous exposure to SDM (chapters 5 and 6)

1.3 Research methods and results

Chapter 4 explores factors associated with adherence among adult patients with asthma in BC. The objective of this cross-sectional analysis is to estimate the burden of non-adherence among adult asthmatics being prescribed controller medication, and to determine the extent to which (administratively collected) patient-level

factors can account for variation in treatment adherence. For this analysis, adherence is defined as the amount of controller medication prescriptions filled over a 12-month period. The results provide further evidence to support the argument that adherence is a complex phenomenon and that very little variation can be explained simply by looking at individual demographic variables using administratively collected data. To provide a more comprehensive explanation of variation in adherence, future research should look closely at additional predictors of non-adherence including but not limited to asthma-related education as well as the patient-physician relationship.

Chapter 5 describes the development and administration of an online survey to a convenience sample from within a previously existing cohort of adult asthma patients. Specifically, the survey work sought answers to the following five research questions:

- What role do asthma patients prefer to take in the decision-making process? (Thesis Research question 3)
- What factors related to patient-physician communication and education explain adherence? (Thesis Research question 5)
- To what extent do asthma patients recall previous exposure to SDM? (Thesis research question 4)
- Is patient-reported engagement in SDM associated with adherence to controller medication? (Thesis Research question 5)

- Is there an association between preferences for decision-making and perceived exposure to SDM?

I first describe the development and recruitment methods used for the online survey of adult asthma patients (chapter 5). Chapter 6 then describes the analyses conducted to address the 5 research questions listed above. Results of the survey (chapter 6) show that patients report a general preference for being involved in most aspects of their treatment decision-making process. Consistent with some existing evidence, younger patients and those with higher income are more likely to prefer an active role in the decision making process (35)

A substantial amount of variation exists in terms of the extent to which participants perceive being involved in the decision-making process. Results of the multivariate model show that participants with previous exposure to an asthma educator are more likely to report being adherent to their controller medication. Conversely, participants who believe that their asthma does not warrant controller medication, and those who are concerned about the side effects of their medication, are more likely to report non-adherence to their current controller medication (research question.

Chapter 7 discusses the strengths and weaknesses of the thesis, and outlines potential clinical implications of my work, and proposes next steps for furthering

this research agenda. The principal clinical implications from my research are summarized below.

1.3.1 Clinical implications

I propose three clinical implications to inform care delivery and research, with the overarching objective of reducing the burden of asthma in British Columbia.

Efforts to increase adherence among asthma patients are likely to benefit from individualized and ongoing discussions, through the use of SDM interventions

The results of chapters 4 and 6 show the difficulty in capturing a complete picture of determinants of medication adherence. More specifically, no clear subset of predictors is shown to have a strong effect on variation in adherence. These results suggest not that it is a frivolous effort to try to explain and predict adherence, but rather that efforts geared toward improving adherence ought to be considered at the individual level. Therefore, healthcare providers treating asthma patients are encouraged to discuss on an individual and ongoing basis their patients' rationales for adherence and non-adherence.

The use of both physician and non-physician care givers in ascertaining patients' disease and medication-related inaccurate beliefs or concerns may help to increase treatment adherence

Results of the survey presented in chapter 6 show that numerous aspects of clinical care, such as asthma education and knowledge about medication, do explain some variation in adherence. In addition, potentially inaccurate beliefs about asthma and medication-related concerns are both common, and are shown to reduce the odds of adherence. Furthermore, results show that efforts to increase adherence may benefit from engaging non-physician caregivers such as asthma educators.

Awareness of the potential benefits associated with SDM may help to increase SDM uptake and improve health outcomes

Results of chapters 2 and 6 raise the concern that that some patients may be systematically excluded from the decision-making process. This may include patients who indicate a preference for a passive approach, or those who are perceived to be less able or willing to engage. The preliminary results of this work show that various aspects of patient engagement can improve overall patient adherence and outcomes, and so, from an equity standpoint, it is possible that sub-populations of patients are not reaping the benefits offered by SDM.

1.4 Conclusions

I have sought to understand and explore the current state of SDM within the context of asthma, and to suggest specific opportunities for improvement. This is a timely and important field of research because, while the support for SDM is increasing and

the evidence base pointing to the benefits of SDM is growing, clinical implementation efforts have been slow.(8,36) The results of this work will guide strategies to improve patient-physician communication and the uptake of existing interventions to facilitate SDM, with the goal of improved patient outcomes. Furthermore, the results can be used to inform future research investigations, especially those targeting improved medication adherence among chronic disease patient populations.

Chapter 2: Physician attitudes toward shared decision-making: a systematic review

2.1 Introduction

Over the past 2 decades, there has been a shift in support, away from a paternalistic model of clinical decision-making, towards an approach wherein the patient takes on a more central role, and decisions are reached in partnership between the patient and the physician.(10) I have adopted the definition of SDM put forth by Charles et al. wherein a truly shared approach requires that both the physician and patient be involved in the information exchange and decision-making process; both the physician and the patient express treatment preferences; and finally, the physician and patient agree on treatment decision.(7,10) Charles and colleagues initially focused their conception of SDM specifically on treatment decisions, but it has been broadened to include a range of health care decisions such as disease management and screening.

Improvements in access to health information and treatment options have facilitated a more active partnership between patients and physicians. Decision-making has also become more complex, with a variety of treatments available that carry different risk profiles as well as uncertainties related to outcomes, adverse events and quality of life.(37) In the presence of uncertainty regarding the optimal treatment option, the involvement of patients in their healthcare and treatment

decision-making becomes important.(38) Related to this is the opinion that SDM may be most appropriate or garner the highest levels of support in scenarios where clinical equipoise is present.(39,40)

SDM has been placed at the forefront of much public and academic discussion in recent years, and efforts have been made to promote patient/physician communication within the clinical and policy sphere.(41,42) Although support for a shared approach has become popular in the academic and policy literature and has been present in that literature since the 1990s, such a shift to a more patient-centered approach, in the clinical arena, has been slow to develop. Shared decision-making within the context of clinical practice has been minimal.(8,43) Previous research suggests that lack of implementation may be due to barriers such as the perceived time required to incorporate patients into the decision-making process, physicians' perceptions that the specific clinical scenario is inappropriate for SDM, or physicians' perceptions that the patient may be unwilling or unable to participate in the process.(8)

Proponents of SDM argue that the more a patient is involved in the treatment decision at hand, the more likely it is that the decision will be consistent with his or her own personal preferences.(44) Particularly for treatment scenarios where there is no "correct" answer or best treatment option, the most appropriate choice would be one that is consistent with the patient's lifestyle, living situation, goals and

personal preferences. Previous research has shown that patients in general wish to participate in the decision-making process and, that doing so may increase their satisfaction with care and treatment decisions (45–48). Furthermore, SDM may reduce healthcare utilization and costs, improve treatment adherence, patient function, as well as improving additional clinical outcomes.(25)

Attempts to determine physicians' attitudes toward SDM has focused on healthcare professionals' perceived barriers and facilitators to incorporating SDM into their practice.(27) Physician reported barriers include but are not limited to insufficient time, perceptions that the patient may be unable or unwilling to participate, and doubts about the appropriateness of SDM in some decision context. Frequently cited facilitators include physicians' perception that the patient has adequate emotional support; the perception that SDM will lead to better patient outcomes, patient knowledge, trust in their physician, as well as physician willingness to participate in the decision-making process.

Since the implementation and the success of SDM are largely dependent on active engagement of the treating physician (and care team),(49) it is important to determine the overall level of support for SDM that exists among physicians. Specifically, the purpose of this review is to determine to what extent physicians currently support the implementation of SDM to routine practice, to identify clinical scenarios that garner the highest levels of physician support and to gain insight into

the rationale behind those attitudes. Since opinions and attitudes can be elicited via both quantitative (e.g. surveys) and qualitative means (e.g. interviews and focus groups), both research approaches are included in this review. The results of this review provide evidence to explain why physicians tend to hold certain views toward SDM, and why resistance to SDM in certain care scenarios may exist. This work represents the first systematic review of the literature on this topic.

2.2 Methods

2.2.1 Search strategy development

I developed the search strategy, in consultation with a research librarian (see appendix A). The complete search was initially developed in Medline and then adapted to each subsequent database. I executed the searches between December 19th and 23rd, 2014. The following databases were searched from 2007 to current: Medline, Embase, CINAHL, Cochrane database of randomized controlled trials, and PsychInfo. Although SDM has appeared in the literature for several years prior to 2007, the objective of this review was to ascertain current levels of support for SDM, rather than to track the evolution of attitudes toward SDM. Following the search of electronic databases and article selection, references of included studies were also reviewed. This review was limited to published and peer-reviewed literature. Publication bias was not formally assessed.

2.2.2 Selection criteria

Studies that involved primary data collection were included in this review if they reported physicians' attitudes or opinions toward SDM in a qualitative or quantitative manner and were published in English between 2007 and 2014.

My definition of "physician" excluded practitioners of other health professions or alternative medicine techniques. Studies that primarily examined physicians' attitudes toward patient decision aids or methods used to implement SDM were also excluded. Review papers were excluded; however, reference lists of all review papers that reported physicians' attitudes toward SDM were scanned to ensure that all potentially eligible papers had been captured.

2.2.3 Research objectives

Primary objectives of the review were to identify:

1. Physician attitudes toward including patients in clinical decision-making (research objective 1)
2. Physician-reported factors that are associated with support or lack of support for SDM (research objective 2)

As there is no single definition used in the literature for SDM, I included all studies that discuss active involvement of patients in the clinical decision-making process.

2.2.4 Article selection

Article selection was conducted in two phases: 1) the title and abstract review phase, and 2) the full text review phase. If a paper met inclusion criteria in phase 1), the full paper was retrieved and reviewed for potential inclusion. Extensive agreement testing at the abstract review phase was conducted. I, along with either NB or SB reviewed approximately 100 identical abstracts, and then met to discuss and resolve discrepancies. This process continued until both reviewers were comfortable with their level of agreement and interpretation of the selection criteria. Two reviewers (either SP and NB, or SP and SB) conducted title and abstract selection independently and in duplicate. In the case of disagreements that could not be resolved, a third reviewer (either SB or NB) was consulted and acted as a "tie-breaker." To assess inter-rater agreement at the full-test review phase, Cohen's kappa was calculated. This statistic was chosen because it is used to quantify agreement for nominal data.(50)

2.2.5 Data abstraction

A data abstraction form was developed specifically for this review (see appendix B). I developed the data abstraction form and pilot tested it with NB. Both reviewers applied the form to a selection of eligible papers until no further revisions to the form were required, and all items were agreed upon. I then completed all data abstraction with verification from one additional reviewer (NB or SB). All disagreements were resolved through consensus discussion.

2.2.6 Outcome reporting

Given the heterogeneity of methods used for physician preference elicitation and outcome reporting, studies that reported outcomes quantitatively were categorized into two separate types:

1. Those that reported a rating of attitudes toward SDM and SDM-related behaviors (e.g. the Patient Practitioner Orientation Scale [PPOS])
2. Those that compared attitudes toward SDM with other decision-making models (e.g. Paternalism)

To categorize the overall level of physician support in each reviewed quantitative paper, and to facilitate comparison across studies, support for SDM by physicians was categorized as follows:

- "Strong support in favor of SDM" (> 80% support for SDM)
- "Mild support for SDM" (60-80% support for SDM)
- "Indifference toward SDM" (40 < 60% overall support)
- "Lack of support for SDM" (< 40% overall support)

For example, to determine the level of physician support, if the study used a 6-point Likert scale as was used in the previously validated PPOS survey; a mean score of 4.8 or higher would be categorized as "strong support for SDM." If a study reported that 80% of physicians support the use of SDM, "strong" support was recorded on

the data abstraction form. I defined "level of support" as reported physician support for joint decision-making between the patient and physician, or support for the patient to make the final treatment decision. Disagreements were resolved through consensus discussion.

This review includes studies that report quantitative frequencies of support for SDM as well as qualitatively reported outcomes. The qualitative studies were narratively summarized in accordance to the manner in which results were reported. Qualitative studies were primarily included to provide further insight into the factors associated with support for SDM, and the rationale behind physician reported attitudes. Given the range of qualitative study designs, decisional topics, and limited data being reported within studies, I did not apply a formal thematic or grounded theory analysis to the qualitative studies.(51,52) However, when comparing qualitative results across studies, themes or "patterned responses" were identified through ongoing discussion between the three raters. A theme was identified if it captured an important concept related to the primary research questions.(51)

Given the heterogeneity of study designs included in the review, quantitative and qualitative findings are reported separately, throughout the results section. Results are reported according to the two primary review objectives. Sub-headings were identified following a review and discussion of each of the study findings. Although I

did not apply a quality-rating tool to the included studies, major limitations were recorded in the data abstraction tool and are reported in summary format in the results section.

2.3 Results

2.3.1 Search results

The electronic search produced 11,761 references. Following abstract review, 123 references were selected for full text review. No additional papers were included following the review of reference lists. One additional paper was included based on the suggestion from a field expert. Forty-three papers were selected for final inclusion after full text review (see figure 2.2). At the full text phase, reviewers had a high level of agreement on the eligibility of articles, with a Cohen's kappa of 0.83.

2.3.2 Characteristics of included studies

Of the 43 studies, 29 reported quantitative results, and the remaining studies consisted of qualitative interviews or focus groups. Fourteen studies considered SDM within the context of primary care, 25 in secondary care, and 4 in both. Individual studies varied with regard to the method of preference elicitation, ranging from pre-validated Likert scale tools such as the PPOS, investigator developed tools, as well as un-validated instruments (see tables 2.1 and 2.2). The context within which physicians were asked to express their levels of support for

SDM varied considerably, and included a single clinical scenario,(53) a specific patient population,(54) or questions asked in terms of general levels of support unrelated to specific patients to clinical scenarios.(55) In addition, studies varied with regard to whether they assessed directly stated opposition to SDM in favour of alternative models (e.g. paternalism), or simply a lack of support for SDM.

Of the quantitative studies, 5 (17%) reported a response rate of 50% or less, and an additional 8 (28%) did not report recruitment or response rates. All 14 qualitative studies and 3 of the 29 quantitative studies (10%) used a sample size of less than 30 participants.

Individual studies varied in terms of how they defined SDM. Sixteen of the 29 quantitative studies (55%) used tools developed by the investigators that described various aspects of SDM, (54–57) while the remaining studies used pre-validated tools to ascertain support for SDM, such as the PPOS,(58–60) or the Control Preferences Scale (CPS) (see table 2.1).(61) Responses therefore were elicited using different response options, comparators, and scales. For example, Shepherd et al. sought to determine physician comfort level with various decision-making approaches,(62) while Caldwell et al. ascertained physicians opinions about the relative importance of SDM on a Likert scale.(55) Conversely, Hamann et al. obtained physician level of agreement about the use of SDM for a range of specific decision topics.(54)

The term “shared decision-making” was not consistently defined in each study. For example, the survey conducted by Davis et al. asked physicians about their preference for the physician or the patient in making the final treatment decision with regard to prostate specific antigen screening. While not explicitly describing an SDM encounter, responses referred to preferred level of patient involvement.(63) Alternatively, the survey conducted by Shepherd et al, provided explicit descriptions of different decision-making models such as paternalism, informed decision-making and SDM.(62) Table 2.1 and 2.2 provide a brief summary of the instruments used in quantitative (table 2.1) and qualitative (table 2.2) work to collect information about physician attitudes toward patient involvement in the decision process.

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Murray 2007, USA (56)	Clinical decision-making: physicians' preferences and experiences	1050	Primary care, medical specialty or surgical specialty physicians	General	Investigator-developed questionnaire: % approval of various aspects of SDM
Butow 2007, Australia (57)	Health Professional and Consumer Views on Involving Breast Cancer Patients in the Multidisciplinary Discussion of Their Disease and Treatment Plan	238	Surgery, radiation oncology, medical oncology	Breast cancer treatment planning	Self-developed questionnaire to elicit preferred role in decision-making.
Shepherd 2007, Australia (62)	The context influences doctors' support of shared decision making in cancer care	64	Oncology	Cancer treatment	Survey developed based on the work of Charles et al.(64) Physicians asked to rate their comfort levels with each of the decision-making approaches on a five-point Likert scale, ranging from "not comfortable" to "extremely comfortable."

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Arnetz 2008, Sweden (65)	Physicians' and Nurses' Perceptions of Patient Involvement in Myocardial Infarction Care	53	Cardiology	Myocardial infarction care	Investigator-developed 4-item Likert scale questionnaire. Responses ranged from "Agree completely" to "Don't agree at all"
Carlsen 2008, Norway (58)	Variation in practice: A questionnaire survey of how congruence in attitudes between doctors and patients influence referral decisions	41	GP	General	PPOS
Pieterse 2008, Netherlands (61)	Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration	35	Oncology	Preoperative rectal cancer radiotherapy	CPS [Control Preferences Scale]
Boivin 2008, Canada (66)	Competing norms: Canadian rural family physicians' perceptions of clinical practice guidelines and shared decision-making	17	GP/ residents	General	Focus groups. Reported percent approval regarding various statements about preferred role in decision-making

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Cohen Castle 2008, Israel (67)	Family physicians' perceptions, beliefs, and attitudes regarding information sharing with prostate cancer patients throughout the course of the disease	382	GP	Prostate cancer treatment	11-item questionnaire concerning information sharing and SDM was designed based on the work of Charles et al.(7)
Caldwell 2008, USA (55)	Evaluating attitudes of first-year residents to shared decision making	70	Residents from 16 specialties	General	Investigator-developed survey to assess perceived importance of SDM. Survey included15 items concerning medical decision-making were tied to a five-point Likert scale anchored at both ends by "Not Important" and "Very Important."
Hamann 2009, Germany (54)	Psychiatrists' use of shared decision making in the treatment of schizophrenia: Patient characteristics and decision topics	181	Psychiatry	Schizophrenia	Investigator-developed questionnaire: questions on whether certain decision topics would be suit- able for shared decision-making

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
van Til 2010, Netherlands (68)	The potential for shared decision making and decision aids in rehabilitation medicine	126	Physical and rehabilitation	Rehabilitation	Questionnaire based on the work of Charles et al.(64), eliciting level of comfort with SDM.
Chan 2011, Malaysia (59)	Differences in physician attitudes towards patient-centeredness: across four medical specialties	67	Surgery, obstetrics & gynecology, oncology, GP	Surgery, obstetrics & gynecology, oncology, GP	PPOS
Davis 2011, USA (63)	Physicians' attitudes about shared decision making for prostate cancer screening	54	Academic clinicians, community clinicians, interns, residents	Prostate Cancer Screening	Investigator-developed 26 item survey eliciting attitudes toward SDM for prostate cancer screening.
Cohen Castle 2011, Israel (69)	Urologists' attitudes regarding information sharing with prostate cancer patients—Is there a common ground for collaboration with family physicians?	54	Urology	Prostate Cancer treatment	An 11 item scale based on the work of Charles et al.(7) eliciting attitudes toward various aspects of SDM.

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Légaré 2011, Canada (70)	Prenatal screening for Down syndrome: a survey of willingness in women and family physicians to engage in shared decision-making	41	GP	Prenatal Down Syndrome screening	Investigator-developed clinical vignette questionnaire regarding their intended decision-making model. Instrument was developed using the theory of planned behavior. Each statement was measured on a 7-point Likert scale ranging from −3 (strongly disagree) to +3 (strongly agree).
van der Horst 2011, Switzerland (71)	Attitudes toward shared decision-making and risk communication practices in residents and their teachers	4487	Internal medicine, anesthesiology, surgery, gynecology, pediatrics, psychiatry, orthopedic surgery residents and teachers	General	Investigator-developed questionnaire regarding attitudes toward SDM. Responses ranged from "does not apply" to "fully applies" on a 5-point Likert scale.
King 2012, USA (72)	Perceptions of shared decision making and decision aids among rural primary care clinicians	174	Rural GPs	General	Investigator developed questionnaire regarding perceptions of SDM

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Olson 2012, Canada (53)	Oncologists' view of informed consent and shared decision making in pediatric radiation oncology	59	Oncology	Pediatric oncology	PPOS responses to a single clinical scenario
Chan 2012, Malaysia (60)	Attitudes and role orientations on doctor-patient fit and patient satisfaction in cancer care	12	Oncology	Oncology	PPOS
De Las Cuevas 2012, Spain (73)	Mental health professionals' attitudes to partnership in medicine taking: a validation study of the Leeds Attitude to Concordance Scale II	225	Psychiatry	Mental health	LATCon II (Leeds Attitudes to Concordance Scale)
Holland 2013, Norfolk (74)	Barriers to involving older people in their resuscitation decisions: the primary–secondary care mismatch highlights the potential role of general practitioners	24	GPs and secondary care clinicians	Resuscitation	Investigator developed questionnaire. 5 point Likert scale indicating the extent to which they agree that it is important to involve patients in resuscitation decisions

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Flierler 2013, Switzerland (75)	Implementation of shared decision making in anaesthesia and its influence on patient satisfaction	213	Anaesthesiologists	Anaesthesia	CPS
Hillyer 2013, USA (76)	A survey of breast cancer physicians regarding patient involvement in breast cancer treatment decisions	136	Oncologists, breast surgeons	Breast cancer treatment	Adapted questionnaire asking physicians to respond to 10 questions regarding decision-making
Abiola 2014, Nigeria (77)	Patient-doctor relationship: the practice orientation of doctors in Kano.	214	Unspecified	General	PPOS
Doring 2014, Not reported (78)	Trigger finger: assessment of surgeon and patient preferences and priorities for decision making.	105	Hand surgeons	Idiopathic trigger finger	Online survey based on the Ottawa decision support frame work and the control preferences scale

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**
Garcia-Retamero 2014, 60 countries (79)	Factors predicting surgeons' preferred and actual roles in interactions with their patients	292	Surgeons	Surgery	Adapted questionnaire asking physicians who should make treatment decisions
Hageman 2014, Not reported (80)	Carpal tunnel syndrome: assessment of surgeon and patient preferences and priorities for decision-making	103	Hand surgeons	Surgery for carpel tunnel syndrome	Survey based off of the Ottawa decision support framework (OSDF)
Ishikawa 2014, Japan (81)	Resident physicians' attitudes and confidence in communicating with patients: a pilot study at a Japanese university hospital	63	Resident physicians	General	PPOS translated into Japanese
Nguyen 2014, France (82)	Treatment decision-making in the medical encounter: comparing the attitudes of French surgeons and their patients in breast cancer care	47	Surgeons	Early stage breast cancer treatment	Survey questionnaire containing examples of four different approaches to treatment decision-making: paternalistic, ''some sharing'', informed and, shared.

Table 2.1: Summary of studies reporting quantitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty [or physician rank where listed]**	**Decision context**	**Instrument**

Table 2.2: Summary of studies reporting qualitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty**	**Decision context**	**Method**
Jaakkola,E. 2007, UK and USA (83)	Physicians' views on the influence of patient participation on treatment decisions	20	Psychiatry, rheumatology, endocrinology, geriatrics, gynecology.	Schizophrenia and osteoporosis	Interview
Thistlethwait 2007, Australia (84)	Shared decision making between registrars and patients	11	GP	General	Interview / focus group
Beaver 2007, UK (37)	Patient participation in decision making: views of health professionals caring for people with colorectal cancer	11	Oncology, Medical oncology, Surgery, GP, Specialist Registrar, Surgical Registrar	Colorectal cancer treatment	Interview
Rotar 2008, Slovenia (38)	How do older patients and their GPs evaluate shared decision-making in healthcare?	26	GP	Elder care	Interview
Watson 2008, UK (85)	Professional centered shared decision making: Patient decision aids in practice in primary care	19	GP	General	Focus groups

Table 2.2: Summary of studies reporting qualitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty**	**Decision context**	**Method**
Matlock 2011, USA (86)	Patient and Cardiologist Perceptions on Decision Making for Implantable Cardioverter-Defibrillators: A Qualitative Study	11	Cardiology	ICD implantation	Interview
Fiks 2011, USA (87)	Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD.	30	Pediatrics	ADHD	Interview
Muller-Engelmann 2011, Germany (88)	Shared decision making in medicine: The influence of situational treatment factors	12	GP	Multiple	Interview
Shepherd 2011, Australia (89)	Factors which motivate cancer doctors to involve their patients in reaching treatment decisions	22	Oncology	Breast, colorectal, gynecological, hematological or prostate/urological cancer.	Interview
Luijk 2012, Netherlands (90)	GPs considerations in multimorbidity Management: A qualitative study	25	GP	Multi-morbidity	Interview
Gachoud 2012, Canada (91)		8	Physicians	General	Interview

Table 2.2: Summary of studies reporting qualitative results					
Author, date of publication, country	**Title**	**N**	**Physician specialty**	**Decision context**	**Method**
	Meanings and perceptions of patient-centeredness in social work, nursing and medicine: a comparative study				
Kahveci, 2014, Turkey (92)	Shared decision-making in pediatric intensive care units: A qualitative study with physicians, nurses and parents	8	Pediatric intensive care physicians	Pediatric intensive care settings requiring life support	Interview
Zeuner 2014, USA (93)	Physicians' perceptions of shared decision-making behaviours: A qualitative study demonstrating the continued chasm between aspirations and clinical practice	20	Surgeons, OB/GYNs, medical oncologists, internists, emergency medicine physician	General	Interview
Shepherd 2014, Manchester (94)	Consultant psychiatrists' experiences of and attitudes towards shared decision making in Antipsychotic prescribing, a qualitative study	26	Consultant psychiatrists	Antipsychotic prescribing	Interview

2.3.3 Physician preferences for patient participation in decision-making (research objective 1)

Quantitative results

In general, there was a relatively consistent level of support for SDM, as reported by physicians. However, support varied by physician specialty and clinical context. Of the 29 quantitative studies, 12 asked physicians directly to rate their level of support for SDM without an explicit comparison of SDM to other models such as paternalism. Of the 12, 33% (4/12) reported strong support for SDM, half (6/12) reported mild support, and 2 (17%) reported indifference toward SDM. Of note, none of the 12 studies found a lack of support for SDM.

Seventeen of the 29 quantitative studies asked physicians to compare their level of support for SDM against alternative models of decision-making. All 17 studies compared a SDM approach to a paternalistic model wherein the physician alone makes the treatment decision. Eighty-two percent of these papers (14/17) reported a strong preference for either a SDM, or for a model wherein the patient makes the treatment decision. The remaining three studies reported mild support for patient participation. Mild support was identified in clinical scenarios regarding anesthesiology and surgery. No studies reported an overall preference for paternalistic decision-making.

2.3.4 Factors associated with variation in physician support for SDM (research objective 2)

Following the review of all included studies, three major themes were identified with regard to the factors associated with support for SDM. The first theme includes physician-related factors such as specialty, concerns about where decisional responsibility should fall, as well as their interpretation of what an SDM encounter constitutes. Secondly, patient-related factors that tend to influence support for SDM include the physician's perception of a patient's willingness or ability to participate in the encounter. Finally, disease and treatment-related considerations also tend to influence a physician's attitude toward SDM. Each of these general themes is discussed in detail, below.

2.3.4.2 Physician-related factors that impact support for SDM

Qualitative results

Physician-reported support for SDM was heavily influenced by physician-related factors such as the availability of evidence and guidelines pertaining to a particular treatment decision, the presence of support for SDM from colleagues, and previous exposure to SDM training. Five studies provided insight into physician-related factors that explain variability in support for SDM. Physicians tend to express support for SDM in situations where they do not feel strongly about one treatment alternative,(85) and less supportive of SDM in situations where compelling evidence or well-evidenced clinical practice guidelines exist in favor of one treatment over

the other.(66,86) In situations where the patient has little choice, or in cases where one treatment option is well established (e.g. surgery in the case of malignant tumor removal), physicians tend to be less favorable towards SDM.(37) For example, Matlock et al.'s interview study with 11 cardiologists found that in the presence of strong guidelines in favor of one treatment option (namely, implantable cardioverter-defibrillators), physicians were less likely to support the involvement of the patient in the decision-making process.(86) As the authors state, where guidelines exist recommending one treatment option, physicians may feel pressured to follow such recommendations, and thus may be less likely to seek involvement from their patient.(95) One study of 20 physicians found that support for SDM was most common among those who had received training in SDM-related communication skills.(93) Conversely, those who worked under physicians who did not support SDM were less likely to incorporate SDM into their practice.

2.3.4.1 Physician attitudes vary by specialty

Quantitative results

Support for SDM varied considerably by physician specialty. For example, Chan et al reported that among a sample of 67 physicians responding to a 6-point Likert scale rating levels of support for SDM, oncology physicians (mean: 5.02, SD: 0.28), GPs (mean: 4.33, SD: 0.57) and physicians specializing in obstetrics and gynecology

(mean: 4.19, SD: 0.76) held positive attitudes toward SDM. In comparison, surgeons reported the lowest levels of support for SDM (mean: 2.88, SD: 0.78.).(59) Conversely, among a nationally representative sample of US physicians (N=1050) responding to a survey about their preferred model of care, physicians from surgical specialties (including obstetricians and gynecologists) were no more likely to support paternalism over shared decision-making, compared to primary care specialists (conditional odds ratio: 0.74, 95% CI: 0.43, 1.29).(56)

In a survey of residents and their teachers, participants were asked to rank on a 6-point scale ranging from "does not apply" to "fully applies," to questions regarding the time required to engage patients, the difficulty associated with engaging patients, and patients' lack of understanding. As such, lower scores indicate higher levels of support for SDM. Regarding self-reported negative attitudes toward SDM, psychiatry (mean: 3.0 SD: 1.16) and gynaecology residents (mean: 2.8 SD: 1.14) reported lowest negative attitudes, compared with internal medicine (mean: 3.28 SD: 1.16), surgical (mean: 3.18 SD: 1.11), paediatric (mean: 3.05 SD: 1.08), and orthopaedic surgery (mean: 3.17 SD: 1.18). In general, results did not differ extensively, although authors did not report whether the results differed significantly from one another. Similarly, attitudes reported by psychology resident teachers were most favourable toward SDM, with the lowest levels of support reported by anaesthesiologists (mean: 3.37 SD: 1.13).(71) Teachers consistently reported more positive attitudes toward SDM, compared with residents, although

the investigators do not provide formal statistical comparisons across ranks. An additional item was included in the survey to ascertain concerns about the time required for SDM. The single item included the following statement: "In the daily routine, too little time is scheduled to explain the advantages and risks of available treatment options to patients." All teacher specialties except for anaesthesiologists reported lower ratings on opinions regarding about lack of time. One potential interpretation of this finding is that more experienced physicians tend to be more supportive of SDM over less experienced and perhaps younger residents. Further investigation into this potential explanation is warranted.

With regard to involving patients in decisions for resuscitation, Holland et al. found that although both groups supported the involvement of patients in the decision-making process, general practitioners rated its importance higher compared with hospital based clinicians.(74) This difference in opinion may have been informed by the fact that on average hospital-based clinicians made significantly more CPR-related decisions per week compared with GPs (4.04 vs. 0.28 p: 0.005), and thus may have had more experience with this specific clinical context.

2.3.4.3 Physicians report concerns with regard to absolving decisional responsibility

Quantitative results

Despite a general support for SDM, some studies addressed physician concerns related implementing a shared approach to their care. When asked, physicians

reported concerns about charging patients with a complex decision and transferring decisional responsibility to their patients. For example, within the context of breast cancer treatment planning, a survey of surgeons, radiation oncologists and medical oncologists reported that 66% thought that including patients in multidisciplinary care meetings could result in information overload, and 53% believed that patients would not understand the information being discussed.(57) Although the majority of oncologists interviewed by Olson et al. supported the information of pediatric patients' parents in the decision-making process, some worried that doing so may be inappropriate given the complexity of the decision being made.(53) Oncologists also mentioned a reluctance to absolve responsibility for treatment decision-making, with the concern that it is the physician's *job* to ensure that the right decision is made. In one scenario where physicians were asked whether they would engage the parents of children with cancer in the decision-making process, one physician feared that if an adverse outcome were to occur, the parents would be left with the guilt.(53)

Qualitative results

Similar concerns arose repeatedly among a selection of qualitative studies, wherein physicians reported a fear that patients would be unprepared to grasp the complexity of the decision, or where patients lack the understanding or ability to focus on the reality of the decision.(38,86,92,93) For example, with regard to elder care, general practitioners qualitatively interviewed by Rotar et al. highlighted the

concern that older patients may not be prepared to engage in the decision-making process, based on their experiences treating this patient population.(38) While some physicians recognized that clinical decision-making is evolving in a direction that allows or requires the patient to take responsibility of his or her own health and treatment, they also reported difficulty in relinquishing control of the final decision, especially in situations where they held a clear recommendation for one treatment alternative over another.(86) Somewhat related to this concern, 20 physicians interviewed regarding their level of comfort with SDM reported that although they generally supported the idea, many were concerned about discussing uncertainty with patients because they feared that they may come across as incompetent.(93) Eight physicians interviewed about SDM in the context of pediatric intensive care decisions reported that the parents of patients lacked the understanding about the decisions being made, and therefore were less supportive of absolving the responsibility for the decision.(92)

Finally, two qualitative (84,85) and two quantitative (53,57) studies report the concern that, if involved in the decision-making process, patients would make "wrong" or "irrational" decisions.

2.3.4.4 Physicians may lack clarity with regard to how SDM is defined

Qualitative results

As previously stated, there is no single and commonly accepted definition for what constitutes a shared approach to decision making. This has implications for both physician competencies, as well as implementation strategies. Among three qualitative studies that reported on how physicians define SDM, findings further support this concern.(85,87,91) For example, although the majority of pediatricians qualitatively interviewed by Fiks et al. were supportive of SDM, 22/30 (73%) of the participating physicians described SDM as a process wherein they tried to convince or persuade the parent to agree to their preferred treatment option. A large minority (28%) of physicians interviewed considered SDM to be a partnership with patients.(87) The results of a focus group conducted with general practitioners reported that participants had a difficult time distinguishing SDM from simple information transfer.(85)

2.3.4.5 Reported versus actual approach to decision-making

Quantitative results

Among 6 studies that reported both preferred and actual decision-making behaviours, the majority (N=4) found that support for SDM did not consistently reflect practical use. Specifically, although physicians tended to report a preference for a shared or collaborative approach to decision-making, decisions were typically made more frequently by the physician alone.(54,68,72,79) For example, in a study

by van Til, 81% of 126 physical and rehabilitation physicians reported a high level of comfort with the SDM approach, but only 50% reported using a shared approach in practice (68). A survey of psychiatrists reported that although there was a high preference for patient participation within the clinical encounter, 151 (44%) of physicians stated that they most frequently applied a paternalistic decision-making model of decision-making, and 173 (51%) reported that they most frequently used SDM. The remaining 5% reported that they most frequently applied an informed choice model.(54) Similarly, 292 surgeons surveyed from 60 countries reported that although 57% preferred an approach wherein physician and patient decide together, only 36% reported this as their decision-making style in practice. While only 26% preferred a process wherein the decision was made solely by the physicians, 52% reported this as their typical decision-making behaviour.(79)

Two additional studies reported that stated actual behaviours were concordant with preferred styles.(56,65) Consistent with high preferences for SDM in the context of myocardial infarction care (other than ICD implantation), 73.7% of physicians stated that they usually informed the patient about various aspects of his or her disease; 65.9% agreed that they usually asked the patient about their personal needs, and 80.0% usually discussed lifestyle changes and provide additional resources to their patients about continuing their care.(65) Similarly, a study of general practitioners reported that 75% prefer an SDM approach, and 73% say they share the decision with their patients.(56)

2.3.4.6 Patient-related factors that affect physician-reported support for SDM

Quantitative results

In general, support for SDM varied when considering patient characteristics such as the physician's perception of patient competency, desire to be involved, and likelihood of benefitting from the shared approach. For example, within the context of schizophrenia, physicians were supportive of an SDM approach in situations where the patient desired to be involved in the decision-making process, was informed about their condition, and was competently able to participate.(54) Conversely, physicians reported lower levels of support for SDM in situations where the patient was unable or unwilling to participate in the decision-making process, cognitively impaired, showed limited awareness about their condition, or was otherwise thought to be limited in their ability to participate in the discussion (e.g., children, and those with chronic pain).(54,66,68,94) Physicians who participated in a quantitative survey about their comfort with SDM within the context of rehabilitation medicine expressed doubt that patients with chronic pain would be able to actively engage in the decision-making process.(68)

Qualitative results

In support of the quantitative findings, the qualitative studies that ascertained rationale for support for SDM found that characteristics such as patient-perceived cognitive ability or likelihood of benefit. Interviews with GPs found that SDM may be

most appropriately applied in situations where the patient was cognitively able to participate in the decision making process.(88) Consultant psychiatrists interviewed by Shepherd et al. highlighted the concern that SDM may be inappropriate in situations where patients have been diagnosed with a mental disorder.(94) Finally, within the context of elder-care, physicians interviewed by Rotar et al. feared that patients may be unable to engage in this relatively new paradigm of decision making.(38)

Two studies in particular discussed the impact of treatment adherence on support for SDM.(54,83) Within the context of decision-making for schizophrenia patients, physicians in Hamann and colleagues' quantitative survey reported reduced levels of support for SDM in situations where patients showed poor adherence with their medications.(54) Alternatively, psychiatrists in Jaakola's qualitative interview study reported that an SDM approach to elicit patient preferences may serve as a useful tool to increase treatment adherence for this patient population.(83) This difference in opinion helps to illustrate the fact that physician attitudes vary depending on the specific patient population under consideration, even within similar treatment contexts (see table 2.3).

2.3.4.7 Condition- and treatment-related factors that affect physician-reported support for SDM

Qualitative results

Physicians tended to support the use of SDM in clinical contexts where a decision could be made in a non-emergency setting, and in situations that have been previously described as "preference-sensitive." For example, results of qualitative investigations found that physicians tended to support SDM in situations of severe or chronic disease, where multiple treatment options exist, where at least one treatment option carries risks of adverse events, where treatment options have the potential to impact a patient's lifestyle and self-image, and where there is uncertainty around the best possible treatment option.(88,89) Decisions made in general practice care settings, such as outpatient physician visits, tended to garner more support for the incorporation of SDM, in comparison with hospital-based management.(84) Muller-Engelmann's qualitative interview study reported that physicians were less supportive of applying SDM to emergency medical situations.(88)

Quantitative results

In support of the qualitative findings, one quantitative study reported higher levels of support for SDM in scenarios where the risk-benefit ratio does not clearly benefit one treatment option over another. GPs and residents tended not to support SDM in emergency medical situations.(66)

Table 2.3: Factors associated with perceived support or lack of support for patient involvement in decision-making from the physician perspective

***Indicates qualitative findings**

	Support for SDM	**Reduced support for SDM**
Physician-related	No strong preference for one treatment option based on the available evidence (85)*	Support evidence in favor of one specific treatment option(37,66,86) Physicians' mentors do not support the use of SDM (93)*
Patient-related	Cognitively able (88)* Poor treatment adherence (83)* Desire to be involved in decision (54,88*) Informed about condition (54)	Cognitively unable to participate (54,66,68,83*,94*) Poor adherence (54) Unwilling to participate (83) Limited insight into condition OR treatment (54,92*,93*) Less educated (93)* Children (68)
Condition- and treatment- related	Chronic disease (66,88,90) * Cancer screening and treatment (57,61–63,67,69) End of life care (66) Severe disease (88)* Multiple treatment options exist (88,89)* Treatment options may affect patient's lifestyle (89,94)* Treatment options carry risks of adverse events (88)*	Chronic pain (68) Emergency medicine (66,88*) Hospital care, specific to psychiatry (54) Diagnostic procedures (54) Pediatric intensive care (92)*

2.4 Discussion and conclusion

2.4.1 Summary of findings

This review provides a comprehensive overview of the current attitudes expressed by various physician specialties regarding SDM (see table 2.3). The quantitative studies provide an overall estimate of support for SDM. For example, of the 12 studies that asked physicians about their level of support for SDM, 10 (83%) reported either mild or strong support, while 2 studies reported indifference toward SDM. In comparison to more paternalistic or doctor-centered decision-making, a shared or patient-centered approach was preferred. Shared decision-making garnered varying levels of support depending on the clinical scenario, patient characteristics, as well as personal opinions about the available treatment options. For example, situations wherein the patient is determined to be cognitively able and willing to participate in treatment or disease management decisions, as well as those treatment contexts within which multiple therapeutic options exist, tended to garner high levels of support as reported by physicians. Physicians tended to report lower levels of support in scenarios that lacked clinical equipoise, in emergency scenarios, where the physician held a personal treatment preference, or where clinical guidelines exist favoring one treatment option.

The qualitative findings provide further insight into physicians' rationale for supporting SDM in their practices, such as the presence of existing guidelines, the influence of mentors who support SDM, and the potential influence of having received training in SDM. In addition, qualitative investigations were able to identify a general lack of consistency among physicians in terms of what constitutes SDM. This finding brings to light the implication that prior to implementation, a shared understanding of what SDM truly is ought to be well established.

With regard to preferred versus actual decision-making styles, it appears that although physicians support active engagement of patients, the decision-making process is more frequently controlled by the physician alone. This finding supports the argument that while SDM has garnered support throughout both the academic and policy literature, uptake has been sparse.

2.4.2 Limitations

The results of this review must be considered in light of the following limitations. Firstly, all included studies relied on physician self-report, and thus may be at risk for social desirability or reporting bias.(66) SDM is advocated in the literature on ethical basis, thereby introducing the potential for an over-reporting of support for SDM.(73) As such, this review may over-estimate the current levels of support for SDM.

Secondly, 17% of the quantitative reported a response rate of 50% or less, and an additional 8 (28%) did not report recruitment or response rates. All 14 qualitative studies and 3 of the 29 quantitative studies (10%) included used a sample size of less than 30 participants. Eleven (38%) quantitative studies provided no indication of instrument validation, which may impact the internal validity of survey or interview responses. There is a risk of selection bias in each of the included studies, since those who choose to participate in observational research considering attitudes toward SDM may report systematically higher levels of support, compared with those who chose not to respond.

The current review was limited to only peer-reviewed publications published in English and accessed through the University of British Columbia; therefore, it is possible that publication bias and language bias limit the external validity of the study findings.

2.4.3 Conclusions

As has been stated previously, SDM from the physician's perspective, is likely to provide the greatest value in clinical scenarios where there is no single "correct" decision, where evidence is inconsistent or absent, or where the best decision is one that is consistent with the individual patient's lifestyle, abilities, values, and goals.(8,96) Further to this, the successful implementation of SDM is not possible unless both the patient and the physician have the intention to engage in a process

of mutual information exchange and understanding.(38) Physicians must have the skills required to navigate difficult decisions, and a clear understanding of the methods available. Evidence suggests that confidence in communicating with patients is associated with a more shared approach to decision-making.(81) As shown here, confusion may exist surrounding the distinction between information transfer, and a truly shared approach. This discrepancy may also explain patients' reported dissatisfaction with current levels of involvement in the decision-making process, as shown previously.(97) A recent review of patient reported barriers to SDM found that even if patients are able to participate in treatment decisions, they may still feel unwilling to engage with their physicians due to modifiable factors such as the belief that their doctors – as experts – know best.(98) Therefore, motivation on the part of the physician to encourage patient participation may also improve patients' willingness to participate.(70) Previous research shows that efforts geared at physician training do increase SDM implementation into clinical practice.(8,99) For these reasons, educational efforts directed at physicians to develop an understanding of what constitutes SDM, and what the intended goals of an SDM approach are, may improve physician support.

2.4.4 Implications

Transitioning to an SDM approach may require extended consultation times, financial inputs, potential revisions to medical school training, as well as an alteration to a physician's common practice which can be a difficult adjustment,

where training and support are both required.(84,100) As a first step, support for SDM must be garnered through additional empirical evidence regarding the outcomes associated with such interventions. Although evidence to date has focused on the impact of SDM in terms of patient reported outcomes such as satisfaction with treatment, decisional conflict, and overall satisfaction with care, its impact on clinical outcomes such as treatment adherence, hospitalizations, ER admissions and healthcare utilization is limited.

Although this review does not identify physician consensus as to the most appropriate scenario within which to assess the effectiveness of SDM, as a primary area of focus, the authors suggest assessing the impact of SDM within a clinical scenario such as chronic disease management where multiple therapeutic options exist, where the incorporation of patient values and preferences may be evaluated in terms of both patient-important and clinical outcomes, and where outcomes such as treatment adherence, adverse outcomes, and clinical improvement or decline may be measured long-term.

As a next step to this research agenda, I have selected asthma as an appropriate case study within which to ascertain the current state of SDM, as well as to determine potential outcomes associated with exposure to SDM. Chapter 4 will provide a comprehensive overview of the rationale for selecting asthma as a clinical scenario to further investigate the role of SDM.

Chapter 3: The burden of non-adherence among adults with asthma: What is the role for shared decision-making?

3.1 Introduction

Shared decision-making (SDM) is supported as a key component for chronic disease management especially where multiple treatment options exist. Shared decision making requires that both physicians and patients are actively engaged in the decision-making process, including information exchange, expressing treatment preferences, as well as agreement over the final treatment decision. Although the concept of SDM appears well supported by patients, practitioners (see chapter 2), and policy makers alike, the current challenge is to determine how best to make SDM a reality in everyday clinical practice.

As stated previously, much of the literature shows that SDM may improve a range of patient reported and clinical outcomes (see chapter 1 and 2). However, SDM may not be appropriate for every clinical decision, nor has it been shown to improve outcomes in all healthcare decision scenarios.(20) In light of this, the results of chapter 2 were used to inform the selection of a decision context a) that is likely to garner support from physicians and patients, b) that is preference sensitive, c) within which the role for SDM can be illustrated, and d) that has measurable

outcomes that have hypothesized outcomes related to SDM. Within the context of asthma, adherence rates to controller medications are poor and are linked to negative outcomes such as poor asthma control, increased symptoms, higher healthcare expenditures, and lower patient quality of life.(101–106) It has been suggested that SDM may improve treatment adherence, and that ignoring patients' personal goals and preferences may result in reduced adherence.(17) However, a more comprehensive understanding of the predictors of treatment adherence is warranted, in order to identify the specific role(s) that an SDM approach may play.

Here I describe why SDM can enhance patient adherence in asthma management and improve clinical and patient-related outcomes, by proposing a theoretical framework that clearly identifies the potential role for SDM. In addition, I will explore the reasons why SDM has not been implemented into routine clinical practice.

Over the past two decades, repeated calls have been made to replace the paternalistic approach to treatment decision-making, in support of a more shared encounter.(6,10) Here I have adopted the definition of SDM proposed by Charles and colleagues, wherein a truly shared approach consists of both physician and patient involvement in the process of information exchange, expression of treatment preferences, and agreement on the treatment plan.(10) SDM is typically considered appropriate when applied to non-emergency "preference sensitive" treatment

scenarios, where multiple therapeutic options exist, and where individual patient values, preferences, goals and lifestyle choices play an important role in deciding upon a particular treatment.(1,10,17,107) Specifically, in clinical scenarios where ongoing self-management of chronic illness is required on the part of the patient, satisfaction and treatment acceptance may be particularly important outcomes of the decision making process.(107)

3.2 The burden of non-adherence to asthma medications

Asthma is a chronic inflammatory disease associated with airway hyper-responsiveness and variable symptoms including cough, wheeze, breathlessness and chest tightness.(108) Asthma, globally, affects approximately 300 million people, including 21.2 million in North America.(103,109,110) The prevalence of asthma is increasing due to multiple factors including greater exposure to antibiotics in infancy, atopic sensitization, changes in environmental exposures like pollution and allergens, and diet.(101) There is also a significant economic burden associated with asthma due to the direct and indirect costs and death.(111) Worldwide, approximately 180,000 people die annually from asthma.(101)

The primary aim of asthma management is to achieve control and prevent future risk, most notably of exacerbations. Patients with very mild asthma may only require reliever medications but if patients require relief more than three times weekly they should normally be prescribed a controller medication. Controller

treatment options vary in terms of administration route (orally, inhaled or injected), convenience, ease and level of skill required for administration, as well as formulation and dosage.(103)

Currently, asthma control is poor among all age groups, and is associated with decreased quality of life,(101) poor symptom control,(104) more frequent use of rescue medications,(104) increased health care utilization,(102) and death.(103,104) Optimal control of asthma requires the availability of medications and their use in the context of a proper self-management strategy. Adherence to the medication regimen is imperative in order for the patient to experience therapeutic benefits.(102,112,113)

Although effective medications exist to treat asthma symptoms and prevent exacerbations, adherence is sub-optimal.(105,106) The term "adherence" is defined as the extent to which a patient takes his or her medication as prescribed.(114) Adherence therefore has three main components: a) initiation, b) implementation, and c) discontinuation. In the case of asthma, especially when presenting in adulthood, discontinuation may be rare because patients require medication on a chronic basis. Medication persistence is defined as the length of time between initiation and discontinuation. As described by Vrijens et al., non-adherence may occur by way of non-initiation, taking medication in a fashion other than what was prescribed, and early discontinuation of medication.(114) A common type of non-

adherence is underuse, when the patient takes less medication than has been prescribed by their physician.(115,116)

Asthma medication adherence can be classified as either intentional or non-intentional.(112) Intentional non-adherence occurs when the patient makes a conscious decision to discontinue use, and may occur in the form of total discontinuation, or adopting a modified regimen. Non-intentional non-adherence may occur due to a lack of understanding about the medication regimen, language barriers, or forgetfulness. Non-intentional non-adherers may wish to be more adherent to their medication, but factors such as treatment complexity, cost of medication or the inability to prioritize their medication regimen prevents such patients from working their medication plan into their daily lives.(104)

The World Health Organization estimates that the current rate of primary non-adherence - when the patient fails to fill their medication prescription - ranges from 6% to 44% of asthma patients worldwide.(104) Adherence is not a dichotomous measurement in asthma, and levels of adherence fluctuate greatly.(104,113) In general, adherence to long-term asthma treatment is poor, and varies according to disease severity.(117,118) Adherence to asthma medication may fluctuate according to seasons, with greater adherence in the Spring and Fall, reflecting the presence of seasonal allergies and viral infections. Estimates of adherence vary depending on how adherence is defined in a given setting. For example, Gamble et

al. found that among 182 difficult-to-treat asthma patients, 65% filled more than 50% of their controller medication prescriptions over a period of 6 months.(119) In a Canadian study of 349 asthma patients aged between 12 and 45 years, investigators found that only 12% of participants self-reported correct use of asthma medication.(120) A recent British Columbian population-based analysis of patients with asthma prescribed combination therapy estimated adherence rates of between 16% and 32% over 2 years, as measured by percentage of days covered.(121) In addition, a patient's adherence to asthma therapies tends to decrease over time, posing a challenge for long-term management.(122)

Poor adherence to controller medications is associated with a broad range of negative outcomes including poor asthma control, increased exacerbations, increased cost, increased hospitalization rates, decreased quality of life, reduced lung function, and other lifestyle limitations for the patient.(102,113,123–125) Therefore, implementation of effective strategies to improve treatment adherence will help to reduce the associated negative consequences, thereby minimizing overall disease burden.

3.3 Proposed solutions

Prospective studies that assessed the effectiveness of a variety of asthma interventions have shown inconsistent findings on patient outcomes. For example, interventions include but are not limited to asthma action plans (a step by step

strategy to manage symptoms and prevent exacerbations), educational interventions, reminder systems and multifaceted interventions.(122,126–134) In response to calls for a more patient-centered approach to decision making, SDM has also been proposed as a valuable tool to improve patient-reported and clinically important outcomes.(17,22) As stated previously, The basic tenant behind SDM is that both patient and physician exchange valuable information and agree on a treatment plan together.(6,100) The key feature of mutual deliberation and agreement on the treatment plan further differentiates SDM from educational interventions that rely on uni-directional information transfer from the healthcare provider, to the patient.(119)

There is no universal characterization of SDM clinical encounters. In fact, the process of SDM may occur during a single encounter, or over multiple encounters.(100) Towle and colleagues have provided a comprehensive framework of proposed physician competencies for conducting an SDM encounter (or a series of encounters) (see Table 3.1).(100) In order for a truly shared approach to be successful, patients must be willing and able to provide their own expertise in the form of values and preferences. To facilitate this open communication between patients and their care providers, patients also need to have a clear understanding of the role that his or her preferences play in the decision process.(6)

Table 3.1: Physician competencies for SDM as proposed by Towle et al. (97)
1. Develop partnership with patient
2. Establish or review the patient's preferences for information
3. Establish or review patient's preferences for role in decision making and the existence and nature of any uncertainty about course of action to take
4. Ascertain and respond to patient's ideas, concerns and expectations
5. Identify choices and evaluate the research evidence in relation to the individual patient
6. Present evidence, taking into account competencies 2 and 3, framing effects etc. Help the patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle
7. Make or negotiate a decision in partnership with the patient and resolve conflict
8. Agree on an action plan and complete arrangements for follow up

Physicians may also use objective measures of asthma-related outcomes such as control or adherence in addition to patient-reported values and preference, to aid in the decision-making process. For example, throughout the process of information ascertainment and exchange, the physician may determine that the patient is both non-adherent and experiencing frequent exacerbations that are impacting his or her quality of life. After discussing with the patient, the physician may discover that the cost of controller medication is a primary barrier to adherence. The physician and patient may deliberate over this barrier and through the process of information

exchange, agree on a treatment that balances cost with other potential outcomes, such as efficacy and side effects.

Patient decision aids (PDAs) have been developed as a tool to help implement SDM within a range of clinical contexts including screening and surgical decision-making, as well as chronic disease management, including asthma.(30) Although the application of PDAs alone does not qualify as a shared approach, PDAs may be incorporated into the shared encounter as a means of informing the patient about their disease and treatment options, as well as the associated risks and benefits. Therefore, PDAs can be used as a part of the SDM process, using print, audio, and video formats.(135) For example, by presenting the evidence about available treatment options (as described above in table 3.1) physicians may recommend a patient decision aid to help the patient more fully understand and comprehend the choice at hand. Patient decision aids are used to not only to increase patient knowledge, but also to help the patient clarify his or her values by looking at personalized information about the evidence and associated risks and benefits of various treatment options.(135) Evidence suggests that PDAs confer a number of important benefits, including: decreased decisional conflict, improved communication between patient and health care provider, increased knowledge about the disease and treatment options, and improved patient trust in the provider. (23,24,26,136–140)

Multiple systematic reviews of the PDA literature have been conducted over the past several years, highlighting the outcomes associated with their application in various disease contexts. For example, a 2005 review of cancer-related PDAs reported improved patient knowledge for screening, prevention and treatment options.(138) Among patients facing surgical decisions, a recent review reported that the use of PDAs resulted in more conservative treatment option choices, increased knowledge and reduced decisional conflict.(139) An earlier review of 17 randomized controlled trials across a range of disease contexts found that the use of PDAs was associated with reduced decisional conflict and increased knowledge.(137) Finally, a 2017 Cochrane review of PDAs for treatment and screening decisions obtained information from 105 independent RCTs. Investigators found that the use of PDAs resulted in increased knowledge among the 52 studies that assessed knowledge as an outcome. The use of PDAs also resulted in decreased decisional conflict (N=63 studies) and increased participation in the decision making process (N=24).(26) Reviews consistently found that the use of PDAs did not systematically increase anxiety.(26,137–139)

3.3.1 Theoretical framework

The proposed framework is adapted from de Vries et al. (2003) and Fransen et al. (2009) and provides a visual depiction of the various factors that impact a patient's motivation to adhere to asthma controller medication (see figure 3.1).(28,141) The proposed framework recognizes that multiple factors impact a patient's willingness

and ability to adhere to their prescribed medication, and assumes that treatment adherence requires patient motivation. Motivation, in turn, is related to a range of predisposing factors. Specifically, predictors of motivation include both modifiable (e.g. knowledge, attitudes) and non-modifiable (e.g. age and sex) factors that serve to influence patients' attitudes and perceived ability to adhere. An underlying assumption of the model is that attitudes (informed by predisposing factors) inform action in a direct manner.(142) Finally, the framework recognizes that despite patient motivation, additional barriers – both patient-level and structural – may negatively impact a patient's ability to fill an initial prescription or take their medication as prescribed. Such barriers include, but are not limited to, the cost of the medication, experienced side effects, or lack of access to a general practitioner or specialist physician.

The theoretical framework has been adapted here to include predictors of adherence that are specific to asthma controller medication. Below I describe the predisposing and motivational factors that have been shown to impact treatment adherence, while highlighting those factors that are specific to asthma treatment. Furthermore, I identify predisposing and motivational predictors that can be addressed through an SDM encounter.

Figure 3.1: Theoretical framework

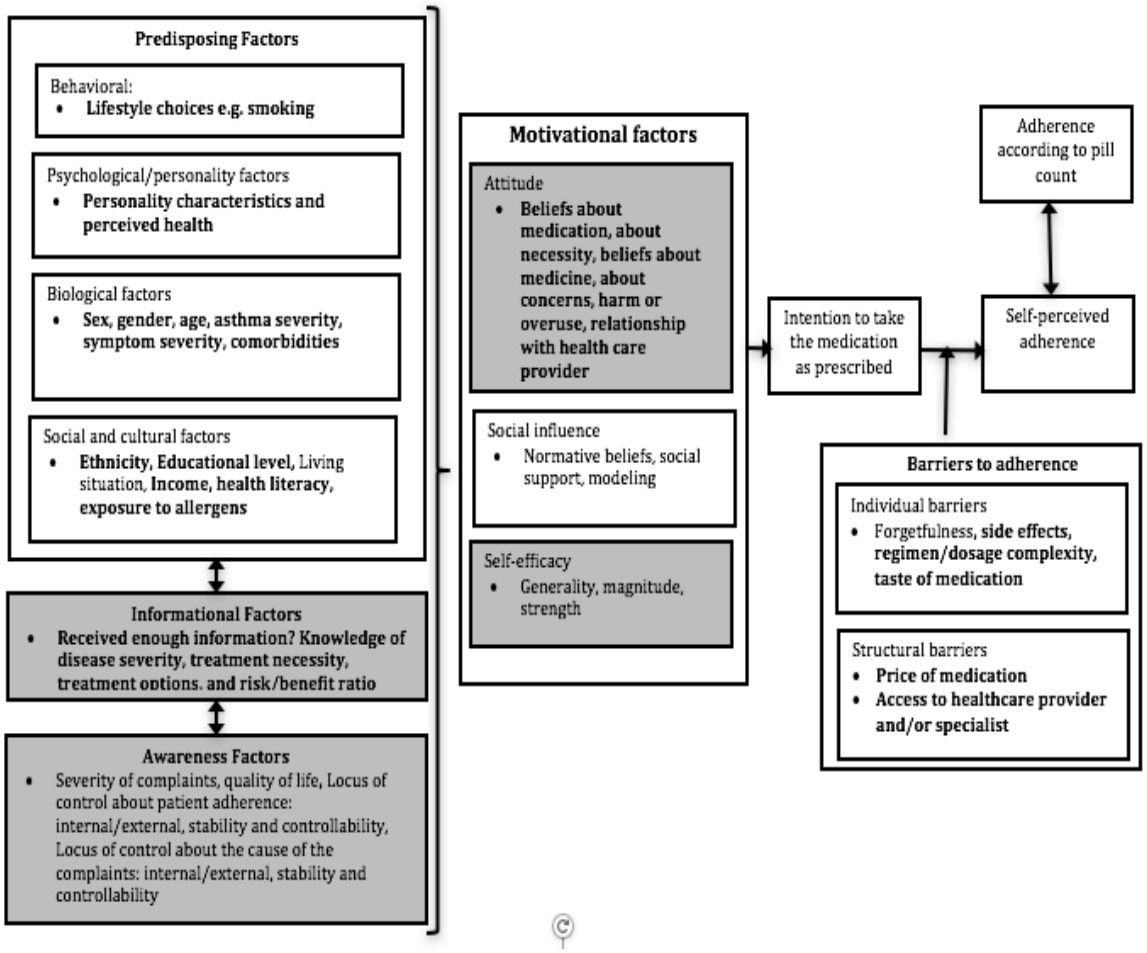


Figure legend
Bold font indicates factors that are associated with adherence to asthma controller medications, as supported by empirical evidence. Grey boxes indicate predictors of adherence that are addressed by SDM interventions.

3.3.1.1 Predisposing factors

Predisposing factors that predict motivation to adhere to asthma controller medications include patient's behavior, personality and biological factors, as well as social and cultural predictors. Personality and biological traits such as neuroticism have been shown to increase adherence to controller medications,(143) as well as patient-reported "good" or "excellent" perceived health.(116,120) African American ethnicity,(104,118,144) lower comorbidity scores,(144,145) mild asthma (compared with severe disease),(144,146) younger age,(144,145) female sex, (119,144,145) the waxing and waning nature of asthma,(147) as well as recent hospitalization (119) have all been associated lower adherence to asthma controller medications. Social and cultural factors such as lower health literacy,(148) less education,(118) lower socio-economic status,(149,150) and lower income (104,118) have also been shown to explain sub-optimal adherence. Knowledge of the disease, severity, treatment options, treatment regimen and dosage among adult patients with asthma, predicts increased adherence, although not to a consistently significant degree.(118,120,151)

3.3.1.2 Motivational factors

Intentional medication adherence requires motivation on the part of the patient to follow the prescribed medication plan. Motivation is informed by a patient's predisposing factors as well as his or her attitude toward their disease, the

medication, and their healthcare providers. Modifiable motivational factors that are associated with poor adherence to asthma controllers include concerns about the medication and dependency,(152) as well as poor patient-physician relationship.(104) Finally, patients who report less fear of medication side effects are more likely to adhere.(118,120) Patients may also be less inclined to adhere to medication if they believe their treatment is ineffective or unnecessary.(146) Some evidence suggests that fear of medication side effects serves as an important predictor of non-adherence to ICS (118), and that such concerns are common among patients. For example, a survey study conducted with adult asthma patients being prescribed an ICS (N=238) found that just under half of participants (44%) reported worrying about the long-term effects of their inhalers.(140) However, a more a recent survey (N=161) found that approximately 79% of patients reported low levels of concern about their ICS.(153)

3.3.1.3 Additional barriers

Despite a patient's motivation to follow their medication regimen, various individual- and system-level factors may serve as additional adherence barriers. Patient-level factors include, but are not limited to, forgetfulness, (154) complexity of treatment regimen,(104,146) as well as patient experience or perception of potential medication side effects (152) including bad taste.(104,119,155) System-level factors that serve as adherence barriers include access to healthcare or more specifically, an asthma specialist, (115,120,146) as well as medication cost.(104)

3.3.1.4 Mediating factors

The relationship between SDM and treatment adherence is unlikely to be simple and linear, but rather it incorporates a range of mediating factors.(156) Although a direct association between lifestyle choices such as smoking and alcohol consumption and medication adherence is unlikely, increased exposure to symptom exacerbating substances may impact a patient's motivation to adhere to controller medication. For example, smoking has been shown to impede the effectiveness of inhaled corticosteroids.(157) Therefore, patients with asthma who smoke may be less likely to continue his or her medication based on the presence of persistent symptoms and the subsequent belief that the medication is ineffective. Other lifestyle choices such as exercise and exposure to allergens may have a similar impact on treatment effectiveness and subsequent adherence.

Other social factors such as living alone, which may be associated with advanced age, sex and the presence of additional comorbidities, have also been shown to predict non-adherence to controller mediations.(158) Predisposing patient characteristics such as illness-specific anxiety may, on the other hand, promote vigilance to disease related symptoms. This increased awareness of asthma symptoms may therefore increase the likelihood of adherence.(159) When assessing the potential effectiveness of any intervention geared toward improving adherence,

one must recognize that multiple patient-specific and structural factors impact a patient's willingness and ability to adhere to their prescribed medication.

3.3.1.5 The role for shared decision-making

In order to ascertain the role for SDM in improving patient adherence, it is important to identify the motivating factors that SDM encounters are able to address. One of the primary components of an SDM encounter is to inform the patient of their disease status and severity, as well as the risks and benefits associated with the available treatment options.(10) Therefore, SDM directly aims to increase patient knowledge. Knowledge serves as an important information factor included in Fransen's adapted theoretical framework, as a predictor of motivation to adhere.

In addition, recent investigations have shown that SDM positively influences patient attitudes towards their disease, treatment options and healthcare providers, by increasing patient satisfaction, satisfaction with the treatment decision, patient participation, emotional status, and by reducing decisional conflict, within various decision contexts.(25,46,47,156,160,161) Factors such as these are situated under the motivational predictors of adherence in the adapted theoretical framework. Interventions or decision support techniques that are adapted to a patient's personal attributes (predisposing factors) with the objective of increasing

knowledge (informational factors) are in turn linked to improved attitude and self-efficacy (motivational factors) (see figure 3.1).

While increased communication between patients and their caregivers may have direct therapeutic effects such as reducing patient anxieties,(162) SDM is likely to further work in an indirect manner by appealing to patients predisposing social, cultural and behavioral characteristics. For example, the physician or care team may apply a decision aid tailored to a patient's specific level of education or health literacy, thereby increasing knowledge and improving attitudes and/or feelings of self-efficacy. Patient empowerment through increased knowledge or ownership of the decision may further increase an individual's perceived ability to adhere. Additionally, through the process of information exchange, providers will consider patient-important factors such as lifestyle and abilities when discussing and weighing appropriate treatment options. Furthermore, SDM promotes communication between patients and their caregivers, which has itself been shown to increase trust, as a predictor of motivation to adhere.(163)

The results of chapter 2 show that there are multiple patient-related factors that physicians believe to be important in determining whether or not to apply an SDM model of care. For example, physicians tend to support SDM in scenarios where patients hold knowledge about their condition as well as the treatment options. As shown, SDM may work directly to improve patient knowledge and awareness,

thereby potentially fostering increased support for engagement from their physicians.

3.3.1.5.1 Existing evidence

Previous investigations have provided strong evidence supporting the relationship between SDM and subsequent adherence, both within asthma,(17) as well as other chronic disease settings.(164) A study published in 2010 assessed the impact of a SDM intervention on multiple asthma related outcomes such as treatment adherence.(17) The 3-arm randomized controlled trial was conducted among poorly controlled asthma patients to determine the effect of: a) a SDM intervention; b) a clinical decision making (CDM) intervention wherein patient goals and preferences were not elicited and the asthma care managers recommended a treatment option to the patient based on current asthma guidelines; and c) usual care. The average lengths of the initial SDM and CDM intervention visits were 106 and 77 minutes, respectively.

Compared with the usual care control group, SDM intervention patients were more adherent over the 12-month follow up ($p<0.001$), had better asthma control, ($p=0.002$), fewer asthma-related medical visits ($p=0.0161$) and higher quality of life scores ($p<0.001$). Over the 12-month follow up period, adherence in the SDM intervention arm was significantly higher than the CDM arm ($p =0 .029$).

Patients in the SDM arm acquired more beclomethasone canister equivalents) (p=0.005), inhaled corticosteroid- long acting beta antagonist (ICS-LABA) and combination inhalers (p=0.005), compared with the CDM arm. Patients in the SDM intervention arm showed improved asthma control (p=0.42), and improved quality of life (p=0.33), although not to a statistically significant level. At follow-up year 1, the mean adherence for the SDM group was 67% compared with 59% in the CDM arm (p= 0.029) and 46% in the usual care arm (p= <0.0001). Adherence was measured using continuous medication acquisition for all controllers. The adherence measure ranged from 0-100% with 100% indicating perfect adherence over the follow up period.

Over the 2-year follow up, adherence to all controllers remained higher in the SDM intervention arm (approximately 47%) compared with CDM (approximately 42%); however, the difference was not statistically significant (p=0.34). Adherence in the usual care group was slightly higher than that of the CDM arm, at 2-year follow up (approximately 43%). As well, SDM intervention patients showed significantly higher regimen potency (p=0.04) and use of combination inhalers at 2-year follow up. Although results were not statistically significant in year 1 or 2, patients in the SDM arm also used less rescue medications, which may be interpreted as an indicator for a greater reduction in asthma symptoms among SDM intervention patients compared with CDM patients. This result is important from a risk-reduction

standpoint, wherein negative health outcomes such as ER admissions and increased healthcare costs are associated with excessive use of rescue medication.(165–167)

The SDM intervention was successful in addressing both predisposing and motivational predictors of adherence. Via the use of information provision, identifying patient goals and preferences, discussing treatment options in light of patient-reported goals and preferences, and negotiation of a final treatment decision, the SDM intervention improved a range of asthma-related outcomes, particularly over the 12-month period. The increased medication adherence and potency and decreased use of rescue medications in the SDM arm may be interpreted as indicators not only of improved knowledge and attitudes about their disease and treatment plan, but also their perceived locus of control and self-efficacy. As previously argued, SDM may empower patients and provide them with the confidence to manage their disease, and increase the perception that they are in control of their illness.

Despite the promising results, several years have passed since this trial was published yet little progress has been made towards implementing SDM into clinical practice.(27) Since SDM is so well supported throughout the policy and academic literature, and interventions such as this one have shown to be effective in improving various patient and clinically important outcomes, why is it not commonplace in clinical settings?

3.4 Implementation challenges

As is so often the case, challenges arise when attempting to implement interventions into clinical practice that have proven themselves to be effective within the confines of well-funded and controlled research venues. As described above, although Wilson et al.'s findings are promising, one concern is whether a similar intervention could be successfully implemented into practice, since healthcare budgets tend not to provide funding for allied health professionals to educate asthma patients. Additionally, the time required to complete similar interventions may not be feasible. A recent review conducted by Stacey and colleagues found that the average time to complete a decision aid intervention is 24 minutes.(26) Particularly in areas that adhere to fee-for-service physician payment models, a lengthily time investment may be an insurmountable barrier to implementation. When asked, physicians frequently cite the time required to engage patients as a significant deterrent to implementing SDM into their practice.(168) Further to this, the costs associated with the proposed intervention and associated time ought to be carefully considered in conjunction with the potential benefits.

Structural processes may serve as additional impediments to SDM through limiting the choice of treatments available. For example, under specific health insurance structures, especially those with limited list formularies, physicians may be permitted to offer only a selection of the available treatment options. In these cases,

the role for patient values and preferences may be limited in light of fewer treatment options.

More recently, investigations have begun to assess efforts to incorporate SDM into clinical practice.(22,169–171) Tapp and colleagues engaged patient and healthcare providers in implementing an asthma-related SDM delivery intervention into 6 practices in the United States.(22) The intervention was well received by both patients and physicians, and participating practices intended to continue the intervention beyond the completion of the study. Although this particular study did not assess outcomes such as improvement in asthma control, adherence or patient satisfaction with treatment, it is a first step to address the ongoing challenge of incorporating SDM into clinical practice. However, the limited evidence that has been produced with regard to SDM implementation further supports the need for a more comprehensive assessment of the current state of SDM in current practice.

3.5 Research implications

While policy makers, physicians and their patients' support increased patient engagement, the evidence particularly regarding clinically important outcomes associated with SDM has been slower to develop. Within the context of asthma, strong evidence suggests that SDM interventions can provide benefits related to adherence, control and symptom resolution. However, little has been done in the last several years to implement SDM into the clinical areas that promise the most benefit. Here, I suggest that future research investigations seek not only to

determine the efficacy of SDM interventions, but also to provide insight into the more prominent effectiveness challenges, namely implementation into clinical practice settings.

Chapter 4 will provide the groundwork for a more comprehensive investigation into the role for SDM in asthma management. Using a large, population based sample of adult asthma patients living in British Columbia, I will answer the following two research questions:

1. What is the prevalence of non-adherence among adult asthma patients who are currently being prescribed controller medication?
2. To what extent can variables related to individual patient demographics and disease severity use explain variation in adherence?

Investigating these two research questions will allow me to further establish asthma as an appropriate venue within witch to ascertain outcomes related to SDM. Furthermore, I aim to highlight the issue that adherence is a complex phenomenon and variation is likely to be influenced by multiple factors, at least some of which can be addressed through the patient-physician encounter.

Chapter 4: Variation in adherence to controller medications in British Columbia: A population-based analysis

4.1 Background

As described in chapter 3, asthma results in a heavy patient and healthcare system-level burden in many jurisdictions including British Columbia,(172) and adherence to asthma therapies is sub-optimal among both pediatric and adult patients.(105,106,121,145,173) Disease control is directly related to adherence to controller medications, and is consistently poor among asthma patients.(105) Furthermore, poor control is associated with decreased quality of life, increased healthcare expenditures, and in the absence of regular anti-inflammatory therapy, potentially death.(103,105,111,174) An important aspect of evaluating adherence and preventing non-adherence is to identify factors that are associated with non-adhere to controller medications. The present chapter consists of a population-level multivariate analysis to investigate demographic and disease related variables that are associated with treatment non-adherence.

4.1.1 Evidence gaps

Multiple studies have been conducted to assess the potential impact of both modifiable and non-modifiable factors on treatment adherence, but uncertainties

remain with regard to the role of various patient-related factors. Prior to selecting variables for the current analysis, a brief review of the literature was conducted to determine which administrative data variables have been used previously to address issues related to asthma controller use. A review of these studies provided insight into how best to capture concepts such as disease severity, using pharmacy records databases. The review produced two types of primary data collection studies, those that do not explicitly provide associations between explanatory variables and treatment adherence (see appendix C), and those that explicitly consider predictors of controller adherence (table 4.2). Based on the results of the literature review, table 4.1 describes both modifiable and non-modifiable factors that have been shown to predict adherence and non-adherence to asthma controller medication, using both experimental and observational study designs. Some factors listed as "modifiable" may be considered to be more long-term goals of increased communication between patients and their care givers (e.g. changing beliefs and attitudes about medication necessity). For example, the role of age,(175–178) sex,(145,178,179) communication with healthcare providers,(145,175,177) has not been adequately established using the available literature. While some evidence supports the claim that lower socio-economic status is associated with poor adherence, results across studies have not been consistent.(145,175,179–181) At least some of the variation in study findings may be due to the considerable variation in study designs, definitions used for adherence, as well as the source and objectivity of the information obtained. Developing a clear picture of the factors that

are associated with variation in adherence will aid in the development of strategies geared toward increasing adherence among at-risk populations.

Table 4.1: Factors independently associated with adherence and non-adherence to asthma controller medication

	Non-modifiable factors	**(Potentially) Modifiable factors**
Factors associated with higher adherence	• Female sex,(179) • Higher age (177,178,182) • Increased length of time since diagnosis (181) • Greater asthma severity (177,178,182)	• Higher self-reported mental health scores (as measured using theSF-36)(181) • Length of time a patient spends with prescriber (177) • Increased self-perceived asthma severity (179,181) • Presence of a fixed asthma medication routine (179) • Having taken physician's advice regarding medication (179) • Belief that controller medication is important (179) • Belief that controller medication is effective (179,181) • Belief that controller medication is necessary (175) • Understanding the benefits of ICS (118) • Belief in the benefit of asthma exacerbation trigger avoidance (181) • Higher number of metered dose instructors (e.g. physicians, respiratory therapists, nurses) (181) • Once daily medication regimen (versus >once daily regimen) (182)
Factors associated with higher non-adherence	• African American ethnicity (118,145,182) • Younger age (145) • Female sex (118,145,182) • Impulsivity (183)	• Lower rescue medication use (145) • Doubts about medication necessity or importance (175,179) • Perceived lack of asthma symptoms (179) • Fear of side effects (175) • Poor communication with health care

Table 4.1: Factors independently associated with adherence and non-adherence to asthma controller medication		
	Non-modifiable factors	**(Potentially) Modifiable factors**
		provider(180) • Concerns about medication (175) • Lower education (180)

Results of the literature review show that administrative variables used to consider research questions related to asthma include patient demographics (e.g. age and sex),(117,178,184) comorbidities,(117) socioeconomic status (e.g. social assistance status and area of residence),(117,178,184) inpatient and outpatient health resource use (e.g. emergency department [ED] and outpatient visits),(121,178,184) and indicators for asthma severity and control (e.g. short acting beta agonist [SABA] and oral corticosteroid [OCS] use).(117,121,178). One study also considered the number of prescribing physicians and prescribing physician's specialty (see appendix C).(184) Likely due to the fact that inhaled corticosteroids (ICS) are most commonly prescribed as part of long-term asthma treatment, such medications were consistently included in the outcome measure.

Table 4.3 shows the methods and results of three studies that were conducted to explicitly explore predictors of controller medication adherence, using pharmacy records databases. Jones et al (2003) sought to determine whether adherence differed between patients being prescribed oral versus inhaled controller therapy, using pharmacy claims data.(185) Authors investigated differences in adherence

rates across treatment regimens. A more recent study conducted by Wells et al (2013) investigated whether once versus multiple daily dosing of controller medication predicted treatment adherence, using data extracted from an electronic prescribing database.(182) Finally, Taylor et al (2014) investigated the role of various demographic and disease related predictors of adherence to ICS medication, using the UK's Clinical Practice Research Datalink (CPRD) database.(177)

Across the three studies, patient-level factors related to increased adherence included older age,(177,182,185) exacerbations,(177) and previous adherence. In addition, annual improvement in severity status was associated with increased adherence to ICS. Conflicting results can be seen with regard to the impact of disease severity on adherence.(177,182,185) One study considered the role of continuity of care, as indicated by the length of time that the patient spent in the cohort, and therefore with a prescriber.(177) Considering the evidence from the three existing investigations into adherence using administrative data, the role of socioeconomic status, sex and continuity of care and disease severity are not well established.(177,182,185) As shown in table 4.2, p-values are not consistently reported in the individual studies.

Table 4.2: Primary data collection studies utilizing administrative data explicitly assessing predictors of adherence to controller medication of effect in relation to higher adherence				
First author (date of publication)	**N**	**Medications included in definition of "controller" (Adherence measure)**	**Explanatory variable (indicator)**	**Direction of effect (P-value)**
Jones, 2003 (185)	23,225	ICS, LTRA, LABA (sum of days' supply of prescriptions dispensed from index prescription date to last refill date/ duration of therapy)	Number of SABA prescriptions (Disease severity) Age	Increased (P-value not reported) Increased (P-value not reported)
Wells, 2013 (182)	1302	ICS	Age Female sex Number of oral corticosteroid and SABA fills in the year prior to the index date (Disease severity) Patient being prescribed additional controller medication	Increased (P-value not reported) Not reported Increased (P-value not reported) Not reported
Taylor, 2014 (177)	97,456	ICS (Prescription possession ratio)	Age (years) The number of years patient spent in the cohort (Continuity of care) Average SABA doses per day (Asthma control) BTS/SIGN guidelines indicators for asthma	Increased (P<.05) Increased (P<.05) Increased (P<.05) Decreased

Table 4.2: Primary data collection studies utilizing administrative data explicitly assessing predictors of adherence to controller medication of effect in relation to higher adherence				
First author (date of publication)	**N**	**Medications included in definition of "controller" (Adherence measure)**	**Explanatory variable (indicator)**	**Direction of effect (P-value)**
			severity	(P<.05)
			Number of exacerbation-related hospitalizations and asthma exacerbations treated in primary care (Exacerbations)	Increased (P <.05)
			Previous adherence	Increased (P<.05)
			Annual improvement in asthma severity status	Increased (P<.05)

Regarding the outcome measure used to estimate adherence, there is a lack of consistency regarding the specific medications included. The two more recent analyses include only ICS in the definition of adherence,(177,182) while Jones et al (2003) include ICS, LTRA, and LABA medications.(185) Likely due to the frequency of ICS prescriptions, ICS are consistently included in the adherence outcome measure.(117,121,177,178,182,184,185)

Based on the existing literature, several evidence gaps exist. Firstly, to the best of my knowledge, no comprehensive population-level analysis has considered demographic and disease-related predictors of adherence, where the outcome measure includes all controller medications. Doing so will capture patients who switch controller medications during the study period, but maintain overall adherence.

Secondly, the role of continuity of care is not well established and warrants further investigation. Specifically, understanding the underlying mechanism that links regular communication with one or a few prescribing healthcare providers to adherence may further highlight the importance of the patient-physician relationship.

Thirdly, the current evidence does not provide an overall estimate of the extent of variation in adherence that can be explained by specific predisposing predictors of adherence (see chapter 3 theoretical framework), such as demographic and

severity-related variables. Providing an overall coefficient of variation will aid in determining whether additional patient-level variables ought to be more carefully considered when both predicting and explaining adherence in this population. This may further establish the role of SDM to address informational and motivating predictors of adherence (see chapter 3 theoretical framework).

Finally, no previous population-level analysis has specifically sought to determine the extent to which adherence to controller medication varies by calendar month. This analysis will add to the existing literature by investigating monthly variation in adherence over a one-year period. As previously stated, prospective analyses using annual measures of adherence typically show low adherence. One hypothesis to explain this finding is that adherence may fluctuate according to environmental triggers that are attributable to seasonality, even in light of the fact that controller medication is intended to be taken regardless of the presence of symptoms.(186–188) Simple yearlong measures of adherence fail to capture the potential for seasonal variability. For example, healthcare use such as ED admissions have been shown to increase during the spring and fall months, among both pediatric and adult populations.(188,189) Correspondingly, it is possible that adherence to controller medication may follow a similar pattern. Although this phenomenon has been suggested, limited population-level evidence exists to support this claim. Previous evidence supports the argument that patients in generally good health have less incentive to adhere to their treatment plan, while adherence improves in the presence of increased exacerbations.(177) Providing a more comprehensive

description of the extent to which patients in various severity categories practice seasonal variation in adherence may serve as a useful tool to physicians treating asthma patients, specifically to identify patients with severe and uncontrolled disease who may benefit from increased and consistent adherence to their treatment plan.

4.1.2 Research objectives

The purpose of the current analysis is to address the following two primary research questions:

a) Research question 1: What are the characteristics of asthma patients who do not fill their controller prescriptions during a one-year period?
b) Research question 2: Which demographic and disease-related factors can explain variation in adherence to controller medications?

and the following secondary research question:

c) Research question 3: Does adherence to controller medications vary by calendar month?

All inferences, opinions, and conclusions drawn in this study are those of the authors, and do not reflect the opinions or policies of the Data Steward(s).

4.2 Methods

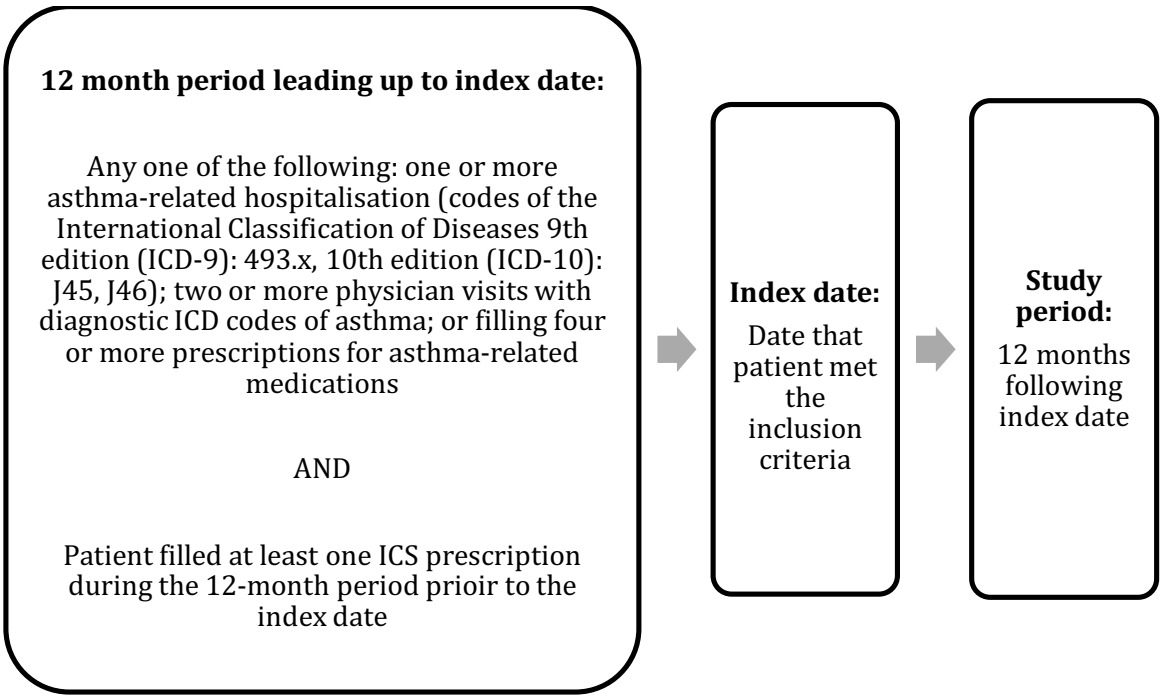
4.2.1 Patient cohort

The BC provincial health insurance program collects information on the health resource use of every legal BC resident. Population Data BC provides data linkage as well as access to the health services database.(190) For the current study, data for fiscal years 1997 to 2011 were retrieved.(191–194) The following components were extracted from the vital statistics, registry and census databases: patient demographics, neighborhood income, and registration status of each subject with the BC provincial health plan.(121) Secondly, the Medical Services Plan (MSP) collects all outpatient services that result in a billing record and includes at least one ICD-9 code for the service. In addition, MSP captures the cost of the service and the specialty of the healthcare professional issuing the code. Thirdly, BC PharmaNet Database records drug dispensations in BC, except for those of First Nations, The Royal Canadian Mounted Police, and the military.(121)

Patients were considered to have asthma using a validated case definition.(195,196) The definition required each patient to have at least one of the following criteria within a 12-month period between 1997 and 2011: one or more asthma-related hospitalization (codes of the International Classification of Diseases 9th edition (ICD-9): 493.x, 10th edition (ICD-10): J45, J46); two or more physician visits with diagnostic ICD codes of asthma; or filling four or more prescriptions for asthma-related medications (see figure 4.1). For the current analysis, patients were required to satisfy the case definition of asthma described above, and to have filled at least

one prescription for an ICS within the 12-month period prior to the index date. The purpose of requiring a previous prescription for an ICS was to increase the probability that the analytic sample would include only asthma patients who were being prescribed controller medications on a long-term basis. I sought to exclude mild asthma patients who were not being prescribed controller medications for their ongoing disease management.

Figure 4.1: Study process



The sample was further limited to adult patients between the ages of 18 and 55. Adults above the age of 55 were excluded to reduce the likelihood that those with chronic obstructive lung disease (COPD) may be falsely categorized as having asthma.(196)

The "index date" was defined as the date at which each patient met the asthma case definition. Patients included in this analysis were required to be enrolled in the database for 12 months leading up to the index date, and 12 months following the index date, in order to be able to ascertain a 12-month measure of adherence. Each patient was followed for 12 months following the index date for the purposes of this analysis, in order to assess adherence. Therefore, the study period constitutes the 12-month time frame following the index date.

4.1.2 Statistical methods

4.2.2.1 Primary outcome variable

Controller medications were defined as ICS, ICS with LABA, LABA alone, leukotriene receptor antagonists (LTRA) or theophylline. Adherence was defined as the proportion of days covered (PDC) during the follow-up period. Proportion of days covered was calculated as the number of days in the one-year period following the index date. Therefore, a PDC of 1 (or 100%) indicates that the patient filled enough prescriptions to be covered for an entire year (365 days), suggesting perfect adherence. A PDC of 0 (or 0%) indicates that a patient did not fill a single asthma controller prescription during the index period (e.g. 0 days covered). Proportion of days covered is a commonly used and recommended measure of adherence calculated using administrative data.(195,197–199) In contrast to other measures such as the medication possession ratio (MPR), PDC provides a more conservative

estimate of adherence, and does not allow for a calculation above 100% (as it does not double count medications with overlapping prescription times).The use of PDC has been validated in multiple disease contexts.(200)

To assess the prevalence of seasonal variation in adherence, an indicator variable was calculated to determine whether or not each patient filled a controller medication prescription during each individual month of follow up.

4.2.2.2 Explanatory variables

Demographic explanatory variables include neighborhood income quintile as an indicator for socioeconomic status (neighborhood income quintile), sex, and age.

The Bice-Boxerman continuity of care (CoC) measure was included in the current analysis.(201) The measure captures the extent to which the patient visited multiple care providers during the 12-months prior to the index date. A CoC measure of 1 indicates that the patient saw exactly one GP or specialist during this period. As the CoC score decreases, a greater number of care providers were visited, indicating a lack of CoC.(201) Previous evidence shows that higher CoC is linked to lower healthcare expenditures, and higher overall quality of care.(201) In addition, CoC may be an indicator of patient-physician communication,(202) which in turn may predict treatment adherence (see chapter 3). Continuity of care related to GP visits was indicated by an outpatient visit with the general practitioner (ICD code: 00). Continuity of care related to specialist physicians was indicated by an outpatient

visit with codes related to internal medicine, clinical immunizations and allergy, and respirology (ICD: codes 15, 45 and 49).(203,204)

Frioozi et al. have developed a combined measure to estimate asthma severity based on administrative health data. The measure categorizes patients into "mild," "moderate," and "severe" disease based on previous 12-month average daily doses of ICS, LABA, LTRA, theophylline, SABA, as well as indicators for asthma exacerbations, such as the use of oral corticosteroids, asthma-related ED admissions, and hospitalizations.(182,205,206) This measure has been validated against the Canadian Asthma Consensus Guidelines, is correlated with lung function, asthma-related hospitalizations and asthma exacerbations,(195,205) and has been used in previous studies as a measure of severity using administrative data.(195,196,207) To describe healthcare use and asthma-related exacerbations during the study period, number of asthma-related hospitalizations and ED visits were obtained, along with number of oral corticosteroid and SABA prescriptions filled. ED visits were calculated using an algorithm based on fee-for-service physician payments, ambulance data, and hospital admissions data. This measure has previously been validated against objective ED data provided by BC's Ministry of Health.(208) Results of the validation study found that the algorithm was able to capture approximately 83% of ED visits, through the use of administrative datasets. Variables related to health resource use and rescue medication are included in the severity measure, and therefore are presented here only in the descriptive univariate analysis.

As an indicator of patients' overall health and comorbidities, the Charlson comorbidity index (CCI) was calculated for each patient. The CCI is a widely used measure of number and severity of comorbidities that is commonly calculated using administrative datasets.(203,204,209)

Finally, given that patients were enrolled into the cohort over an extended period (1997 to 2011), the potential for a period effect was captured by including the year that each patient entered the cohort.

4.2.2.3 Multivariate modeling

To address the first research question, a multivariate logistic regression was conducted to determine whether significant differences exist between those patients who filled at least one controller prescription during the study period, and those who filled no controller prescriptions during the study period. To address the second research question, a multivariate linear regression analysis was conducted, wherein PDC was included as a continuous variable. It was expected that adherence would follow a non-normal distribution and therefore would not facilitate a linear regression analysis. Furthermore, I anticipated that a proportion of patients may have not filled any prescriptions during the index period, resulting in a PDC of 0. For this reason, it is unlikely that the conditions for the validity of inference based on linear regression (namely the normality of residuals) would be met. As such, a linear regression with parametric bootstrapping was considered.(210) In this approach,

inference (calculating p-values, quantifying confidence intervals) is made through generating multiple bootstrap sets of data and fitting linear regression separately within each set. P-values and confidence intervals were then derived from the point estimates of regression coefficients across bootstrap sets.

Both multivariate models were constructed to include all explanatory variables that explained adherence at the p=0.05 significance level. To address multicollinearity at the multivariate level, changes to standard errors and effect estimates were reviewed. For the linear model, multicollinearity was further addressed by reviewing tolerance statistics. A tolerance of less than 0.01 (and a corresponding variance inflation factor above 10) may indicate potential multicollinearity.(211)

Finally, to address seasonal variation in adherence, descriptive statistics were produced to determine whether any clear patterns exist, across various disease severity levels. All analyses were conducted using SAS Enterprise 4.3, Cary, NC, USA.(212)

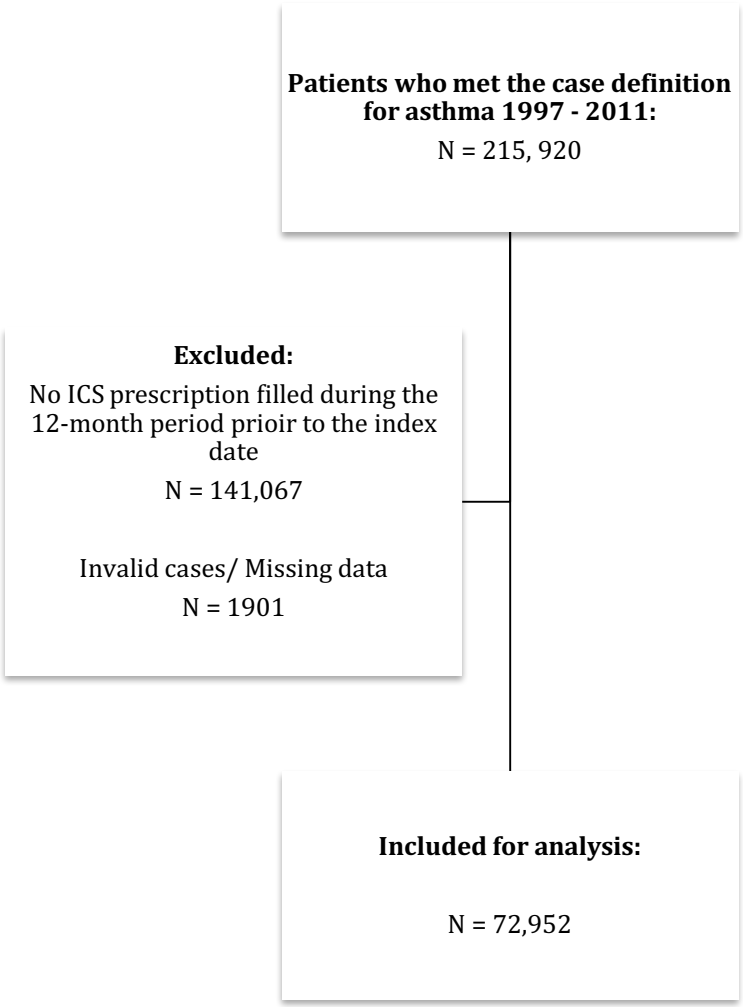
4.3 Results

4.3.1 Characteristics of the study sample

A total of 215, 920 patients met the case definition for asthma during the entire study period (1997 to 2011). After applying additional exclusions, 72,952 patients

were included in the analysis. Given the minimal amount of missing data points (2.5%), I applied case-wise deletion to handle the missing data (see figure 4.2).

Figure 4.2: Study flow diagram



4.3.2 Descriptive statistics for explanatory variables

The mean age of this sample was 37 years (SD: 11) (see figure 4.3). Thirty-six percent of the sample was male. Socio-economic status was relatively evenly distributed across the 5 categories (see tables 4.2 and 4.3).

Ninety-four percent (N = 68,597) of the patient sample was identified as having mild asthma, while 5.1% (N = 3,703) and 0.9% (N = 684) were moderate and severe, respectively. During the 12-month period prior to the index date, 6.5% of patients visited an asthma specialist, while 55% of patients visited a GP for their asthma.

During the 12-month period following the index date, 99.2% of the sample was not hospitalized for an asthma-related reason. The number of hospitalizations among the remaining 480 patients ranged from 0-16. Some 4.5% of the patient sample was admitted to the ED for asthma related reasons at least once. Thirty-one percent of the patient sample did not fill any SABA prescriptions, while the remaining 70% filled between 1 and 50 SABA prescriptions. Over 98% of patients filled 12 or fewer SABA prescriptions during the 12-month period following the index date. Eighty-five percent of the sample did not fill any oral corticosteroid (OCS) prescriptions during this period, while the remaining fifteen percent filled between 1 and 67 OCS prescriptions. Close to 100% of patients filled 12 or fewer OCS prescriptions during the 12-month period following the index date. Only 10 patients filled greater than 21 prescriptions for an OCS during this period.

Among 70,045 patients who had visited a GP during the index period, the mean value was 0.5 with a median of 0.045 (see figure 4.3). Among 18,592 patients who had visited a specialist during the index period, the mean value was 0.17 and a

median value of 0.03 (see figure 4.4), which suggests a highly skewed and bimodal distribution. Both of these measures indicate overall low continuity of care.

Figure 4.3: Continuity of Care Index (GP)

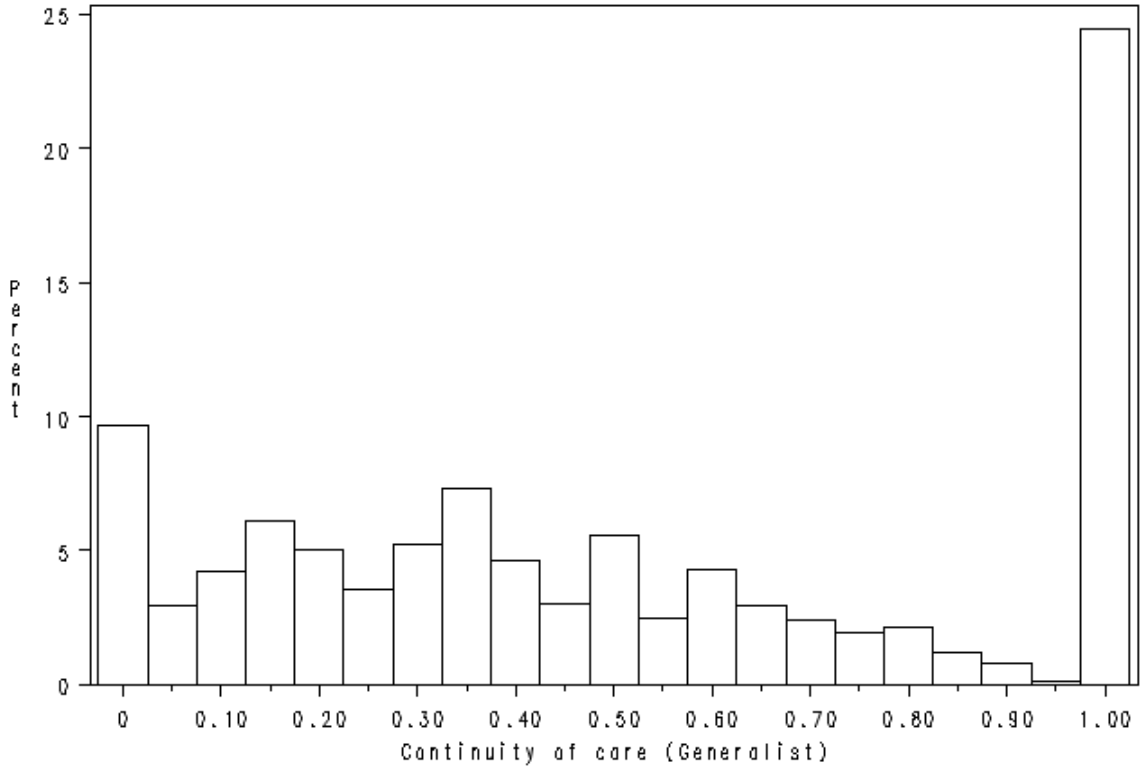
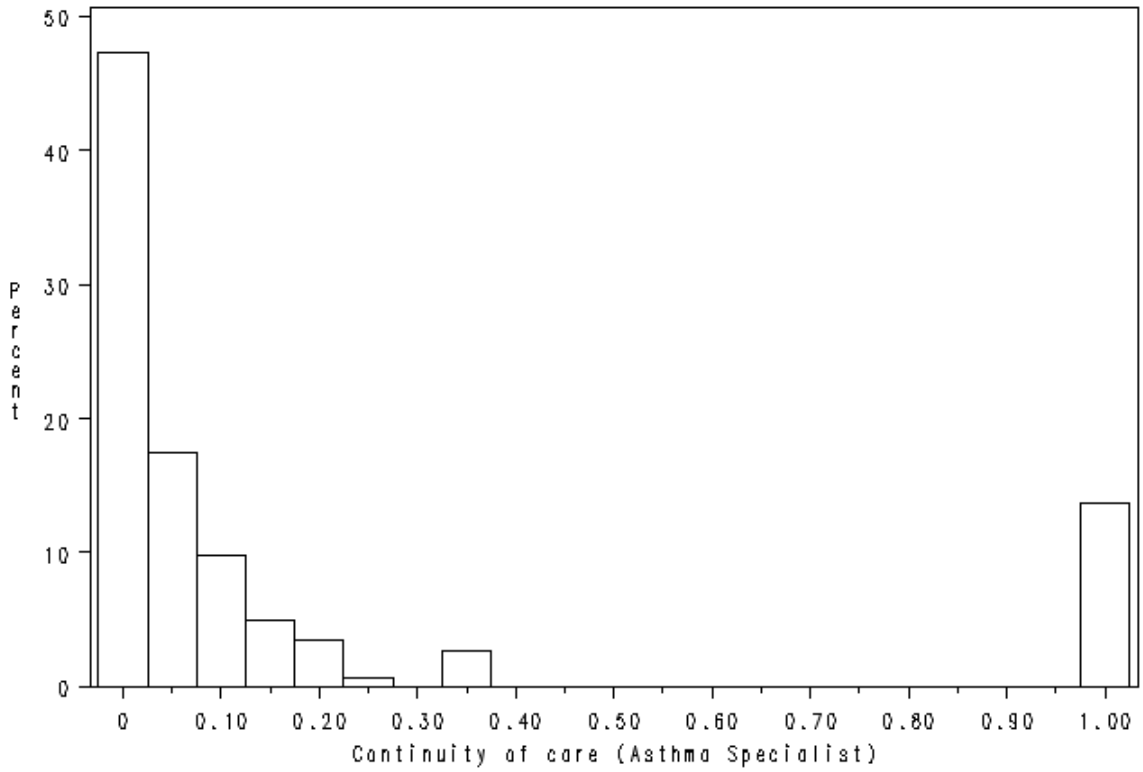
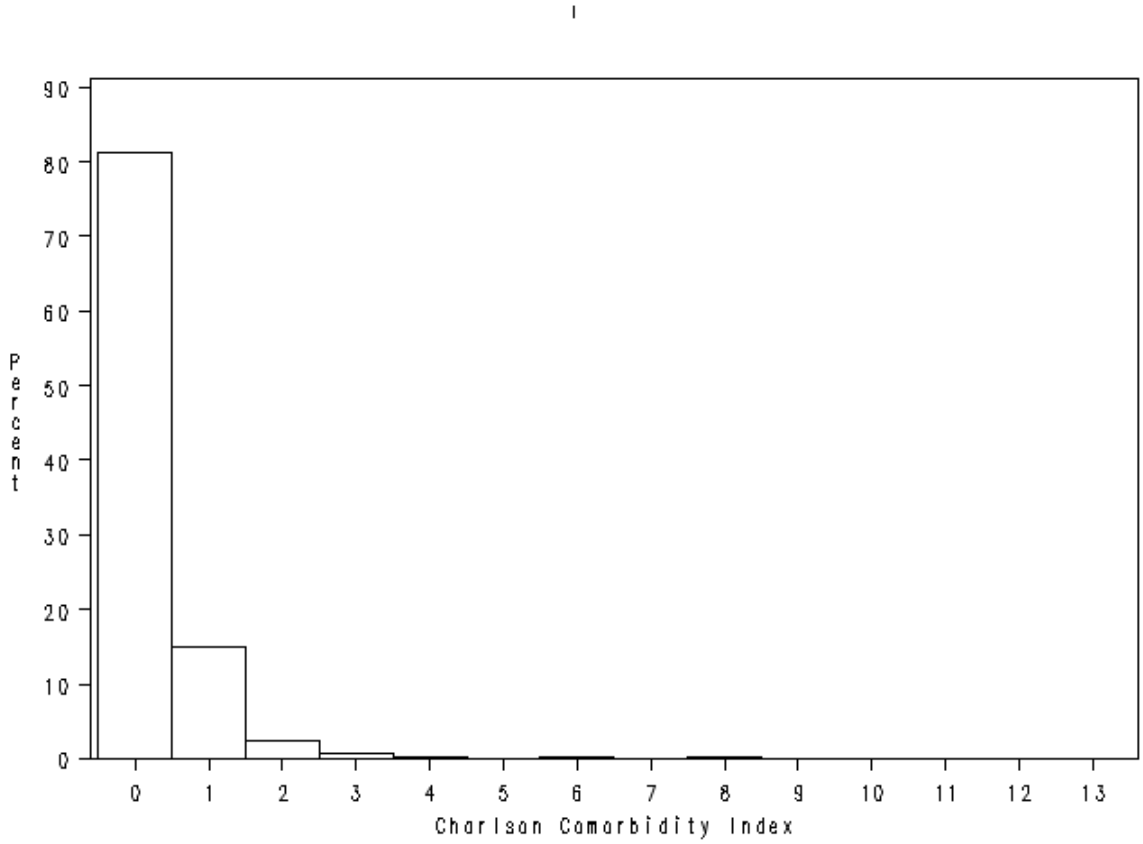


Figure 4.4: Continuity of Care Index (Asthma Specialists)



As a measure of patient comorbidities, CCI scores ranged from 0-13 with a mean of 0.27 and a median of 0. The distribution of CCI was highly skewed, with 96% patients having a CCI of 0 or 1. (see figure 4.5)

Figure 4.5: Charlson comorbidity index



Finally, 45% of patients entered the cohort prior to 2000, and the highest proportion of patients (23.28%) entered the cohort in 1997 (see figure 4.6). See tables 4.4 and 4.5 for a description of each variable distribution. The highly skewed distribution is not surprising in light of the fact that enrollment into the cohort began in 1997.

Figure 4.6: Distribution of year of cohort entry

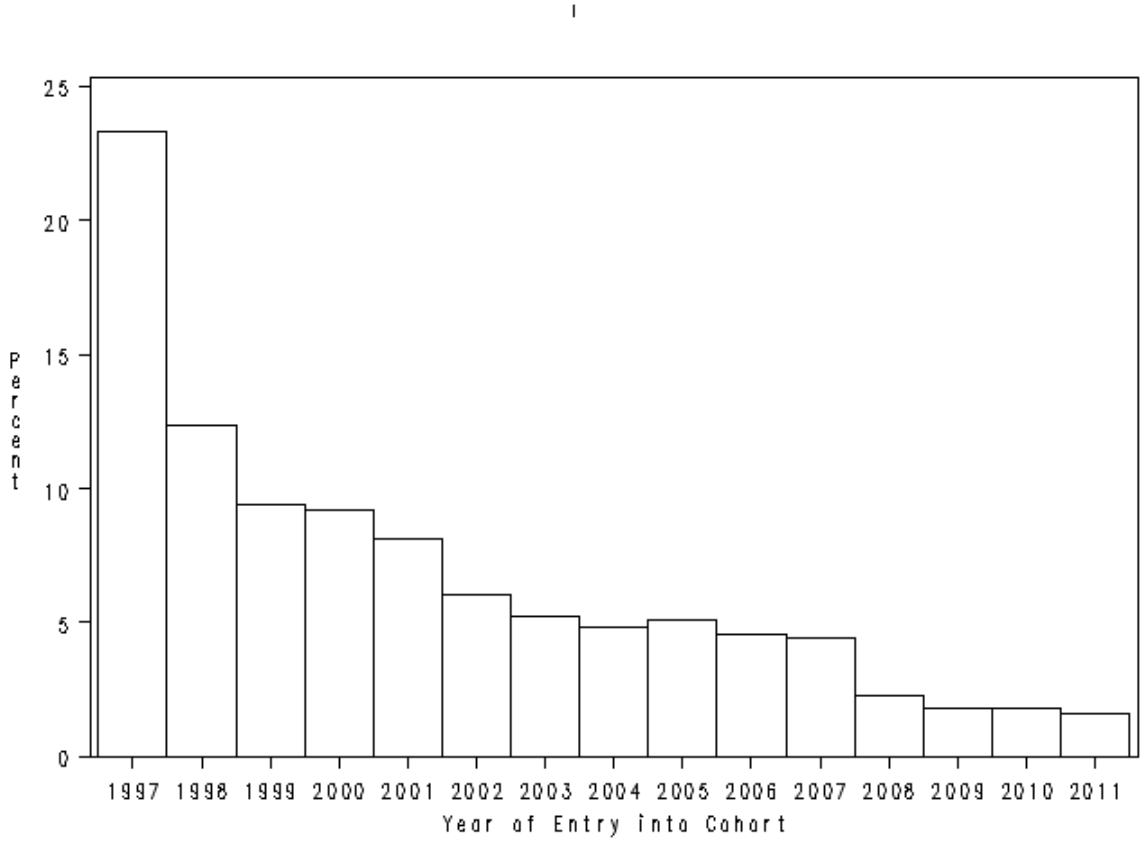


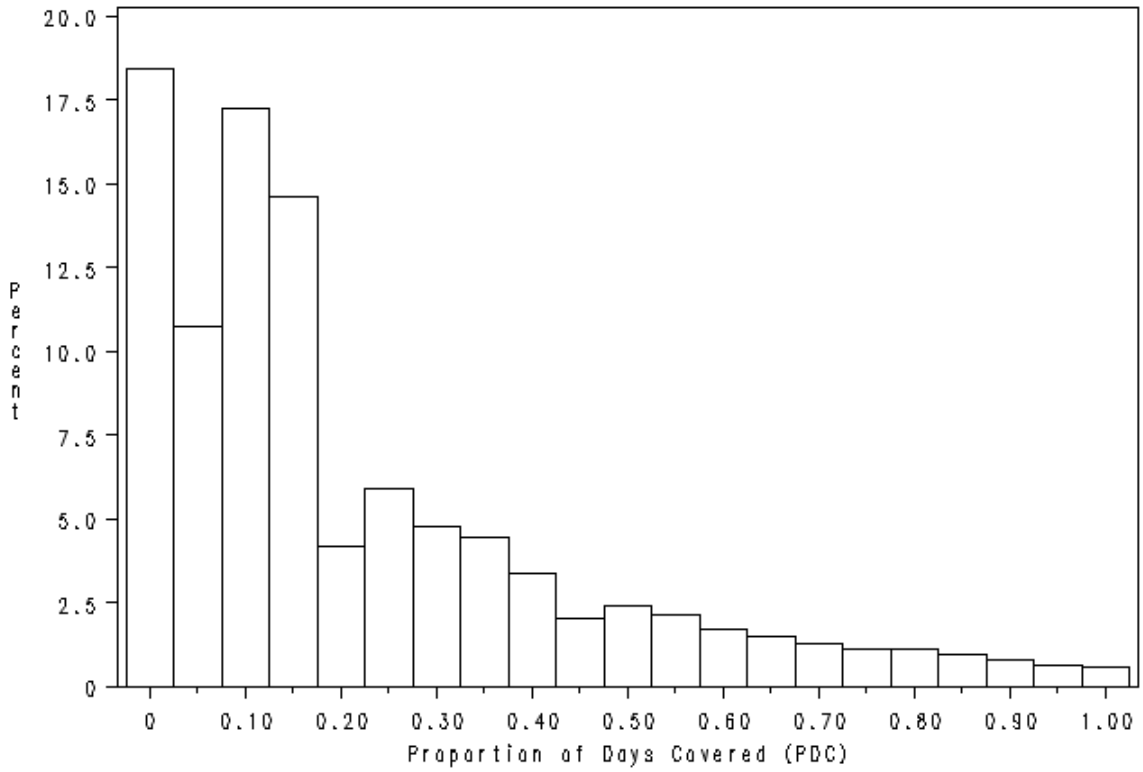
Table 4.3: descriptive statistics for continuous variables **N= 72,952**					
Continuous Variable	**Range**	**Mean**	**SD**	**Median**	**IQR**
Adherence (PDC)	0-100	21.7%	22.8%	13.9%	24.38%
Age	18-55	37.43	11.03	38.5	18.39
Charlson comorbidity index	0-13	0.27	0.77	0	0
Number of SABA prescriptions filled (12-month period following index date)	0-50	2.06	3.02	1	3.0
Number of OCS prescriptions filled (12-month period following index date)	0-67	0.27	0.98	0	0
Continuity of care GP Specialist	 0-1 0-1	 0.5 0.18	 0.35 0.33	 0.45 0.03	 0.69 0.13

Table 4.4: descriptive statistics for categorical variables **N= 72,952**	
Categorical variable	**Frequency**
Controller prescription filled (12-month period following index date)	83.4%
Sex Male	 36%
Year of cohort entry 1997-1999 2000-2002 2003-2005 2006-2008 2009-2011	 45.0% 23.3% 15.2% 11.3% 5.2%
Socioeconomic status Quintile 1 Quintile 2 Quintile 3 Quintile 4 Quintile 5	 22.12% 20.85% 19.93% 19.26% 17.83%
Patients with at least one asthma-related GP visit (12-month period leading up to index date)	55%
Patients with at least one asthma-related Specialist visit (12-month period leading up to index date)	6.5%
Patients with at least one asthma-related ED visit (12-month period following index date)	4.5%
Patients with at least one asthma-related hospitalization (12-month period following index date)	0.008%
Firoozi severity index (12-month period leading up to index date) Mild asthma Moderate asthma Severe asthma	 94% 5% 1%

12-month Proportion of Days Covered

83.4% of the sample filled at least one controller medication prescription during the study period (see figure 4.7). The distribution of adherence was positively skewed with a median PDC of 13.9% (IQR: 24.38%)

Figure 4.7: Distribution of Adherence as measured by PDC



Among those patients with a PDC >0, adherence ranged from 0.27% to 100% with a mean of 26.1% (SD: 22.6%) and a median of 16.9% (IQR: 27.12%) Only 35.6% of the sample had a PDC greater than 75% indicating overall poor adherence with substantial variation, consistent with previous research.

4.3.3 Re-categorization of continuous variables to facilitate bivariate and multivariate analysis

Following initial data exploration, CCI, CoC, and year of cohort entry were categorized based on their distributions. Although there is no well-determined

threshold for categorizing the Bice-Boxerman CoC Index, previous investigators have used the distribution to inform the categories.(213,214) For both specialist and GP CoC variables, a substantial number of patients did not visit a healthcare provider during the index period (see section 4.3.2). These individuals are categorized as "No GP visits during the index period." Among those that did visit a GP or specialist during the index period, CoC variables range from 0-1. Charlson comorbidity index was re-defined into three categories: those with a CCI of 0, 1 and greater than 1, given the highly skewed nature of the distribution. Finally, to reduce the number of "year of entry" categories, the variable was re-defined using 3-year differentials.

Where appropriate (e.g. age and CCI) multiple categorizations were tested. Likely given the large sample size and corresponding small effect sizes, the impact of alternative cut points was minimal. Therefore, the original variable distributions were maintained (e.g. age) or categorized according to meaningful thresholds (e.g CCI and CoC).

4.3.4 Research question 1: What are the characteristics of asthma patients who do not fill their controller prescriptions?

At the bivariate level, all potential explanatory variables were significantly associated with the dichotomous outcome variable (PDC = 0, PDC >0) except socioeconomic status, age and CoC for specialist visits. (See table 4.5)

Table 4.5: Unadjusted and adjusted logistic regression to determine differences between patients with a PDC = 0 and PDC > 0

	Unadjusted logistic regression			Adjusted logistic regression		
	Odds ratio	**95% CI**		**Adjusted odds ratio**	**95% CI**	
Age	1.024	1.022	1.026	1.022	1.020	1.024
Charlson comorbidity index						
CCI = 0	0.682	0.609	0.763	0.762	0.679	0.854
CCI = 1	0.953	0.842	1.079	1.005	0.887	1.139
CCI > 1	Ref.					
Year of cohort entry						
1997-1999	1.941	1.788	2.107	1.688	1.551	1.836
2000-2002	1.317	1.210	1.434	1.254	1.150	1.367
2003–2005	1.272	1.163	1.391	1.237	1.130	1.355
2006–2008	1.189	1.084	1.305	1.178	1.071	1.294
2009–2011	Ref.					
Firoozi severity index						
Mild	0.588	0.458	0.756	0.378	0.293	0.486
Moderate	0.757	0.58	0.989	0.594	0.454	0.777
Severe	Ref.					
Continuity of care (GP)						
No. GP visits during the index period	2.497	2.125	2.934	2.454	2.087	2.886
0 - 0.2	0.618	0.584	0.655	0.743	0.700	0.789
0.2 - 0.45	0.681	0.643	0.722	0.741	0.698	0.785
0.45 - 0.89	0.776	0.732	0.824	0.782	0.737	0.831
> 0.89	Ref.					
Continuity of care (specialist)						
No. specialist visits during the index period	1.025	0.922	1.14			

Table 4.5: Unadjusted and adjusted logistic regression to determine differences between patients with a PDC = 0 and PDC > 0						
	Unadjusted logistic regression			**Adjusted logistic regression**		
	Odds ratio	**95% CI**		**Adjusted odds ratio**	**95% CI**	
0 - 0.32	0.984	0.876	1.106			
0.32 - 0.132	1.088	0.956	1.239			
0.132 - 0.999	1.219	1.039	1.431			
1	Ref.					
Sex						
Female	1.05	1.009	1.095			
Male	Ref.					
Neighbourhood income quintile						
Quintile 1	1.011	0.95	1.076			
Quintile 2	0.957	0.898	1.018			
Quintile 3	0.953	0.894	1.015			
Quintile 4	1.023	0.959	1.092			
Quintile 5	Ref.					

At the multivariate level, a lower odds of adherence was attributable to patients with a CCI of 0 versus patients with a CCI of 1 (AOR = 0.762, 95% CI = 0.679, 0.854). Higher disease severity was associated with increased odds of adherence, following a dose-response pattern (see table 4.4). Consistent with some existing literature, higher age was also associated with a very slight increase in the odds of adherence (AOR = 1.022, 95% CI = 1.020, 1.024).

Patients with no general practitioner (GP) visits in the 12-month pre-index period had approximately 2.5 times the odds of adherence during the index period, compared to those with a CoC score greater than 0.89 (95% CI = 2.087, 2.886). However, among patients with a CoC score, a higher score was associated with increased odds of adherence.

Finally, evidence for a period effect can be seen by assessing the relationship between "year of cohort entry" and adherence. Patients entering the cohort earlier, tended to show higher odds of adherence compared to those entering the cohort between 2009 and 2011.

Likelihood ratio and Wald statistics both produced a p-value of <.0001, indicating that at least one of the predictor variables values is not equal to 0, which suggests overall model significance.(215) As a measure of predictive power using the Cox & Snell's pseudo-R squared measure,(216) the logistic model explains approximately 4% of the differences between those patients with a PDC = 0 to those with a PDC >0.(217)

4.3.5 Research question 2: Which demographic and disease related factors explain variation in adherence to controller medication?

At both the bivariate and multivariate levels, all explanatory variables served as statistically significant predictors of adherence. The results of the multivariate linear regression are generally consistent with the logistic regression (research question 1), showing that higher adherence is associated with higher age (Mean = 0.002, 95% CI = 0.002, 0.003), higher CCI, earlier year of cohort entry, higher disease severity, and higher socioeconomic status (see table 4.6). Compared to males, females show slightly lower adherence with significance (Mean = -0.004, 95% CI = -0.009, 0.001). However, the impact of disease severity is more pronounced. For example, the mean

change in PDC comparing those with mild disease to those with severe disease is -0.228 (95% CI = -0.261, -0.192).

Table 4.6: Unadjusted and adjusted parametric bootstrapped linear regression to explain variation in adherence to controller medication*

	Unadjusted linear regression					Adjusted linear regression				
	Mean	**SE**	**95% CI**		**P value**	**Mean**	**SE**	**95% CI**		**P value**
Age	0.003	<0.001	0.002	0.003	<0.001	0.002	<0.001	0.002	0.003	<0.001
CCI										
CCI = 0	-0.056	0.007	-0.072	-0.044	<0.001	-0.042	0.007	-0.057	-0.031	<0.001
CCI = 1	-0.014	0.007	-0.031	-0.002	0.014	-0.007	0.007	-0.023	0.004	0.090
CCI > 1	Ref.									
Year of cohort entry										
1997 – 1999	0.079	0.006	0.067	0.091	<0.001	0.065	0.006	0.053	0.077	<0.001
2000 – 2002	0.002	0.006	-0.009	0.014	0.354	0.006	0.006	-0.005	0.017	0.133
2003 – 2005	0.003	0.006	-0.010	0.015	0.351	0.009	0.006	-0.002	0.021	0.059
2006 – 2008	-0.001	0.007	-0.014	0.012	0.443	0.008	0.006	-0.005	0.020	0.111
2009 – 2011	Ref.									
Firoozi severity index										
Mild	-0.175	0.017	-0.208	-0.141	<0.001	-0.228	0.017	-0.261	-0.192	<0.001
Moderate	-0.067	0.019	-0.103	-0.030	<0.001	-0.101	0.018	-0.135	-0.064	<0.001
Severe	Ref.									
Continuity of care (GP)										
No. GP visits during the index period	0.155	0.009	0.139	0.174	<0.001	0.153	0.009	0.137	0.171	<0.001
0 - 0.2	-0.073	0.004	-0.081	-0.066	<0.001	-0.051	0.004	-0.059	-0.044	<0.001
0.2 - 0.45	-0.068	0.004	-0.075	-0.060	<0.001	-0.056	0.004	-0.064	-0.049	<0.001
0.45 - 0.89	-0.056	0.004	-0.065	-0.049	<0.001	-0.054	0.004	-0.063	-0.047	<0.001

Table 4.6: Unadjusted and adjusted parametric bootstrapped linear regression to explain variation in adherence to controller medication*

	Unadjusted linear regression					Adjusted linear regression				
	Mean	**SE**	**95% CI**		**P value**	**Mean**	**SE**	**95% CI**		**P value**
> 0.89	Ref.									
Continuity of care (specialist)										
No. specialist visits during the index period	0.01	0.007	-0.002	0.023	0.056	0.004	0.006	-0.008	0.017	0.259
0 - 0.32	0.029	0.008	0.013	0.045	<0.001	0.025	0.008	0.010	0.041	0.001
0.32 - 0.132	0.041	0.009	0.024	0.059	<0.001	0.030	0.009	0.013	0.047	<0.001
0.132 - 0.999	0.021	0.010	-0.001	0.039	0.028	0.015	0.010	-0.005	0.034	0.075
1	Ref.									.
Neighborhood income quintile										
1	-0.004	0.005	-0.014	0.005	0.179	-0.003	0.005	-0.013	0.005	0.218
2	-0.015	0.004	-0.023	-0.007	<0.001	-0.012	0.004	-0.020	-0.004	0.001
3	-0.014	0.004	-0.022	-0.006	<0.001	-0.011	0.004	-0.019	-0.003	0.003
4	-0.005	0.005	-0.014	0.004	0.138	-0.005	0.005	-0.014	0.004	0.147
5	Ref.									
Sex										
Female	-0.017	0.001	-0.022	-0.011	<0.001	-0.004	0.002	-0.009	0.001	0.042
Male	Ref.									.

*Mean estimates are reported using non-bootstrapped linear regression. All standard errors, confidence intervals and p-values use bootstrapped estimates.

The R^2 value shows that the model explains approximately 10.3% of the variation in adherence. With a model F-statistic p value of <0.001, the overall fit of the model is statistically significant.

4.3.6 Research question 3: Does adherence to controller medication vary by calendar month?

Table 4.7 shows the proportion of patients who filled at least one controller medication prescription in each calendar month. Patients were categorized according to the number of ICS prescriptions they had filled in the 12-month period prior to the index date. Unsurprisingly, adherence proportions increase with higher numbers of ICS prescriptions filled prior to the index date. This supports the claim that previous adherence predicts future adherence, but is likely confounded by additional factors such as disease severity and date of asthma diagnosis.

Table 4.7: Percentage of patients having filled a controller by calendar month according to the number of ICS prescriptions filled in the 12-month period prior to the index date			
Month	**1 ICS Rx 12-month period prior to index date (N = 62,549)**	**2 ICS 12-month period prior to index date (N = 8,769)**	**3 or more ICS 12-month period prior to index date (N: 1,634)**
January	10.8	18.78	27.72
February	10.46	17.92	27.17
March	11.42	20.44	27.36
April	10.95	19.14	28.09
May	11.01	19.91	28.95
June	10.28	19.6	29.99
July	10.22	19.2	28.46
August	10.09	18.38	30.91
September	11.29	19.92	29.31
October	11.56	21.12	27.91
November	11.75	20.88	31.7
December	11.57	20.55	31.09

The greatest amount of monthly variation can be detected among those who have filled at least 3 ICS prescriptions during the pre-index period. Comparing across ICS categories, adherence proportions tend to be highest in November and lowest in March.

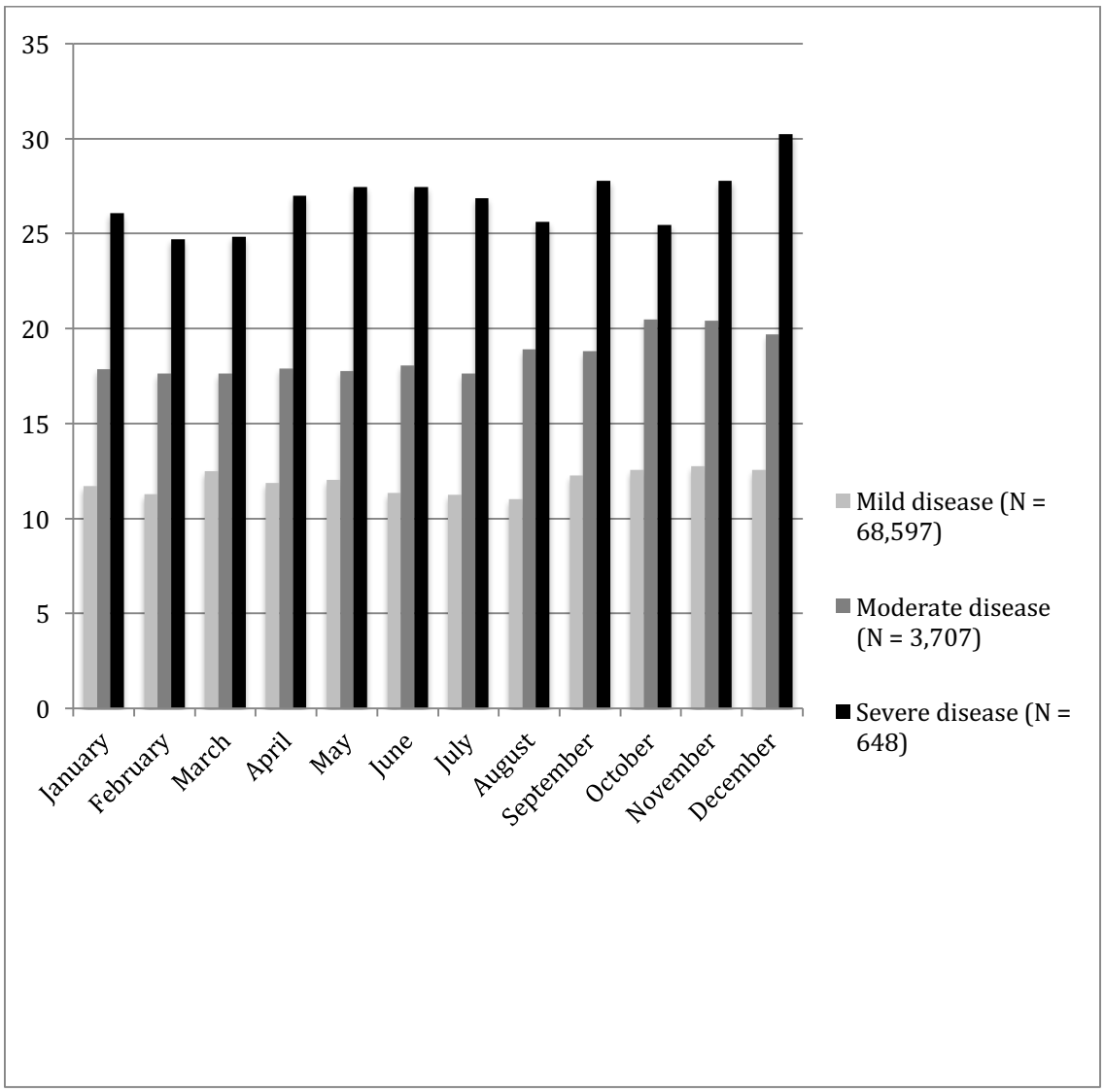
A similar descriptive analysis was calculated according to disease severity (see table 4.8 and figure 4.8). Patients with more severe disease had the highest proportions of

adherence within any calendar month, and overall. These results are consistent with the current multivariate analyses as well as the existing literature.

Within the severe disease category, the greatest amount of variation could be detected. The lowest proportions of controller medication prescription fills are shown in February and March, with the highest proportions shown in November and December. The multi-modal distribution shows that while the variation may not necessarily be attributable to a specific seasonal effect, some variation by month does appear to exist. Little variation can be detected in the mild disease category, however, there is a slightly increased prevalence of prescription filling during the late spring and again in the fall.

Table 4.8: Percentage of patients having filled a controller by calendar month according to disease severity			
Month	**Mild disease (N = 68,597)**	**Moderate disease (N = 3,707)**	**Severe disease (N = 648)**
January	11.70	17.86	26.08
February	11.29	17.64	24.69
March	12.48	17.64	24.85
April	11.88	17.89	27.01
May	12.05	17.78	27.47
June	11.36	18.05	27.47
July	11.25	17.64	26.85
August	11.02	18.91	25.62
September	12.26	18.80	27.78
October	12.56	20.47	25.46
November	12.77	20.42	27.78
December	12.57	19.69	30.25

Figure 4.8: Percentage of patients having filled a controller by calendar month, according to disease severity



4.4 Discussion

4.4.1 Summary of findings

The results of the multivariate analysis highlight patient-related factors that are associated with adherence to long-term asthma controller medication, and may help to provide potential explanations for variation in adherence.

4.4.1.1 Adherence

Descriptive analyses of this population-based sample show that 12-month adherence to controller medications among adult asthma patients living in British Columbia is poor, with approximately 16% of this patient population having not filled any prescriptions during the index period. This finding is consistent with previous evidence.(105,106,218) These results may be impacted by the fact that the majority of patients included in this sample are considered to have mild disease, despite attempts to reduce the sample to only those with a true diagnosis of asthma.

4.4.2.3 Comparison across the two multivariate models (research questions 1 and 2)

Both multivariate models show consistent results in terms of the direction and magnitude of effect. In summary, higher age is associated increased adherence, as is higher disease severity, higher CCI and lack of GP visits. However, among patients who did visit a GP during the pre-index period, those with a higher CoC (GP) showed greater adherence.

Although previous evidence is conflicting, the current analysis shows that more severe asthma is associated with better treatment adherence. These results are not surprising in light of the fact that patients with severe disease likely require more frequent medication to reduce asthma symptoms.

Higher CCI was shown to be associated with higher adherence in both the linear and the logistic regression models. CCI may be an indicator for medication regimen complexity, suggesting that patients who are being prescribed fewer medications are likely to be more adherent. These results may suggest that the medication regimen complexity attributable to higher CCI scores may positively impact a patient's ability or willingness to remain adherent to a daily treatment plan. These results are surprising since one prevailing hypothesis is that patients managing multiple comorbidities may incur additional challenges with managing their medication plans.(178) Furthermore, there may be personal cost implications that serve as additional barriers to adherence, among those patients who are being prescribed multiple medications. However, these results may suggest that patients managing multiple comorbidities may be more vigilant with their medications, or this finding may be influenced by increased frequency of healthcare use or communication with healthcare providers.

Based on the results of the two multivariate analyses, the role of sex in explaining adherence is minimal. There was no difference in the odds of having filled a controller prescription when comparing males and females (research question 1). According to the linear regression, being female was associated with lower mean adherence scores, but only to a very minimal extent. These findings are consistent with previous literature that has not found evidence for an association between sex and adherence.(145,179,182)

Finally, when comparing patients who do and do not fill any of their controller medications (research question 1), SES and CoC (specialist) did not explain differences between the two groups. However, when addressing variation in adherence (research question 2), these two variables were shown to explain adherence. Results of the linear regression show that that higher SES is associated with better adherence as measured by PDC, although no gradient was found across the 5 levels of SES. As stated previously, studies explicitly addressing the link between SES and adherence are not consistent in their findings.(145,175,179,180) However, some additional work has shown that adherence inferred via symptom control is associated with higher SES.(149,150) The mechanisms by which SES may influence disease control and severity may include increased exposure to pollutants or irritants.(150)

The linear regression also shows that a CoC (specialist) score of 1 (indicating high continuity of care) is associated with reduced adherence, when compared with lower CoC categories (excluding 0). This finding is inconsistent with the conventional wisdom, that continuity of care is associated with greater adherence. The hypothesized causal pathway is that having a single prescriber would facilitate increased communication and therefore increased adherence. CoC did not appear to be collinear with disease severity. These results may be impacted by the fact that approximately 75% of the sample did not visit a specialist during the 12-month period.

Finally, both models show that having entered the cohort earlier increased the likelihood of adherence. According to the linear analysis, lower adherence was shown among patients who entered the cohort between 2009 and 2011, compared with those who entered the cohort between 1997 and 1999. Unmeasured confounders may help to explain this finding, such as changes to prescribing patterns, clinical practice guidelines for asthma management, or changes in patient attitudes toward asthma medication, over time.(219) safety concerns related to the use of LABA were announced by the Food and Drug Administration (FDA) in 2005, which subsequently resulted in a decreased use of ICS-LABA among both pediatric and adult populations.(54) In 2007, the National Heart, Lung, and Blood Institute practice guidelines echoed these concerns.(220) Additionally, a Canadian 3-year prospective analysis conducted between 1996 and 1998 showed a decreasing trend in ICS prescriptions.(221) Although the decreasing trend in ICS prescriptions cannot be extrapolated beyond the length of the study, results suggest that prescribing patterns may fluctuate over time. It is possible that some of this variation in adherence may be explained by policy or prescribing changes, or changes in patient behaviours.

4.4.2.4 Variation in adherence

The results of the exploratory analysis addressing variation in adherence by calendar month suggests that variation can be detected, particularly within patient groups with a previous history of prescription fills, and greater disease severity.

There are two potential limitations that may impact the interpretation of these findings.

Firstly, the current analysis provides only a brief snapshot of potential seasonal variation in adherence. In order to capture a valid measure of variation, patients ought to be filling their prescriptions on a semi-regular basis over an extended period of time. Among the sub-group of severe asthma patients who are likely to have filled the greatest number of prescriptions over the 12-month period, slight increases in prescription filling can be detected around April, May, September, November and December (figure 4.9). It should also be noted that only 648 patients (< 1%) in this sample are categorized as having severe disease.

Secondly, in the province of BC, health insurance plans such as Fair PharmaCare reset on January 1st of each year, at which point registrant deductibles are re-calculated based on family income.(222) The majority of BC residents are covered by Fair Pharmacare. Therefore, the higher proportions of prescriptions being filled in December may be attributable to patients desire to reach their deductible by the end of the year. Patients may wish to fill their most recent medication prescriptions within the current year. If this is the case, it is not surprising to see lower adherence proportions in the early months (particularly February and March), since controller medications are often prescribed in 100-day dosages.(223) Despite these potential explanations, the findings of this preliminary analysis are consistent with previous

research that suggest asthma-related symptoms and healthcare use vary according to seasonal changes and increases in environmental triggers.(188,189)

4.4.2 Strengths

This investigation adds a valuable contribution to the existing literature by further clarifying the role of various demographic and disease related variables that explain adherence to controller therapy among adult asthma patients. I further highlight the finding that adherence is a highly complex phenomenon that cannot adequately be explained by demographic and disease related variables. One potentially valuable implication of this finding is that it serves to identify the potential role of addressing issues related to non-adherence at the individual level. Patient behaviors that predict adherence are likely to be informed by a multitude of factors including but not limited to attitudes and beliefs, concerns, self-efficacy and lifestyle (see chapter 3). Therefore, I propose that further efforts to explain and predict adherence on an individual and ongoing basis are warranted. Furthermore, the results of this investigation can be generalized to the population of adult asthma patients in BC due to the population-level nature of the sample. Finally, this analysis provides initial insight into the potential seasonal nature of adherence, while proposing potential implications and avenues for future research.

4.4.3 Limitations

This analysis is limited to the variables that were available using the administrative dataset. As such, some of the variables selected as indicators, may lack construct validity. For example, the measure of SES is based on a pre-defined neighborhood income quintile. A more robust and individual-level indicator of SES may include household income or individual education level. Of course, both of these preferred variables are not consistently captured using administrative datasets. Existing evidence suggests that, among asthma patients, aggregate measures of SES are not consistent with individual-level SES such as patient reported income and education.(224) As stated previously, a measure of continuity of care that captures the frequency of physician visits may provide further insight into the relationship between patient-physician communication and adherence.

Although PharmaNet is a useful and comprehensive resource for capturing prescription refill history, there are limitations associated with its use. Firstly, the database only captures the extent to which each patient filled his or her medication. The corresponding assumption is that all medications dispensed by the pharmacies were inhaled and inhaled correctly. Regarding the latter, inhaler misuse is a common occurrence among asthma patients, and is strongly associated with poor control.(225–227) Therefore, it is likely that adherence calculated using proxy measures over-estimate true adherence. A future study with the objective of estimating adherence rates would benefit from obtaining information about patient inhaler technique, and the presence of inhaler use related education.

Secondly, PharmaNet only captures medications dispensed through pharmacies. While this measure does capture the majority of medications being dispensed, it does not account for medications purchased online or sampling. Individuals may choose to purchase medications if they are under-insured and are able to locate cheaper medications through online vendors or from overseas which is a common experience especially in subjects from China and India.(228) Therefore, the population of patients captured by the PharmaNet database may not be completely representative of the BC adult asthma patient population. However, as stated previously, it is likely that this sample is largely representative of asthma patients in BC given that the majority of prescriptions are filled and recorded through pharmacies.

4.4.4 Implications and future research

Findings from the current analysis illustrate that a wide range of patient-related factors help explain adherence to long-term asthma controller therapy, although the vast majority of variation in adherence is left unexplained. These results support the claim that adherence is a complicated outcome that cannot be explained or maintained by simply addressing demographic patient characteristics, disease severity or comorbidities. Results of the current analyses can be used to inform further investigations into additional variables that may play a more prominent role in treatment adherence to medication for chronic conditions – namely the factors that inform individual behaviours. Additional insight is likely to be gained by

broadening the types of explanatory variables to include those related to the quality of the patient-physician relationship. For example, previous research supports the claim that increased education and communication with physicians may serve as a valuable tool to increase adherence.(17,130,229–231) As stated previously, variables related to the patient-physician encounter – such as continuity of care - are difficult to capture using administrative data. A future investigation ought to consider whether the quality of patient-physician encounters further explains variation in adherence. Increase patient engagement in care using methods such as shared decision making (SDM), have been proposed to improve various asthma related outcomes including but not limited to treatment adherence (see chapter 3). Chapters 5 and 6 of this dissertation will specifically address the extent to which SDM has been recently implemented into asthma care in BC, and to begin to explore the potential association between SDM and treatment adherence among a sample of adult asthma patients.

With regard to the secondary research question, further research into the prevalence and implications of seasonal variation in controller medication adherence is warranted. Results of the current analysis suggest that there may be some variation in adherence attributable to seasonality, particularly among patients with severe disease. An important next step in this research investigation is to provide a more valid estimate of the prevalence of seasonal variation in adherence, and to determine whether seasonal variation in adherence can be linked to disease control. More specifically, do patients who practice seasonal adherence show

greater symptoms, use of rescue medication and health resource use? If the answer to this question is "no," then perhaps long-term adherence measures that capture averages (e.g. PDC and MPR) may be suboptimal indicators of disease control. If it is the case that patients who practice seasonal adherence experience systematically higher disease burden, physicians may use this information to increase communication with these patients and ensure their understanding of the value of maintaining annual adherence, even in the absence of symptoms and environmental triggers.

Chapter 5: A survey to describe the state of shared decision making in asthma management: Consent process, recruitment procedures and participant demographics

5.1 Background

In chapter 3, I proposed a theoretical framework suggesting that various modifiable and non-modifiable factors are associated with adherence to controller medications among adult asthma patients. Subsequently in chapter 4, I investigated the extent to which select patient demographics and severity-related variables may explain variation in adherence. Based on the analysis results, I conclude that little variation in treatment adherence is attributable to patient-related factors such as age, sex and SES In order to further my research investigation, I proposed a next step, to seek a more comprehensive explanation of variation in adherence behaviour, through the collection of information from asthma patients on modifiable aspects of the clinical encounter. Here I seek to consider more comprehensively the role that SDM may play in addressing the informational and motivational predictors of treatment adherence (see chapter 3 theoretical framework). I have taken this forward through a formal survey, the specific objectives of which were to answer the following descriptive questions.

1. What role do asthma patients prefer to take in the decision-making process?

2. What factors related to patient-physician communication and education explain adherence?
3. To what extent do asthma patients recall previous exposure to SDM?
    a. Is patient-reported engagement in SDM associated with adherence to controller medication?
    b. Is there an association between preferences for decision-making and perceived exposure to SDM?

Chapters 5 and 6 serve to address these 5 research questions in relation to the over-arching objective of the thesis which are to ascertain the extent to which components of SDM are being incorporated into clinical care, and to determine whether these efforts are linked to improved adherence among adult asthma patients. The current chapter describes the demographic characteristics of asthma patients who agreed to participate in a cross-sectional survey about their use of asthma medication and healthcare decision-making. Chapter 6 describes the survey development process, the outcomes measured in the survey, as well as the results relating to all primary and secondary research objectives.

5.2 Patient population

Patients recruited for participation in the current survey consist of adult asthma patients who previously participated in the Economic Burden of Asthma (EBA) study.(232–234) EBA patients were initially recruited using a random-digit dial technique, sampling from BC's Vancouver and Okanagan census sub-divisions,

which together included both urban and rural households.(232) Individuals were eligible for the EBA study if they:

1. Had a diagnosis of asthma by a physician;
2. Had a self-reported health care interaction related to asthma (physician visit, ED visit, hospitalization) in the past 5 years; and
3. Were able to read and speak English.

Patients were excluded from the EBA study if they:

1. Were unable to provide informed consent due to language difficulties or cognitive impairment;
2. Had a smoking history of greater than 10 pack/year (this would have excluded patients with possible COPD);
3. Planned to move out of the province in the next 12 months; or
4. Were unable to undergo methacholine challenge test due to non-asthma related reasons (e.g. patients with cerebral aneurysm, pregnant and breastfeeding participants).

For the current survey, EBA patients under the age of 19, and those who were unable to complete an online survey were excluded.

5.3 Recruitment and consent procedures

My initial sampling frame consisted of EBA patients who had previously consented for future research. Potential survey participants were contacted either by telephone or email. A maximum of three attempts at initial contact were made for each participant. If contact was made and the participant expressed interest in

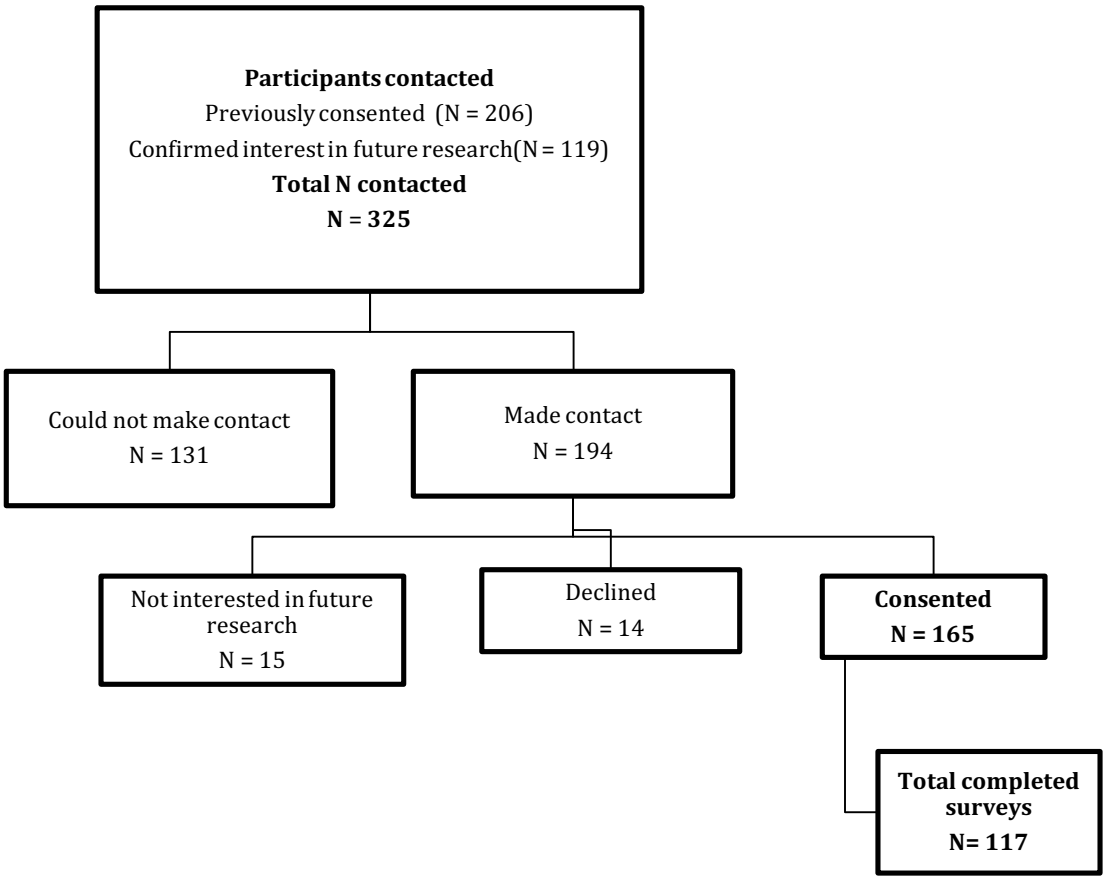
participating in the online survey, the participant was then sent their participant ID code, and the survey link, which included the online consent form. Those who did not respond to the survey invitation within a minimum of one month received a reminder email, and then a telephone call one week later.

Patient recruitment occurred between March and September 2016. In total, 471 telephone and email attempts were made to recruit participants. Of 325 patients who were successfully contacted, 165 agreed to participate, and 117 completed the survey. I was unable to obtain the characteristics of those EBA patients who did not choose to participate (see figure 5.1).

Fewer than 90 participants had completed the online survey following initial recruitment efforts. Given this limited number of respondents, I decided to increase the sampling frame. Following the completion of the original EBA study, not all participants had been successfully followed up to ask whether they would be willing to participate in future research. For phase 2, EBA participants for whom I did not have documented preference regarding their wish to participate in future research were contacted. As per guidance from the UBC Clinical Research Ethics Board, initial contact was made via email for those EBA participants who had provided a valid email address during the EBA study I contacted potential participants via telephone only in situations where no valid email address was recorded in the EBA patient file. Only a single attempt at communication was made. Following the receipt of a completed survey, a $15 gift card was mailed to each participant.

Eighty-five percent of patients that were successfully contacted (N=194) consented to participate in the survey (N=165). In total, 14 potential participants explicitly stated that they did not wish to participate in the survey. Stated reasons for refusal included not having access to a computer or an email address (N=9), or personal circumstances (N=1). Three potential participants did not provide a rationale for refusal, and one believed that his/ her asthma was too mild such that he/she should not be considered eligible (see figure 5.1).

Figure 5.1: Participant recruitment



Of the 165 participants who consented to participate, 93 (56.3%) completed the survey without being followed up. Following up with 72 participants resulted in an additional 24 surveys submitted (33.3%). Participants most often could not recall being sent the survey materials, or had simply forgotten to complete the survey. Most often, no reasons were given, and attempts made to follow up with the participant were unsuccessful, therefore rationale for dropouts are not reported (see appendix D).

5.4 Privacy and confidentiality of study data

I developed and distributed the survey using UBC's FluidSurveys.(235) To safeguard anonymity of responses, I did not collect participant names and email addresses through the survey. The research coordinator assisting with the survey retained and stored the list of EBA IDs and corresponding four-digit survey IDs on a password protected computer in a locked office at Vancouver General Hospital. Participant ID codes were not attached to their survey link, to ensure participant anonymity. An ID code was required in order to link their responses to their EBA ID so that they could be identified and reimbursed for participation. I maintained all survey data downloaded from Fluid on the Centre for Clinical Epidemiology and Evaluation's Shared Drive. The Shared Drive is password protected.

This survey study received approval from the University of British Columbia's Clinical Research Ethics Board (H10-01542).

5.5 Participant demographics

Following 471 attempts at contact, 165 patients consented to participate in this online survey, resulting in 117 completed surveys that were used for the analysis presented in chapter 6. In general, the sample was variable in terms of age, with a generally high annual household income, high education, with relatively low recent asthma-related healthcare resource use. A small majority of participants were female (58%). Eighty-two participants self-reported as white/Caucasian ethnicity,

and 69% reported having completed 4-year college or university. Fifty-eight percent of respondents reported an annual household income of $80,000 or more. The mean age of participants was 56 (range: 22-86, SD: 14.4) (see table 5.1).

The majority of respondents reported having at least one comorbidity with a range of 0-6. The distribution of the number of comorbidities was highly positively skewed. The most commonly reported condition was back pain (N= 35) followed by osteoarthritis (N= 27) and high blood pressure (N=22). Thirty percent of participants (N=35) reported having no comorbidities.

Table 5.1: Participant demographics	
Demographic variable	**N (total N = 117) or Mean (SD)**
Gender Female Male Other	 68 (58%) 49 (42%) 0
Ethnicity White/Caucasian Chinese South Asian Philipino Other	 96 (82%) 9 (7.6%) 4 (3.4%) 3 (2.6%) 5 (4.3%)
Age	Mean: 56 (SD: 14.4) Missing data: 2
Number of comorbidities per survey respondent 0 1 2 3 4 5 6	Median: 1 (range: 0-6) 35 (29.9%) 39 (33.3%) 26 (22.2%) 7 (5.9%) 6 (5.1%) 2 (1.7%) 2 (1.7%)
Annual household income Less than $20,000 $20,000 to $39,999 $40,000 to $59,999 $60,000 to $79,999 $80,000 or more	 6 (5.4%) 10 (9%) 16 (14.1%) 14 (12.6%) 65 (58.6%) Missing data: 6
Education (total N) Four-Year College/ University Some college High school Middle school Primary school	 81 (69%) 32 (27.3%) 2 (1.7%) 1 (0.85%) 1 (0.85%)

Healthcare use within the past year	
Visited a doctor for asthma	58 (49.5%)
Visited the hospital	1 (0.85%)
Visited the ER	4 (3.4%)

5.6 Generalizability of study sample

The current sample can be generalized to three separate populations: the population of the original EBA cohort, adult asthma patients in BC, and the sample of BC asthma patients used for the chapter 4 cross-sectional analysis.

Although I do not have demographic information on the non-responders, previous publications that have reported the demographic characteristics of the entire adult EBA cohort are useful in determining the representativeness of the current sample.(232) Participants in this survey and the larger EBA cohort were predominantly older individuals with high education, income, with a majority reporting white/Caucasian ethnicity. Table 5.2 shows the distribution of comparable demographic characteristics with the primary and larger EBA cohort.(236) In general, the characteristics of the current analytic sample are very similar to those of the larger EBA cohort (see chapter 7), suggesting a lack of non-repose bias based on the variables that I assessed.(237,238) For example, the current analytic sample is similar to the larger adult EBA cohort on measured characteristics such as age, gender distribution, ethnicity, income and education.

In comparison with the general population of asthma patients over the age of 12 in Canada, a much higher proportion of the current analytic sample reported well-controlled disease (75% v. 34.4%) and exposure to an asthma educator (38% v. 5.6%).(239,240) Characteristics related to sex and recent healthcare use were very similar. Given the differences in characteristics between the current sample and the larger population of adult asthma patients in BC, this impacts the generalizability of the study findings. For example, those who participate in research studies may be systematically more interested in their own health due to previous involvement in and completion of a longitudinal cohort study, reflecting higher adherence rates, preferences for SDM, and perhaps even the ability to recall encounters with their healthcare professionals.

Demographic characteristics for the current analytic sample compared with the analytic sample in chapter 4 are similar in terms of gender distribution, recent healthcare use and the presence of comorbidities (see table 5.2). I cannot compare age distributions because the analytic sample for chapter 4 included only those individuals age 18 to 55, versus the current sample that ranges in age from 22 to 86.

Table 5.2: Generalizability of the survey sample				
	Current analytic sample (age 18+) (chapter 5 and 6)	**Adult asthma patients (age 18-55) in BC (chapter 4)**	**Adult EBA cohort (232)**	**Canadian asthma patients over the age of 12 (109,239)**
Mean age	56	37	52	NR
Female	58%	64%	67%	58%
Median number of comorbidities	1	0 (CCI)	NR	NR
Ethnicity (% white)	82%	NR	82%	NR
Recent GP visit	49% (previous 12-months)	55% (12-months prior to index date) 96% (index period)	NR	62%
Recent hospitalization	0.85%	NR	NR	NR
Income: > $60,000	67%	NR	72%	NR
Education: post-secondary	69%	NR	75%	NR
Well-controlled asthma	75%	NR	NR	34%
Ever having seen an asthma educator	38%	NR	NR	5.6%

NR = not reported

5.7 Strengths and limitations of recruitment methods

5.7.1 Strengths

Multiple strengths contribute to the validity of the findings that will be reported in the next chapter. Firstly, the online survey format was selected for purposes of speed, and cost.(241) In addition, electronic survey administration reduces the need for data cleaning, and reduces the potential for error related to interpreting imputing hand written data.

Secondly, the online nature of the anonymous survey instrument served to eliminate interviewer bias, and to reduce social desirability bias, while allowing participants to complete the survey at their own pace. As stated previously, I hypothesize that participants may over-report socially desirable responses such as those related to medication use and asthma control. Using an online format and ensuring participant anonymity (through the use of the four-digit ID codes) likely reduced the potential for associated information biases.

Thirdly, participants were permitted to return to the survey multiple times before submitting. The objective for allowing multiple attempts was to reduce the potential for respondent fatigue, and non-response. Anecdotally, when speaking with participants about the length of the survey, a few stated that they were relieved to hear that they were not required to complete the survey in one sitting.

Finally, I developed the survey to be completed within 30 minutes to minimize respondent burden. The average time to completion was approximately 20 minutes. Previous research has shown that instrument brevity is associated with increased response rates.(242,243)

5.7.2 Limitations and challenges

5.7.2.1 Recruitment

Among contacted potential participants, the final response rate was 60%, and 71% among consenting participants. While no formal meaningful threshold for response rates has been adopted in the literature, a threshold of 60% is often reported as adequate.(243,244) As response rates are dependent on the characteristics of those being recruited, it may not be surprising to see a relatively high rate, given that our sampling frame was well-educated with a high average income and a previous interest in research related activities.(245)

Two issues were identified as impacting recruitment:

1. Inability to make initial contact with potential participants
2. Failure to obtain completed surveys from consenting participants

Of 325 potential participants approached, 131 (40%) could not be contacted. Failure to communicate with participants was typically due to incorrect/outdated contact information on file, or lack of response to telephone and email messages. Few

participants returned such calls, suggesting that further attempts at communication initiated by the researcher may be more successful than relying on the participant to return a phone call or email.

Given that the original EBA cohort study was completed 3 years prior, it is possible that participants had moved or changed their contact information. This remains a limitation of relying on previously collected data. Finally, the effectiveness of initial attempts at contact as well as follow up reminders sent via email may also have been impacted by individuals' use of email filters and junk mail folders.(246)

5.7.2.2 Participant follow up

Attempts made to follow up on participants who had consented to participate but did not return a completed survey were only mildly successful. A potential explanation for this lack of success is that much of the follow- up phase of recruitment was conducted between June and August. Although pre-notification and follow up reminders have shown to increase participation and response speed, any potential benefit may have been mitigated by attempts to recruit and follow up during the summer months.(247)

Additionally, follow-ups were delayed due to a change in study personnel. For this reason, initial follow up for some participants occurred 2 to 3 months after they had initially consented to participate. Consequently, participants who had previously consented but were not followed up within a shorter time frame may have forgotten

about the survey or lost interest due to this time lag. A future research study using similar methods would benefit from contacting participants for follow up within a shorter time frame.

5.7.2.3 Non-response bias

Several attempts to reduce non-response were used, including personalized telephone and email communication, as well as follow up reminders.(241,246) It is unclear whether attempts to follow up on previously consented participants and increase the sampling frame decreased nonresponse bias, although the efforts did increase the overall sample size, thereby reducing random error.

Further attempts to reduce non-response included ensuring that participants understood that the survey was anonymous and that they were not required to provide an answer to each question on the survey. The only question that participants were required to complete was the consent procedure, and the item asking for their four-digit ID. A concern identified a priori was that given the nature of the questions (disease status, medication names, and demographics) participants may view the survey items and subsequently decide not to participate. Ensuring that participants were aware that they could skip questions was intended to reduce complete non-response.

This survey required that participants be familiar and comfortable with computers, thereby excluding those who are unwilling or unable to participate in electronic

research studies. While less than 10 participants explicitly declined participation due to the online format, it is possible that a larger group of potential participants refused participation for this reason, without communicating this to the study team. However, when comparing the age, ethnicity and education distributions between the current analytic sample and the larger EBA cohort, there is no clear evidence of under-representation (see table 5.2). In the following chapter I will describe the methods used to develop the survey instrument and for data analysis. Further to this, the results of the survey findings will be presented.

Chapter 6: Asthma controller adherence and the role for patient engagement: survey development and results

6.1 Background

Over the past 20 years, a significant amount of attention has been paid to outcomes related to patient participation in their own healthcare decision-making. Some studies have shown that patients who actively participate in their healthcare decision-making report higher levels of satisfaction(46), reduced decisional conflict (160) and improved emotional status.(25,161) Evidence also suggests that shared decision-making (SDM) may improve clinical outcomes such as symptom resolution,(161) a reduction in hospital re-admissions, (17) as well as improved disease monitoring.(248,249) While dependent on clinical and patient context, both patient and physician preferences for a more active approach have increased in recent years.(1,250) Although high quality evidence has identified several potential benefits to be associated with active patient involvement as well as patients' reported desire to participate, clinical uptake has been low.

6.1.1 Objectives

This survey research was a response, in part, to current concerns that SDM implementation has been slow across multiple disease contexts. The overarching goal of this survey was to provide a description of the state of SDM in asthma care in

BC, as well as to suggest potential avenues for clinical implementation. In light of this, below I describe the three specific research objectives.

In chapter 2, I reported that physicians are generally more supportive of engaging patients who are both able and willing to participate in the decision-making process.(1,54,88) Factors that may also be related to this preference are a patient's perceived literacy, numeracy and socioeconomic status.(54,92,93) A potential implication of this finding is that physicians may be more likely to engage a patient in their treatment decision if they perceive that the patient is interested in participating. If physicians are systematically engaging only patients whom they believe will benefit from a shared encounter, this may result in a specific population of patients being underserved by SDM. The potential inequity resulting from a systematic exclusion of certain patient groups may further contribute to increased but preventable disease burden within specific clinical subpopulations. Therefore, a primary objective of this investigation is to identify the characteristics of patients who do and do not desire to participate in SDM (research question #1).

As a second objective, I will investigate which factors related to the decision-making encounter explain adherence to asthma controller medications (research question #2). This research question was developed in response to the existing literature, as well as chapter 4 which reports that adherence cannot be fully explained at the population level, and that further insight into aspects of the patient/physician relationship and the clinical encounter may be warranted. Previous work supports

this hypothesis. For example, several factors that serve as individual components of the SDM encounter have been shown to increase adherence, including but not limited to increased length of consultation time, treatment acceptance, patient satisfaction with the physician's education skills, and decision aids.(249,251–256) A smaller number of studies have explicitly investigated the link between treatment adherence and comprehensive SDM interventions, although there is currently a lack of consistency between studies (see table 6.1). Studies that assess only the impact of decision aids on SDM are excluded from table 6.1.

Table 6.1: Primary data collection studies assessing associations between SDM and treatment adherence								
First author	**Year**	**N**	**Study design**	**Clinical decision context**	**Adherence measure**	**Patient perceived vs. actual level of SDM measured**	**Intervention format**	**Association between SDM and adherence ($p < .05$)**
Aljumah (257)	2015	220	RCT	Depression	Self-reported	Actual	Comparison of SDM versus usual care control. Pharmacists in the SDM group were trained in SDM competencies.	Yes
Bauer (164)	2014	1523	Prospective cohort	Diabetes	Pharmacy records	Perceived	Written survey/ web based survey/ Interviewer assisted interview (Modified IPCI instrument)	Yes
Matthias (258)	2014	79	Cross sectional	Mental health	Self-reported	Actual	Patient-physician clinical encounters were recorded and coded for SDM components	Yes
De Las Cuevas (259)	2014	967	Cross sectional survey	Psychiatric medication	Self-reported	Perceived	Face to face (control preference scale)	No
Tinsel (260)	2013	1120	Cluster RCT	Anti-hypertensive therapy	Self-reported	Perceived	Comparison of SDM versus usual care control. Physicians in the SDM group were trained in SDM competencies.	No
Wilson (17)	2010	612	RCT	Asthma	Pharmacy records	Actual	Comparison of SDM and clinical decision-making intervention	Yes
Loh (47)	2007	405	Cluster RCT	Depression	Self-reported (Physician and patient assessments)	Actual	Comparison of SDM versus usual care control. Physicians in the SDM group were trained in SDM.	No

Finally, the current investigation seeks to further this research agenda by looking more closely at specific aspects of SDM that may serve as effective strategies to improve adherence among adult asthma patients. As such, the third objective of this study is to describe the extent to which asthma-related education and SDM are being incorporated into clinical practice (research question #3).

In summary, the primary objectives of the current chapter are to address the following research questions:

1. What role do asthma patients prefer to take in the decision-making process?
2. What factors related to patient-physician communication and education explain adherence?
3. To what extent do asthma patients recall previous exposure to SDM?
    a. Is patient-reported engagement in SDM associated with adherence to controller medication?
    b. Is there an association between preferences for decision-making and perceived exposure to SDM?

Addressing these five research questions will help to fill the current evidence gaps with regard to patient preferences for involvement in their care, the potential role for SDM in improving treatment adherence to asthma controller medication, as well as to address the state of SDM clinical implementation.

6.2 Methods

6.2.1 Survey development

I developed the initial draft of the survey tool, and revisions were made in consultation with thesis committee members. The survey was piloted on a small number of asthma and general population individuals throughout the fall of 2015. The survey was piloted using multiple devices including Mac and PC computers, iPads, iPhones and Android phones. Feedback was requested for item clarity, instructions, format, and survey length. Piloting continued until no further suggestions for revision were made.

As stated in chapter 5, the only items that participants were required to complete were the entry of their 4-digit ID and the provision of consent, in order to proceed to the main survey. Items were not randomized. Nested questions were included such that, for example, if a participant was not being prescribed controller medication, he or she would not be asked questions regarding controllers or the decision-making process for controllers. Between 1 and 10 items were included per page. The survey was a total of 30 pages long (including the consent form and 4-digit ID entry page). Where relevant, an item indicating "I am unsure" or "I cannot remember" was included.

See Appendix E for a complete list of survey items. The following domains were included:

1. Patient demographics including age, gender, income, education, time since diagnosis and comorbidities
2. Self-reported adherence and patient identified barriers to adherence
3. Exposure to asthma-related education (e.g. inhaler instructions, asthma action plans and asthma educators)
4. Asthma medications being prescribed
5. Asthma control
6. Health-related literacy and numeracy
7. Number and type of recent healthcare use
8. The extent to which patients desire to be involved in decisions about their asthma medication
9. The extent to which patients report that they were involved in the decision about their current controller medication

The following describes the items chosen for inclusion in the survey instrument. See appendix F for a description of the pre-validated instrument variable definitions used for the analysis.

6.2.1.1 Adherence

Self-reported adherence to controller medication is based on the Adult Asthma Adherence Questionnaire (AAAQ).(261,262) I included the statement, "I follow my asthma medication plan" as an indicator of patient adherence.(262) The AAAQ

adherence indicator been shown to have high construct validity, and predicts adherence as measured through administrative databases.(261) Other measures of self-reported adherence are lengthy and therefore add to respondent burden, (263) or lack the predictive power of the AAAQ.(264) The additional AAAQ items pertain to patient perceived barriers to adherence (e.g. cost of medication and medication side effects). One additional item was included to capture patient-reported concerns about controller medication side effects.

6.2.1.2 Perceived exposure to SDM

The 3-item CollaboRATE tool was used to determine the extent to which patients believed that effort was made to engage them in the decision making process about their controller medication.(265,266) Although a paucity of tools exist to ascertain patient-reported perceptions of involvement in their care – such as the OPTION scale - many are lengthy, focus on one specific clinical encounter, or rate low on various validity metrics.(265,267) In contrast, the CollaboRATE scale has been developed to be completed within 30 seconds thereby reducing respondent burden, and demonstrates discriminant and concurrent validity, intra-rater reliability as well as sensitivity to change, when compared against other measures such as the 9-item SDM-Q-9.(266) Furthermore, the brevity and validity associated with CollaboRATE have popularized the instrument, thereby facilitating comparison across clinical scenarios and patient populations. The CollaboRATE survey has been validated and tested on various patient populations using both a 10-point scale and a 5-point anchored scale. Since there is no evidence to suggest which scale option is

superior, I used the 5-point anchored scale option.(266)

6.2.1.3 Preference for involvement in the decision-making process

The Problem Solving Decision-making Scale (PSDM) patient survey was included to capture the extent to which asthma patients wish to be involved in their decisions about controller medication.(268). The tool uses as a 5-point Likert scale and determines patients' reported preferences for involvement in various aspects of the decision-making encounter. Based on the responses to the 6 questions, the instrument then categorizes respondents into support for a either passive role in decision-making, autonomous, or shared preference for both the "problem solving" questions (N=4) and the "decision-making" questions (N=2).(269) This item was selected for its brevity, as well as the fact that the PSDM scale specifically addresses multiple facets of the clinical encounter.

6.2.1.4 Exposure to asthma-related education

To ascertain the extent to which patients had been exposed to existing clinical interventions, I included the following items:

1. Have you ever heard of an asthma action plan, before today?
2. Did you ever get a written action plan for managing your asthma?
3. Were you involved in developing your asthma action plan?
4. Have you seen a specialist for your asthma?
5. Have you ever had teaching from an asthma educator?

Individual items were selected on the basis of consultation with asthma specialists and committee members. A selection of the items chosen had previously been included on the EBA patient survey (e.g. questions 2, 4 and 5).

6.2.1.5 Health literacy and numeracy

Health literacy can be defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health-related decisions."(270) Within the context of asthma, poor health literacy is associated with decreased adherence, asthma control, quality of life, lower medication-related knowledge, difficulty managing the disease, poor inhaler technique, days lost from usual activities, as well as increased morbidity and hospitalizations.(151,271–275) The 3-SQ tool has been previously validated and shown to have high sensitivity and specificity when compared against pre-existing measures such as the Short Test of Functional Health Literacy in Adults and the Rapid Estimate of Adult Literacy in Medicine.(276–278)

The Subjective Numeracy Scale (SNS), developed by Fagerlin and colleagues, provides a subjective measure of health numeracy.(279) The three-item short form SNS is used to assess patient perceptions of their comfort level with numbers. While objective measures of numeracy have been developed (e.g. Test of Functional Health Literacy in Adults and Objective Numeracy Scale), many research participants dislike aptitude tests as part of a survey.(279) The three-item SNS has been validated against the previously existing SNS (8-item) with high correlation, internal

reliability, and validity.(280) The original (8-item) SNS has been validated against objective measures of numeracy, with high internal consistency and correlation. Furthermore, both the 8 and 3-item SNS can be completed in less time than existing objective measures of numeracy.(279) I therefore chose the 3-item SNS to further reduce respondent burden while obtaining a valid estimate of health numeracy.

6.2.1.6 Current asthma control

The Asthma Control Test (ACT) was included to measure patient-perceived asthma control. The ACT is a brief 5-item instrument that provides an indication of how well the patient's asthma is controlled.(281) ACT response options refer to the frequency of various symptoms experienced within the past 4 weeks. Scores range from 1 to 25. A score of ≥20 indicates potentially well-controlled asthma, and lower scores indicate poorer control.

6.2.1.7 Additional survey variables

A range of additional variables were collected to ascertain information about participant demographics, current medication use, concerns about inhaled steroids, exposure to asthma related education as well as asthma action plans. See Appendix E for a complete list of survey items.

Two additional variables were created after survey responses were received, to capture:

a) Length of time passed since initial asthma diagnosis (Current age – Age at diagnosis)
b) Number of asthma rescue or controller medications currently being prescribed for their asthma (obtained from participant reported names of medications)

6.2.2 Analytic methods

6.2.2.1 Initial data exploration

To begin, outcome and explanatory variables were explored to determine measures of central tendency, variation, and frequency. I chose to collapse or dichotomize specific variables in the event of small cell sizes or limited variation in the item (e.g. income and education). Variables with little to no variation were removed from further analysis (e.g. having been taught how to use an inhaler).

Throughout the process of univariate analysis, I assessed the prevalence of missing data points (e.g. questions with no response). Case-wise deletion was selected as the method to handle missing data in the case where less than 5% of cases included missing data points. Multiple imputation (MI) was considered for the final multivariate model if greater than 5% missing data was identified within the analytic sample. Multiple imputation allows for the use of the complete sample size by predicting the value of a missing data point based on the distribution of the observed values.(282) MI does not distort standard errors and hypothesis tests in the way that simpler methods such as mean imputation may.(283) R software, using

the “mi” package, completes the missing values with imputed values that are randomly sampled from the observed dataset, using a bootstrapping mechanism.(284) A priori, no ceiling effect was applied such that in the case of a specific proportion of missing cases, the variable would be excluded from analysis.

6.2.2.2 Multivariate analysis

The appropriate model (multiple linear or logistic) was initially selected based on the distribution of the outcome variable. Given the explanatory nature of the models, I included all explanatory variables that were shown to be statistically significant at the p=0.05 level of statistical significance. R software was used for all analyses.(285) Both unadjusted (bivariate) and adjusted (for all additional explanatory variables) results are presented.

6.3 Results

The results presented here are based on responses from 117 completed surveys. Details about recruitment and response rates, along with participant demographics were presented in chapter 5 (see table 5.1). The following sections describe data cleaning and the distributions and frequency of remaining survey items.

Returned surveys were largely complete and free of identifiable errors. The variable for age at first asthma diagnosis did require data cleaning. Upon initial data exploration, 6 respondents (presumably) entered in the year that they were diagnosed (e.g. 1999), instead of entering their age at diagnosis. Since current age

was included as a survey item, the following formula was used to calculate correct age at diagnosis (*Age at Diagnosis Corrected*):

Time Since Diagnosis = 2016 – (participant entered year of diagnosis)

Current age – Time Since Diagnosis = Age at Diagnosis Corrected

6.3.1 Descriptive statistics for predictor variables

The mean length of time since initial diagnosis was 29 years (SD: 16.3) with a range of 0 to 75 years and 3 missing data points. One participant indicated that he or she was diagnosed for the first time in 2016, which may indicate a misunderstanding of the question, since everyone having participated in the EBA study were required to have a physician diagnosis of asthma at the time of cohort entry. The median age at initial asthma diagnosis was 22 (SD: 20.1) with a range of 1 to 78. Twenty-five percent of the 114 respondents were diagnosed on or before the age of 10.

Numeracy scores were highly negatively skewed toward the top score. For this reason, I re-coded the combined numeracy variable into tertiles based on the initial distribution (see table 6.2). Very little variation was shown on each of the literacy items. For each individual question, 93% (109) of respondents provided either of the two highest confidence ratings. For this reason, the literacy items were excluded from the bivariate and multivariate analyses.

Sixty-one percent of respondents had heard of an asthma action plan but only 18% of the sample had received a plan. Fifty-seven percent of those who had received a

plan had participated in the development of their action plan (N=12). Nearly all respondents (N=115) reported having received at least some form of training with their inhalers (variable excluded from further analysis), and frequently listed family doctors, specialists, asthma educators, nurses and pharmacists as those who provided the training. Given the lack of variability on this item, "having received training with inhalers" was removed from further analysis.

Just fewer than 50% (N=58) of respondents had visited a doctor within the past year for their asthma, but few had been admitted to the emergency department (ED) (N=4) or the hospital (N=1) during that time. Because of the low event rate, ED and hospitalizations were excluded from further analysis.

Of 117 respondents, 89 reported currently (within the past 12 months) being prescribed controller medication, and 84 reported that they were currently being prescribed a rescue medication. When asked to list the names of their medications, 27% of those being prescribed controllers listed a rescue medication (e.g. Ventolin) or another type of medication (e.g. homeopathic remedy) as their current controller.

Respondents reported having well-controlled asthma, on average. The median score among 115 respondents who provided valid data was 22, with a range of 8 to 25, indicating that this sample is generally well-controlled. For the bivariate and multivariate analyses, the total ACT variable was categorized as "well-controlled" or

"not well-controlled" using a cut point of 20. This cut point is used in the publically available online version of the ACT.(286)

Forty-four percent (N=39/89) of respondents reported being adherent to their asthma medication plan (see figure 6.7). Of the 89 respondents currently being prescribed controllers, 91% (N=81) had reportedly filled their most recent controller prescription. One respondent did not report an answer to the adherence item. Eleven percent of patients either agreed completely or mostly to the statement that they forget to take at least one of their inhaled steroids doses each day. Alternatively, 33% completely disagreed with this statement, suggesting general adherence to their controller medication.

Among patients who had been prescribed a controller within the past year (N=89), 43% agreed either completely or mostly with the statement that their asthma is mild and therefore does not require controller medication. An additional 35% either disagreed completely or mostly with this statement. Fifty-seven percent of patients being prescribed controllers disagreed completely or mostly with the claim that inhaled steroids cause side effects. Conversely, 16% agreed completely or mostly to this statement. Twenty-five percent of respondents reported being concerned about medication side effects (either completely or mostly agreeing), and 47% lacked concern. Finally, 76% of patients disagreed with the statement that they could not afford their medication, while only 7% agreed. To investigate the potential validity of this finding, I tested the hypothesis that perhaps patients who are well controlled

are more likely to report that their disease is mild and does not warrant regular controller medication. This hypothesis is based on the assumption that higher disease severity is associated with poor-control. No association was found between the belief that asthma is mild, and current asthma control (AOR: 1.045, 95% CI: 0.951, 1.152). This finding suggests that that perceived disease severity is independent of disease control.

Based on the results of the initial data and the associated small within-cell sample sizes, I dichotomized several variables to facilitate the bivariate and multivariate analysis (see appendix G). See appendix H for a description of missing data points. Bivariate statistics were conducted using case-wise deletion. The following will describe the results pertaining to each of the three objectives posed at the outset of this chapter.

6.3.2 What role do asthma patients prefer to take in the decision-making process?

6.3.2.1 Descriptive statistics

Using the PSDM scale, respondents were asked 6 questions about their preference for participation in making the diagnosis, selecting treatments, identifying and weighing the acceptability of risks and benefits and making the final treatment decision.

A “problem solving” (PS) score was created for the 4 items that pertain to diagnosis and treatment options.(269) Fifty-seven percent of respondents wanted the physician alone or mostly the physician to diagnose the health issue. No respondents wished to make this determination on their own. The majority of respondents (74%) also wished for the physician to play the main role (doctor alone or mostly the doctor) in determining what the treatment options are, what the associated risks and benefits are (62%), and the likelihood that those risks and benefits are to happen (70%). On a scale from 1-5, the mean problem-solving score was 2.0 (SD: 0.63) with a maximum of 3.2 (see figure 6.1). A score of 1 indicates that the participant preferred the doctor to make the decision, whereas a score of 5 indicates that the patient preferred the sole responsibility.

A “decision-making” (DM) score was created for the two items pertaining to who should decide about the acceptability of the treatment option risks and benefits, and who should make the final treatment decision: (269)

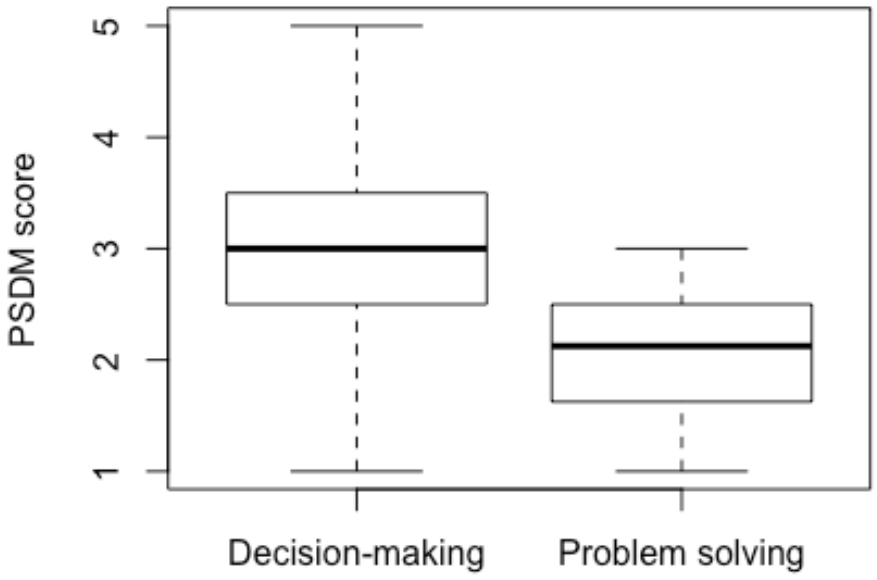
> *Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?*
> *Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?*

Respondents wished to take a more active role in determining how acceptable those risks and benefits are, and in determining the final treatment option. Forty-two percent thought that they alone or mostly they should decide how acceptable the

risks and benefits of treatment options are, and 40% thought that this should be a joint decision with their physician. Regarding the final treatment choice, 27% of respondents thought that they alone or mostly they should make this decision, and an additional 46% thought that the patient and physician should share this responsibility, jointly. The continuous DM variable was normally distributed with a mean score of 3.1 (SD: 0.88), indicating a preference for a shared approach (both physician and patient should make these decisions together, sharing equal responsibility) (see figure 6.1).

As hypothesized, patients preferred to take a more passive role in determining treatment options as well as the risks and benefits associated with those available treatment options, but preferred to take a more active approach to deciding on the *acceptability* of the risks and benefits, and making the final treatment choice (see figure 6.1). Results of the t-test show that there is a significant difference in means for the two PS and DM scores (<.0001).

Figure 6.1: PSDM "problem solving" and "decision making" score distribution



I selected the continuous, normally distributed "decision-making" (DM) score as the primary outcome variable to address this research question. I conducted unadjusted linear regression to ascertain linear relationships between the outcome variable and all potential explanatory variables (see table 6.2). All bivariate associations with a p-value of p=0.25 or less were investigated for inclusion in the final model.

Table 6.2: Unadjusted and adjusted linear regression of role preference (active v. shared) for asthma treatment decision-making						
Explanatory variable	**Unadjusted linear regression analysis**			**Adjusted linear regression analysis**		
	Beta	SE	P-value	Beta	SE	P-value
Gender Male Female	-0.159 Ref.	0.166	0.34			
Age	-0.016	.006	0.005	-0.013	0.005	.018
Ethnicity White/ Caucasian Non-White/ Caucasian	0.2121 Ref.	0.213	0.322			
Number of comorbidities 0 1 2 3 or more	Ref. -0.113 -0.209 -0.287	0.207 0.230 0.263	0.586 0.366 0.277			
Number of asthma medications 0 (or did not report) 1 2 or more	Ref. -0.172 0.095	0.271 0.245	0.527 0.700			
Currently being prescribed controller medication **Not currently being prescribed controller medication**	-0.123 Ref.	0.192	0.522			
Length of time since asthma diagnosis	0.009	0.005	0.065			
Greater than $80,000 annual household income **Less than $80,000 annual household income**	0.602 Ref.	0.160	0.001	0.550	0.157	0.0006
4-year university **Less than 4 years university**	0.309 Ref.	0.176	0.082			
Well controlled asthma	0.105	0.189	0.58			

Table 6.2: Unadjusted and adjusted linear regression of role preference (active v. shared) for asthma treatment decision-making						
Explanatory variable	**Unadjusted linear regression analysis**			**Adjusted linear regression analysis**		
Not well-controlled asthma	Ref.					
Has heard of an asthma action plan	-0.259	0.166	0.123			
Has not heard of an asthma action plan	Ref.					
Has an asthma action plan	-0.183	0.213	0.393			
Does not have an action plan	Ref.					
Ever had teaching from an asthma educator	-0.219	0.168	0.196			
Never had teaching from an asthma educator	Ref.					
Has seen a specialist for asthma	-0.164	0.192	0.396			
Has not seen as specialist	Ref.					
Past year asthma-related GP visit	-0.186	0.163	0.256			
No past year asthma-related GP visit	Ref.					
Numeracy						
Score 3-14	Ref.					
Score 15-17	0.199	0.199	0.321			
Score 18	0.590	0.206	0.005			

6.3.2.2 Results

At the bivariate level, increased preference for participation in the decision-making process was associated with younger age, higher income, higher education level, and higher numeracy.

Using unadjusted linear regression, 7 variables were identified as having a linear association with the DM score, at the 0.25 significance level. The following variables were investigated further for the multivariate logistic model:

1. Age
2. Education
3. Income
4. Heard of an asthma action plan
5. Teaching from an asthma educator
6. Length of time since asthma diagnosis
7. Numeracy

The multivariate model included all significant ($p < 0.05$) explanatory variables. I began with a model including only the outcome variable and age. Following the inclusion of each subsequent variable, I assessed changes to the p-value, the estimate and the standard errors. With 7 missing cases (5.9%), I applied multiple imputation to the final multivariate model.

The final model included only age and income as statistically significant explanatory variables (see table 6.4). Self-reported annual household income of $80,000 or greater (Beta = 0.550, $p = 0.001$) and lower age were associated with a greater preference for a more active approach to the final decision-making process (Beta = -0.013, $p = .018$)

The results of this analysis show that while those with higher income and those who are younger tend to prefer a more active approach to the decision-making process, these patient characteristics alone do not serve to explain a substantial amount of variation in preferences (See appendix I for regression diagnostics).

6.3.3 What factors related to patient-physician communication and education explain adherence?

As a second research question, I sought to determine the extent to which adherence could be explained by modifiable predictors related specifically to the healthcare encounter. With reference to the theoretical framework presented in chapter 3, for the multivariate model I chose to explicitly include variables related to "informational" and "motivational" predictors of adherence (see chapter 3). The outcome was defined as a dichotomous variable, indicating self-reported adherence. Bivariate analyses were conducted using case-wise deletions.

6.3.3.1 Results

At the bivariate level, being older, having more comorbidities, better asthma control, previous exposure to an asthma educator, and having seen a specialist in the past year, were shown to increase the odds of adherence. Conversely, factors associated with decreased odds of adherence included male gender, higher income, greater preference for an active approach to decision-making, the belief that asthma is mild and does not warrant controller medication, as well as concerns about asthma medication.

Table 6.3: Unadjusted and adjusted logistic regression Outcome: Adherence to controller medication						
	Unadjusted logistic regression			**Adjusted logistic regression**		
Explanatory variable	**Odds ratio**	**95% CI**	**P value**	**Odds ratio**	**95% CI**	**P value**
Gender Male Female	0.569 Ref.	0.226, 1.385	0.221			
Age	1.028	0.998, 1.062	0.076			
Ethnicity White/Caucasian Non-white	0.993 Ref.	0.350, 2.889	0.990			
Number of comorbidities 0 1 2 3 or more	 Ref. 1.125 2.363 4.000	 0.214, 1.085 0.356, 3.571 0.772, 7.571	 0.840 0.137 0.060			
Number of asthma medications 1 2 3 or more	 Ref. 1.231 0.727	 0.442, 3.511 0.188, 2.699	 0.692 0.636			
Length of time since asthma diagnosis*	1.006	0.980, 1.032	0.643			
Time since decision was made (0-36 years)	0.981	0.926, 1.036	0.501			
Income						

Table 6.3: Unadjusted and adjusted logistic regression Outcome: Adherence to controller medication						
	Unadjusted logistic regression			**Adjusted logistic regression**		
Explanatory variable	**Odds ratio**	**95% CI**	**P value**	**Odds ratio**	**95% CI**	**P value**
Income $80,000 annual household income or greater Less than 80,000 annual household income	 0.329 Ref.	 0.131, 0.801	 0.016			
Education 4-year college/university less than 4-year college university)	 0.722 Ref.	 0.285, 1.819	 0.488			
Well-controlled asthma* Yes No	 2.768 Ref.	 1.082, 7.607	 0.0389			
Has heard of an asthma action plan Yes No	 1.378 Ref.	 0.590, 3.238	 0.459			
Ever had teaching from an asthma educator Yes No	 3.594 Ref.	 1.499, 8.956	 0.005	3.8	1.42, 10.95	0.009
Past-year asthma-related specialist visit Yes No	 3.069 Ref.	 0.976, 11.740	 0.071			

Table 6.3: Unadjusted and adjusted logistic regression Outcome: Adherence to controller medication						
	Unadjusted logistic regression			**Adjusted logistic regression**		
Explanatory variable	**Odds ratio**	**95% CI**	**P value**	**Odds ratio**	**95% CI**	**P value**
Past-year asthma-related GP visit						
Yes	1.380023	0.592, 3.258	0.457			
No	Ref.					
Numeracy						
Score 0-14	Ref.					
Score 15-17	0.617	0.210, 1.789	0.373			
Score 18	1.169	0.389, 3.535	0.780			
Decision-making score (PSDM)	0.565	0.324, 0.936	0.033			
Problem-Solving score (PSDM)	0.620	0.302, 1.24	0.181			
Physician provided a sample of controller medication						
Yes	0.3589		0.405			
No	Ref.					
My asthma is mild and does not require regular preventative treatment:						
I agree[1]	0.247	0.098, 0.593	0.002	0.273	0.099, 0.710	0.009
I disagree[2]	Ref.					
My inhaled steroid causes side effects:						

[1] "I agree" was a collapsed variable based on the following responses: "I agree completely," "I agree mostly," and "I agree somewhat."
[2] "I disagree" was a collapsed variable based on the following responses: "I disagree completely," "I disagree mostly," and "I disagree somewhat."

Table 6.3: Unadjusted and adjusted logistic regression Outcome: Adherence to controller medication						
	Unadjusted logistic regression			**Adjusted logistic regression**		
Explanatory variable	**Odds ratio**	**95% CI**	**P value**	**Odds ratio**	**95% CI**	**P value**
I agree	0.888	0.354, 2.196	0.799			
I disagree	Ref.					
I am concerned about the side effects of my inhaled steroids:						
I agree	0.417	0.171, 0.987	0.0496	0.289	0.099, 0.773	0.0169
I disagree	Ref.					
I can't afford my inhaled steroid medication:						
I agree	0.769	0.230, 2.423	0.657			
I disagree	Ref.					

After removing variables not directly related to the healthcare encounter from the model (age, gender, comorbidities, income, asthma control and income) the following variables were investigated further for the multivariate analysis:

- Having had teaching from an asthma educator
- Past year asthma related specialist visit
- Decision Making score (indicating preference for role in decision making process)
- Problem Solving score (indicating preference for role in decision making process)
- Belief that asthma is mild and does not require regular preventative treatment
- Concern about medication side effects

Results of the multivariate investigation show that patient-reported exposure to an asthma educator, beliefs about disease severity and concerns about medication side effects help to explain the odds of self-reported adherence (see table 6.3).

Having reported exposure to an asthma educator was associated with an increased odds of adherence (OR= 3.8, 95% CI: 1.42, 10.95), while concerns about steroids as well as the belief that asthma is mild and does not warrant controlled medication were both associated with decreased odds of adherence (OR = 0.29 and 0.27, respectively). While recognizing the wide variation (confidence intervals) in the expected estimates, the results show that multiple features of the clinical encounter related to accurate knowledge and beliefs may potentially impact a patient's likelihood of adhering to his or her medication (see appendix J for regression model diagnostics).

6.3.3.1.1 Investigating the specific role of asthma educators

Given the large measure of effect shown between previous exposure to asthma educators and adherence, I sought to more closely consider potential differences between those who reported exposure to educators, and those who had not. The purpose of this secondary analysis was to investigate potential systematic differences between patients who do and do not report ever having attended an educator appointment. (see table 6.4).

Table 6.4: Unadjusted logistic regression for patients having visited an asthma educator			
Explanatory variable	**Total N**[3]	**Odds ratio**	**95% CI**
Gender Male Female	117	 0.506 Ref.	 0.227, 1.096
Age*	115	1.028	0.998, 1.062
Ethnicity White/Caucasian Non-white	117	 0.975 Ref.	 0.373, 2.674
Number of comorbidities 0 1 2 3 or more	117	 Ref. 1.618 4.622 1.204	 0.601, 4.523 1.589, 14.415 0.313, 4.309
Number of asthma medications 1 2 3 or more	88	 Ref. 1.231 0.727	 0.442, 3.511 0.188, 2.699
Length of time since asthma diagnosis*	114	0.992	0.968, 1.016
Time since decision about current controller medication was made (0-36 years)	52	1.017	0.963, 1.076
Income* $80,000 annual household income or greater Less than 80,000 annual household income	111	 0.407 Ref.	 0.184, 0.885
Education 4-year college/university less than 4-year college university	117	 0.924 Ref.	 0.414, 2.101

[3] Sample size is included because some survey items were provided to a subset of participants. For example, only those who were currently being prescribed controller medication (n=89) and who could recall the decision-making encounter (N=52) were provided with the Collaborate instrument. All demographic questions and items pertaining to role preferences were asked of the entire sample.

Table 6.4: Unadjusted logistic regression for patients having visited an asthma educator			
Explanatory variable	**Total N**[3]	**Odds ratio**	**95% CI**
Well-controlled asthma	115		
Yes		0.969	0.411, 2.361
No		Ref.	
Has heard of an asthma action plan	117		
Yes		5.347	2.412, 12.337
No		Ref.	
Past-year asthma-related specialist visit	116		
Yes		3.661	1.364, 11.688
No		Ref.	
Past-year asthma-related GP visit	117		
Yes		2.508	1.172, 5.514
No		Ref.	
Numeracy	117		
Score 0-14		Ref.	
Score 15-17		0.934	0.372, 2.351
Score 18		0.405	0.144, 1.095
Decision-making score (PDSM)	117	0.754	0.487, 1.153
Problem-Solving score (PDSM)	116	1.333	0.733, 2.461
Physician provided a sample of controller medication	89		
Yes		1.483	0.637, 3.492
No		Ref.	
I forget to take at least one dose of my inhaled steroid each day	88		
I agree		0.457	0.166, 1.168
I disagree		Ref.	
My asthma is mild and does not require regular preventative treatment:	89		
I agree		0.426	0.177, 0.997
I disagree		Ref.	
My inhaled steroid causes side effects:	89		

Table 6.4: Unadjusted logistic regression for patients having visited an asthma educator			
Explanatory variable	**Total N**[3]	**Odds ratio**	**95% CI**
I agree I disagree		2.286 Ref.	0.931, 5.735
I am concerned about the side effects of my inhaled steroids:	88		
I agree I disagree		1.576016	0.672, 3.748
I can't afford my inhaled steroid medication:	89		
I agree I disagree		1.877611	0.610, 5.906
Previous exposure to SDM (CollaboRATE: 0-12)	52	1.062	0.888, 1.281
Adherent to controller medication	88		
Yes No		3.69655 Ref.	1.546, 9.199

At the bivariate level, a higher OR of having seen an asthma educator was associated with past year encounter with a GP (OR = 2.508, 95% CI = 1.172, 5.514) or a specialist (OR = 3.661, 95% CI = 1.364, 11.688), having heard of an asthma action plan (OR = 5.347, 95% CI = 2.412, 12.337), and lower income (OR = 0.407, 95% CI = 0.184, 0.885). Patients who agreed with the claim that their asthma is mild and does not require controller medication, were less likely to report having seen an educator (OR=0.426, 95% CI = 0.177, 0.997). Patients who reported having 2 comorbidities were more likely to report having seen an educator when compared to those with

no comorbidities (OR = 4.622, 95% CI = 1.589, 14.415) although there was no significant relationship reported when comparing those with 3 or more comorbidities to those with none. As previously discussed (research question #2), patients who self-reported as being adherent to their controller medication had 3.7 times the odds of reporting exposure to an asthma educator (95% CI = 1.546, 9.199).

The results of this hypothesis generating exploration suggest that asthma patients who are interacting more frequently with their physicians (GPs or specialists) about their asthma are more likely to visit an educator. These findings are not surprising, since it is likely that patients who have more severe disease or require more resources to help manage their disease are likely to be more frequently be referred to an asthma educator. Exposure to asthma educators may therefore serve as an indication of disease severity, or patients' difficulty managing medications. Interestingly, exposure to asthma educators was not consistently associated with current asthma control, number of medications being taken for asthma, or number of comorbidities.

6.3.4 To what extent do asthma patients recall previous exposure to SDM?

6.3.4.1 Descriptive statistics

The final main objective of this study was to estimate the extent to which SDM has been implemented into clinical practice, from the perspective of asthma patients

having made a decision about asthma controller medication. Of the 89 respondents who reported receiving a controller medication within the past 12 months, 52 (58%) recalled the decision-making encounter wherein their current prescription was first prescribed. The median length of time respondents reported since they were first prescribed their current controller was 8 years (2008). The range of recall for this encounter was 0-36 years.

Among the 52 respondents being prescribed controllers who recalled the decision-making encounter(s), CollaboRATE scores were roughly normally distributed with a mean score of 7.1 (SD: 3.1) and a range of 0-12. Two respondents indicated that no effort at all was made to help the patient understand his or her health issues, listen to what mattered to him or her, or to include what mattered to him or her most in choosing what to do next (indicating a CollaboRATE score of 0). Alternatively, 7 patients rated that every effort was made by the physician on each of these three items (indicating a score of 12).

6.3.4.2 Is perceived exposure to SDM associated with adherence to controller medication?

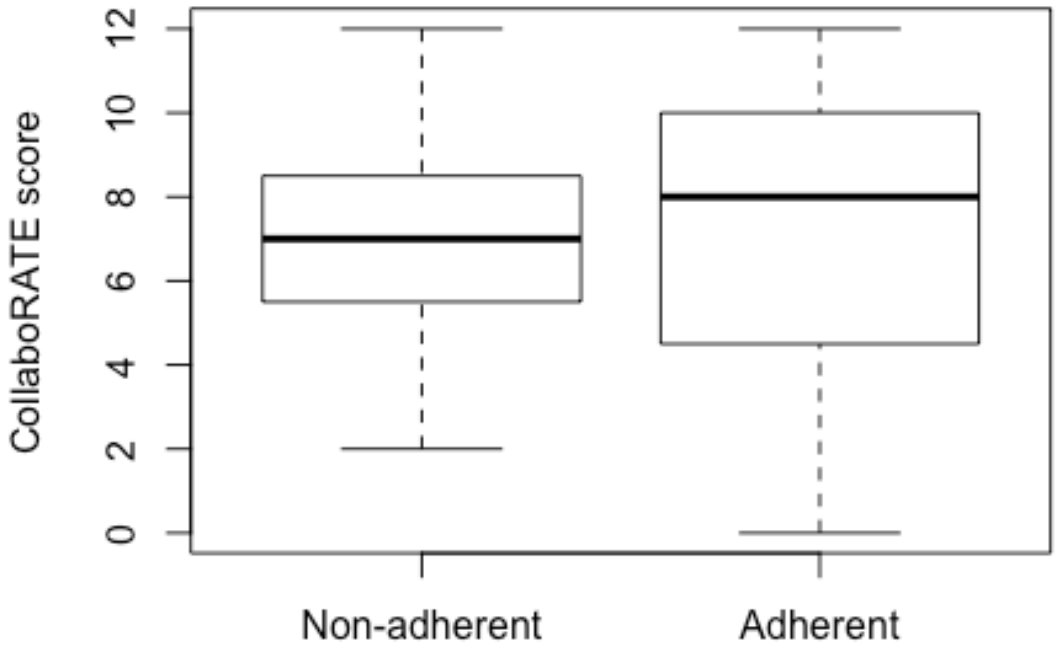
Of the 89 patients having been prescribed a controller medication in the previous 12 months, 52 recalled the encounter with their physician where the decision was made to prescribe the current treatment. Table 6.5 shows that less than 25% of patients reported that no effort was made at all to help them understand their

health issues, listen to the things that matter most, or include what matters most to the patient in choosing what to do next. Conversely, between 15 and 17% reported that every effort was made, on each of the three survey items. These results show that variation exists with regard to the extent to which patients believe that they are being involved in their treatment related decisions.

Table 6.5: Previous exposure to SDM for current controller medication(s) (N=52)		
How much effort was made to help you understand your health issues?	No effort/a little: Some/ a lot: Every effort:	10 (19%) 33 (63%) 9 (17%)
How much effort was made to listen to the things that matter most to you about your health issues?	No effort/a little: Some/ a lot: Every effort:	10 (19%) 23 (44%) 8 (15%)
How much effort was made to include what matters most to you in choosing what to do next?	No effort/a little: Some/ a lot: Every effort:	13 (25%) 20 (38%) 9 (17%)

Results of the simple logistic regression provided a p-value of 0.84 (AOR: 1.0185, 95% CI: 0.851, 1.222) suggesting no difference in CollaboRATE scores when comparing those who are and are not adherent to their controller medication (see figure 6.2).

Figure 6.2: Adherence and exposure to SDM



6.3.4.3 Is there an association between preferences for decision-making and perceived exposure to SDM?

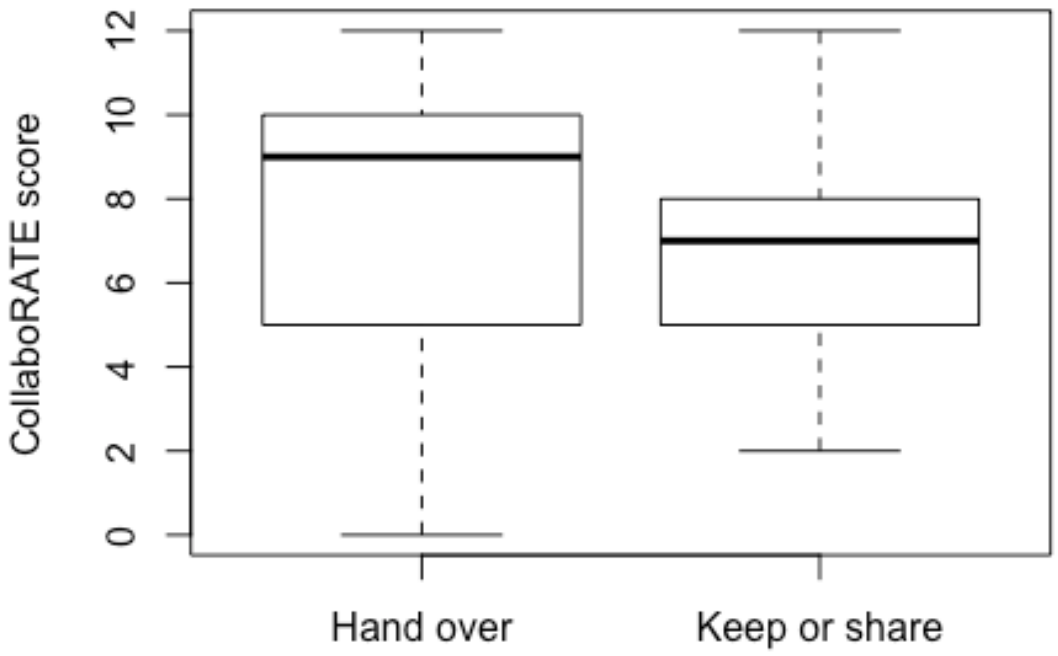
As a final research question, I assessed the association between increasing desire to take an active approach to decision-making and perceived previous exposure to SDM. Addressing this question helps to answer the question of whether patients are participating in their healthcare encounters to the extent that they would like.

Of 89 patients currently being prescribed controllers, 52 recalled the encounter(s) where the decision was made regarding their current controller medication.

Initially, decision-making scores ranged from 1-5 and CollaboRATE scores ranged from 0-12. The Pearson's correlation coefficient of -0.01 (p-value =0.89) suggests that there is no association between decision-making preference and perceived exposure to SDM.

When coding the decision-making variable as a dichotomous outcome, 33 respondents (63%) preferred to keep or share the decision, whereas 19 preferred to hand over the decision to their physician (see figure 6.3).

Figure 6.3: Collaborate scores by DM preference



No significant difference in mean CollaboRATE scores comparing those who prefer an active/shared (keep or share decisional responsibility) versus a passive approach (hand over decision to physician). This very preliminary investigation suggests that patients may not be playing the role that they would prefer to, in their decision-making encounters. Interestingly, patients who preferred to hand over their decision to physicians reported a systematically higher CollaboRATE score, indicating that they may have been playing a more active approach than they would have preferred. Conversely, patients who preferred to play a more active role by keeping the decisional responsibility or sharing in the decision-making process, had a slightly lower mean CollaboRATE score. A more highly powered analysis would likely provide more insight into this relationship.

Results of further initial bivariate data exploration show that reported engagement in the treatment decision-making process was not associated with any of the explanatory variables under consideration (data not shown). This finding suggests that there are no consistent differences between those who report exposure to SDM, and those who do not.

6.4 Discussion

6.4.1 Role preferences

Patient-reported role preferences shown here are consistent with previous research that has used this item. That is, patients prefer increased physician involvement

with regard to the problem solving items, but wish to take a more active role in weighing the acceptability of risks and making the final treatment decision.(35) These results are consistent with clinical contexts showing that younger individuals tend to prefer a more active role in their decision-making process.(35) This may reflect the changing medical decision-making model; wherein younger people are used to being more actively involved in their care. While younger age may be associated with the desire to take an active approach, at the bivariate level, age was not associated with reported exposure to SDM. This finding supports the claim that self-reported preference for involvement in the decision-making process is not necessarily reflective of patient reported experiences in the clinical encounter. These findings are consistent with a recent Cochrane review reporting that, within cancer, patients prefer a more active role than the role that they experienced.(287)

6.4.2 Controller medication adherence

Patient-reported adherence was consistent with existing literature, and was higher than the adherence reported using the administrative data set (chapter 4).(105,106,288) This may be explained at least partially by the self-reported nature of adherence, although attempts were made to reduce social desirability bias by using a pre-validated measure of adherence. Using a sampling frame of patients with previous participation in research may have resulted in a more highly adherent sample than can be generalized to the broader population of adult asthma patients.

Referring back to the theoretical framework proposed in chapter 3, multiple informational and motivating factors were shown here to be associated with self-reported adherence. The multivariate analysis addressing modifiable predictors of adherence shows that the belief that regular medication is unnecessary decreases the odds of adherence, along with concerns about medication side effects (AOR = 0.27 and 0.29, respectively). Having been exposed to an asthma educator is also associated with increased odds of adherence, when accounting for beliefs and concerns about disease status and medication necessity (AOR = 3.8). These findings are consistent with previous studies suggesting that inaccurate beliefs and concerns about medications are associated with decreased adherence, further validating the current findings.(175,179) For example, a recent observational study of adult asthma patients found that those who held the beliefs that asthma does not exist in the absence of symptoms and that asthma is curable, self-reported lower adherence.(288)

These findings, coupled with the results of the current study, suggest two potential implications. Firstly, inaccurate beliefs about medication and asthma are likely to be prevalent among adult asthma patients, and secondly, the presence of such inaccurate beliefs may have detrimental implications on a patient's motivation to adhere to their treatment plan. If the assumption is true that misguided fears, beliefs or concerns can be addressed through improved communication with healthcare providers, then these findings support the use of more active engagement in decisions about asthma treatments.(180)

An additional explanation is that the belief that medication is unnecessary may not exclusively be based on lack of education about the disease. Some asthma patients may consciously choose to take "medication holidays" wherein the prescription is followed during periods of disease flare-ups only (e.g. Spring and Fall months).(289) The concept of "medication holidays" or "educated non-adherence" has been discussed previously in chapter 4. While some variation was identified, a clear seasonal pattern could not be inferred. Future research ought to investigate the rationale behind medication cessation, as well as the long-term outcomes of those patients who practice educated non-adherence.

Forty-eight percent of respondents reported that they agreed "somewhat," "mostly," or "completely," with the statement that they were concerned about the side effects of their controllers. These results confirm the potential presence of "corticophobia" – wherein patients fear taking ICS due to perceived likelihood of side effects.(290,291) Previously reported misconceptions include: the idea that ICS dosages need to increase over time, that they build muscle, cause brittle bones and infection, and that the continued use of ICS can lead to weight gain and stunted growth.(290) A number of these concerns are related to the misconception that ICS contain anabolic steroids and therefore will carry the same effects. These results further support the important role of educating patients about their disease and medication options.

Forty-nine percent of respondents who were being prescribed controller medication agreed (completely, mostly or somewhat) that they were concerned about their controller's side effects. Given that concerns are related to likelihood of adhering to the prescribed medication plan, one potential implication of this finding is that increased communication with patients about the risks associated with inhaled steroids may serve to alleviate concerns and motivate patients to remain adherent. Similarly, informing patients about the necessity of daily medication may increase motivation to adhere. Previous reports suggest that patients infrequently relay this information to their physicians.(290)

Respondents who reported exposure to an asthma educator were more likely to report adherence to their medication, both at the bivariate level and as part of the multivariate model. One potential explanation for this finding is that patients who are referred to asthma educators differ systematically from those who do not. Within the Canadian context, patients who are referred to specialty clinics are more likely to be exposed to an educator. This patient population typically has more severe and poorly controlled disease, compared with the larger population of asthma patients. A typical patient whose disease is being managed by their GP is less likely to be referred to an asthma educator. Therefore, the strong magnitude of effect with adherence may potentially be confounded by increased exposure to respirologists or disease severity.

Alternatively, previous studies support the current findings, that exposure to asthma educators and personalized educational interventions are associated with numerous improved health outcomes such as increased knowledge, improved inhaler technique and asthma control, higher adherence, and reduced unscheduled healthcare use.(130,290,292) Consistent with the results of this survey, these findings support the use of educators within the asthma care and management team as an existing clinical intervention that may currently be underutilized. Future investigations should more comprehensively ascertain specific differences between those who are and are not being exposed to asthma educators. More specifically, an important research question to pose is whether those who are most likely to benefit from the use of asthma educators (e.g. those with poor control, low adherence or those who lack accurate knowledge about their medications) are able and willing to access these resources.

With reference to the theoretical framework proposed in chapter 3, the results of this survey show that awareness, informational and motivational predictors of adherence play significant roles in explaining adherence to controller therapy among adult asthma patients. While difficult to measure, awareness, informational and motivational factors that are impacted through increased knowledge and communication with the healthcare team may in turn bear on the patient's self-efficacy, and further serve to increase the likelihood to adhere to one's treatment plan.

6.4.3 Perceived exposure to SDM

At the univariate level, there was a wide range of variation reported regarding the extent to which patients perceive being involved in the decisions about their current controller medication. The results of the CollaboRATE item are consistent with previous studies addressing patient-perceived involvement in their care. For example, a recent survey using the SDM-Q-9 questionnaire found that among a nationally representative sample of 479 patients, the mean score was 67.6 with a standard deviation of 26.6, with higher scores (0-100) indicated greater perceived involvement in the decision-making process. A more recent survey of psychiatric (mean perceived involvement: 68.38 SD: 19.7) and primary care patients (mean perceived involvement: 67.5, SD: 21.9) provided similar results.(293)

These results suggest that there is no standard method or frequency of patient involvement in decisions about their controller medication. One explanation for this lack of consistency is that perhaps physicians are deciding to engage patients based on individual patient-level characteristics, as was suggested in Chapter 3. However, initial bivariate analyses show that there were no systematic differences in mean CollaboRATE scores on a wide range of demographic, education and barrier related variables. It is likely that this result may be impacted by the small sample size available for the analysis.

At the bivariate level, no association was found between patients' self-reported perceived exposure to SDM, and adherence to their current controller medication.

While these results are inconsistent with some previous findings, there are important differences to note.(17) Firstly, the confidence in the effect estimate is limited due to sample size. Secondly, and as previously stated, the ability to accurately recall this encounter may have been difficult, and may have been biased by their subsequent experience with their treatment, or their overall relationship with their provider. However, despite the limitations of this study design, it is alternatively possible that the way in which patients are being engaged in their care for decisions about controller medication does vary considerably and is not associated with increased adherence.

Once again, given the limited sample size used for this investigation, it was not possible to investigate comprehensively concordance between role preferences and perceived exposure to SDM, or the impact that concordance may have on treatment adherence. The bivariate analysis showed no significant association between a patient's preferred role, and their perceived exposure to SDM. However, future research should consider this relationship in a more comprehensive manner, to determine the importance of ascertaining a patient's preference for participating in their healthcare encounter.(259)

6.4.4 Strengths

This online survey was administered to capture information about the state of SDM within the context of asthma, using a sample of adult asthma patients. This survey is the first of its kind to specifically address outcomes associated with specific aspects

of SDM in clinical practice for asthma. The survey provides an analysis of the frequency of patient engagement in healthcare decisions about asthma, the characteristics of those patients, the specific ways in which patients are being engaged, and how patient engagement may link to treatment adherence. Administering this online survey to a sample of adult asthmatic patients also provided the opportunity to explore hypotheses regarding the possible role of extending implementation of SDM beyond the role of the treating physician to include non-physician asthma educators. The results of this survey may be used to generate further hypotheses regarding SDM implementation efforts, and to further investigate specific outcomes associated with SDM.

As stated in chapter 5, the sample is representative of both the EBA cohort and the general population of asthma patients living in BC, on a number of measured, demographic characteristics. These results further suggest that survey findings may be generalized to the larger population of adult asthma patients, despite the use of a small analytic sample.(288) Finally, the use of pre-validated survey tools allows for comparison of the results across different studies and different clinical populations.

6.4.5 Limitations

6.4.5.1 Information bias

The results of this survey must be considered in light of several methodological limitations. Firstly, information that is self-reported may be biased due to issues

related to recall and social desirability. For example, survey participants may be likely to over-report desirable behaviors such as adherence, resulting in an invalid prevalence estimate. To address the validity of this item, I assessed the adherence measure against asthma control scores, based on the known association between adherence and control. Results show that respondents with better control are nearly 3 times more likely to report adherence, compared with those who are not well-controlled (OR: 2.768, 95% CI: 1.082, 7.608). Finally, when comparing the prevalence of adherence reported in the current analysis with previous uses of the AAAQ, there does not appear to be any obvious sign of systematic over-reporting. These findings support the use of the adherence outcome measure applied in this survey. In addition, the use of an anonymous online survey may have helped to reduce the potential for social desirability bias.

A second potential limitation relates to measurement error. While the majority of survey instruments had been previously validated (e.g. CollaboRATE, SNS, PSDM), some survey items were included specifically for this investigation. Although the completed survey was pilot tested on a small sample of asthma patients and general population participants, the newly included items did not undergo formal sensibility testing. Such testing would have investigated adequate understanding of the new items, redundancy or missing items, as well as appropriateness of items.(294) Given the limited number of new items included in the survey in addition to the use of a pilot testing phase, lack of formal sensibility testing should be considered a minor limitation to this work.

A more problematic limitation concerns the issue of recall bias. As stated previously, patients were asked to recall a treatment decision making encounter that occurred between 0 and 36 years prior (with a median of 8 years prior). Given the extensive time lapsed since the decision-making encounter, recalled estimates may lack validity. There is a wide literature that addresses issues related to measurement error, and the accuracy of relying on self-reported data, across a range of exposures.(295,296) Recall may be related not only to the specific exposure being considered, but also to other factors such as social desirability, patient characteristics, the manner by which the information is obtained, and the significance of the event.(296) Although no clear threshold for recall is recommended when being asked to recall one specific event, a shorter recall period is likely to reduce the potential for measurement error.(295) A future investigation would likely overcome this limitation by surveying patients at the time of the decision-making encounter(s).

Thirdly, the results of this survey cannot adequately estimate the extent to which patients are *currently* being engaged in their decisions. As stated previously, 50% of patients made the decision about their current controller between 8 and 36 years prior to the survey. Given the recent attention being paid to SDM throughout the healthcare and policy literature, it is possible that clinical care encounters have changed considerably over the past several years. An initial bivariate analysis (t-test) shows that there are no differences in reported exposure to SDM when

comparing those who made their treatment decision within the past 7 years to those who made the decision 8 years prior, or later ($p = .51$). Although it is challenging to predict whether estimates of exposure to SDM are systematically under or over-reported by this sample, the estimate is likely to be subject to recall error.

Fourthly, with regard to perceived exposure to SDM and other education related sources, it is possible that large number of the sample may have been exposed to a small number of GPs and Specialists. I do not have information about the names of physicians that patients had visited for their asthma treatment. However, given that patients were recruited through random digit dial - the likelihood that the estimates of SDM exposure are based on a small number of care providers is minimal.

Finally, the results should be considered in light of confounding variables that may further impact the relationship between explanatory variables and the measured outcomes. For example, as discussed in chapter 4, income may serve as an important third variable when considering predictors of adherence. While FairPharmaCare may cover individuals to a certain extent, the cost of the medication beyond the deductible may be prohibitive to certain patients. For this reason, a future investigation may further consider structural barriers to adherence that could potentially be addressed through an SDM encounter, such as the potential cost of a medication.

6.4.5.2 Sample size

Secondly, a major limitation of this survey is the relatively small sample size. For this reason, much of the analyses presented in this chapter should be interpreted as hypothesis generating. For example, a relatively small number of patients were able to recall and provide information about the process by which they came to the decision about their controller medication (n=52). Therefore, I was unable to conduct a multivariate analysis to address factors that explain perceived exposure to SDM.

Furthermore, the limited sample size and dichotomization of select variables may have resulted in error related to the estimates. For example, at the bivariate level, lower income was shown to be associated with increased adherence, a finding that runs counter to the existing evidence (OR = 0.0329, 95% CI: 0.131, 0.801). One potential explanation for this is that the true variability in income is masked due to the dichotomization of the variable. Patients were categorized as self-reporting an annual household income of above or below $80,000. Doing so relies on the assumption of within-category homogeneity. It is possible that a larger sample would have allowed the use of a continuous measure of income (or a greater number of categories) and may have produced a more accurate result. The current hypothesis is that higher income and other indicators of socioeconomic status are in fact associated with higher adherence.

The results do, however, provide preliminary insight into the potential direction of effect, with regards to the characteristics of patients reporting involvement in their care, and the potential association between adherence and SDM. Therefore, these findings must be interpreted as hypothesis generating, and may be used to further investigate similar associations using a larger sample of patients.

6.4.5.3 Characteristics of the sampling frame

This sample was recruited from a highly educated and well-controlled population of asthma patients. As a result, the current sample lacked variability on a number of variables, such as literacy, numeracy, education, and income. It is likely that by using a more heterogeneous sampling frame, I would see a more variation on these items. As a result of the lack of variability, many of the variables included in the bivariate and multivariate analyses were collapsed or dichotomized, resulting in a loss of information. Given the characteristics of this sample, these results cannot be generalized to a broader population of poorly controlled asthma patients.

6.4.5.4 Cross-sectional study design

Firstly, this survey uses a cross sectional study design, and therefore no inference about causal relationships can be made. For example, while adherence is associated with exposure to an asthma educator, it is possible that those patients who are more likely to be adherent to their medications are also more likely to take an active approach to their care by attending educator appointments. Similarly, while

concerns about medication may result in reduced adherence, lower adherence may result in poor control and increased symptoms, in turn raising patient concerns about the effectiveness of their prescribed controller. The results of this survey should be used to posit potential relationships as well as to inform future prospective investigations assessing both predictors of patient participation in healthcare decisions, as well as modifiable predictors of adherence.

6.4.6 Implications

6.4.6.1 Non-physician caregivers

Based on the current findings, existing interventions such as asthma action plans and asthma educators are potentially being underutilized. Additionally, results of the survey show that the addition of non-physician caregivers such as asthma educators may serve as important resources to improve communication and adherence among adult asthma patients. Before recommending that additional health resources be directed to implementing more educators into clinical practice, it is important to consider potential explanations for this finding.

Firstly, it is possible that systematic differences between patients who are provided with access to asthma educators through referrals, and those who are not referred to these services. Similarly, differences may exist between those patients who follow through with a referral to an asthma educator, compared with those who choose not to, with regard to their level of adherence to asthma medication and disease control.

Therefore, the variation in adherence shown between the two groups may be confounded by specific patient characteristics such as socioeconomic status, disease severity, physician attitudes, or patient comorbidities. A future investigation would benefit from determining whether there are there specific patient groups who are being systematically denied equitable access to these services.

Results of the survey as well as the existing literature show that exposure to asthma educators is low in BC and Canada. This may be due to the fact that access to asthma educators in BC is typically provided through specialty clinics, rather than through primary care settings, which speaks to the non-integration of structured education into regular asthma care.(297) Furthermore, many institutions do not offer asthma education services even within specialty practices.(298) Therefore, only a small number of asthma patients are being referred to educators by their physicians.(297,298) Hesitancy to refer patients to educators may be due in part to physicians' preference to maintain exclusive care of their patients.(298) Finally, many patients are not aware that asthma educator services are available to them. Of those who are aware, some may be unable or unwilling to attend the appointment after being referred through their physician.(297)

In addition to asthma educators, decision coaches have been suggested to aid patients in the decision-making process regarding preference sensitive decisions.(299–301) A role that can be taken on by health professionals such as nurses or genetic counselors, decision coaches work with patients to determine

levels of decisional conflict, apply decision support techniques such as decision aids, and assess potential barriers to implementing the decision. Decision coaches may be external to the healthcare team. Alternatively, the role of the decision coach may be adopted by a nurse or other caregiver already integrated into the care process. Available evidence suggests that that patients who undergo decision coaching benefit in terms of increased knowledge and satisfaction.(301,302) Barriers to the implementation of decision coaching are similar to those of SDM, such as the lack of awareness or knowledge about decision coaching, and availability of training for decision coaching.(300)

Finally, further economic evaluation including of asthma educators and decision coaches into standard asthma care is warranted. Previous cost-effectiveness studies in both adult and pediatric populations show that the use of asthma educators is associated with cost savings attributable to reduced hospitalizations, reduction in length of hospital stays, and ER visits.(303,304) Although a recent Cochrane review showed that the impact of SDM on the length of consultation times is unclear,(99) physicians often state time constraints as a barrier to implementing SDM into practice.(27) However, despite evidence in favour of asthma educators, there is no standard funding model in place to support the use of these and other non-physician care providers within the asthma care process.(297)

In summary, research into the issues surrounding the potential under-use of non-physician caregivers to assist the adoption of SDM may inform further

implementation efforts. Specifically, addressing issues related to access, barriers such as intervention duration, and a more comprehensive look at both patient-related outcomes and cost-effectiveness outcomes, is a valuable and timely next step to the current research endeavor.(300)

6.4.6.2 Medication-related beliefs and concerns

Linking back to the theoretical framework described in chapter 3, motivating factors such as beliefs and concerns were shown here to correlate with adherence to controller medication. For example, despite being prescribed at least one controller asthma medication in the 12-months prior to the survey, 55% of patients held the belief that their asthma is mild and does not require regular controller medication. This finding suggests that although patients are being prescribed medications that are intended to be taken daily, patients may be undereducated about their disease status or the purpose of the medication. An additional finding suggests that the absence of treatment-related side effects does not necessarily reflect a lack of concern about their potential, and that the presence of disease and medication related beliefs and concerns are shown to be associated with decreased self-reported adherence. Therefore, future clinical efforts may focus on ensuring that patients hold accurate beliefs about their disease, and that concerns are elicited and considered when determining the treatment plan. Implications of this finding, with regard to clinical implementation, is discussed in further detail in chapter 7.

6.4.6.3 SDM implementation

Despite the limitations described above, the results of this survey help to highlight considerable variation with regard to the extent to which patients are being engaged in their healthcare decisions for asthma controller medication. These hypothesis-generating results suggest that, to date, there is no standard frequency or method for engaging patients in their care about decisions for asthma treatment. As previous authors have stated, there is a gap between the mounting evidence in favour of SDM, and the limited extent to which the knowledge has been translated into practice. My findings support this argument.

Chapter 7: Conclusions

7.1 Introduction

Attempts to reduce the overall burden of asthma in Canada are ongoing. Shared decision-making (SDM) has been proposed as a potential solution to reducing the health burdens associated with non-adherence to controller medication. This dissertation has provided an evidence-based investigation into the role of SDM in improving adherence among adult asthma patients in BC. The results of this project provide further support for the use of SDM in regular clinical care of asthma patients, and suggest recommendations for potential clinical implementation strategies.

Throughout the preceding chapters I have shown that both physicians and patients generally support the use of SDM. I have proposed a theoretical framework that clearly defines the role of SDM in improving outcomes related to asthma – namely adherence to controller medication. Further to this, I have conducted a population level analysis to show that adherence cannot be easily explained or predicted, and that effective solutions for reducing non-adherence ought to consider individual-patient level barriers. Finally, the results of the empirical survey show that variation in adherence can be explained by patient level factors that may be directly addressed through increased communication between patients and their asthma

care providers. Below I summarize the main findings of this thesis, and outline implications for both clinical care and future research.

7.2 Summary of main research findings

The primary objectives for this thesis were to address the following 5 research objectives:

1. To describe the extent to which physicians support the implementation of SDM, and in which specific clinical contexts (chapter 2);
2. To identify the role for SDM within the context of asthma (chapters 3 and 4);
3. To determine the extent to which asthma patients desire to participate in their decision making (chapters 5 and 6);
4. To explore the extent to which SDM and specific components of SDM are being implemented in asthma clinical care in BC, and the characteristics of those patients who are more likely to report being engaged (chapters 5 and 6)
5. To determine whether current self-reported adherence may be associated with perceived previous exposure to SDM (chapters 5 and 6)

The following summarizes the main findings of the thesis work.

7.2.1 Support for SDM

Chapters 2 and 6 provide evidence to support the claim that both physicians and patients desire patient involvement in the decision-making process. Physicians generally support the use of SDM in situations where patients are willing and able to participate, and where decisions are preference-sensitive. Patients in particular prefer to participate in decisions about the acceptability of treatment option risks and benefits, as well as the final treatment decision. Although support varies according to a number of patient, physician and condition-related factors, these findings provide further support for the claim that there exists an overarching desire for patient participation, particularly in chronic disease management decisions.

7.2.2 Establishing the role for SDM in asthma

Chapters 3 to 6 provide novel contributions to the existing literature by further establishing the role of SDM in the context of asthma. Chapter 3 contributes to the overarching research agenda by clearly describing the role for SDM in reducing the health burden of asthma by increasing treatment adherence.

The results of the population-based analysis presented in chapter 4 support the argument that further insight into individual patient behaviours may more comprehensively explain variation in adherence to controller medication. The lack

of variation in adherence explained using demographic and disease-related variables highlights the need to consider patient rationale for adherence at the individual level, with closer attention being paid to the patient-physician relationship.

Finally, the patient survey (chapters 5 and 6) shows that multiple components related to the clinical encounter such as exposure to asthma educators, as well as disease and treatment-related beliefs and concerns help to further explain adherence to controller medication. Combined, the results of these 4 chapters suggest that there is a clear role of SDM in asthma management in reducing the health burdens associated with non-adherence.

7.2.3 Asthma care in BC

The results of chapter 6 suggest that considerable variation exists with regard to patient-reported perceived exposure to SDM for asthma care. Participants also report variation in exposure to various forms of asthma-related education such as asthma action plans and asthma educators, and exposure to asthma educators is shown to increase adherence to controller therapy. Until recently, many SDM interventions have focused on the role of physicians in implementing SDM into their practice. These findings may prompt further investigations into the potential role of increasing communication between patients and their asthma caregivers, not limited to physicians.

7.3 Strengths

Firstly, the systematic review adds to the existing literature that addresses SDM implementation barriers by proposing clinical scenarios wherein physicians are most likely to support the use of SDM in their practice, such as preference-sensitive chronic disease scenarios, and encounters wherein the patient is deemed to be both able and willing to participate.(8,27)

As further background to providing a clear linkage between SDM and asthma treatment adherence, chapter 3 presents a theoretical framework focused specifically on the role for SDM in asthma. The theoretical framework can be adapted and modified to other chronic disease contexts.

The primary strength of the population-based cross-sectional analysis (chapter 4) is to highlight the complex nature of adherence, and the challenges with measuring adherence using administrative data. From a statistical modeling perspective, the multivariate regression analyses fail to adequately capture adherence. However, from a clinical and policy perspective, the analyses provide valuable insight into the challenges in explaining why one individual may adhere to their medication, and another patient may not.

Finally, the online survey provides insight into the extent to which components of SDM are being implemented into clinical practice, and further explains variation in

adherence at the individual level, by specifically addressing factors related to the decision-making encounter and the patient-physician relationship.

7.4 Limitations

The implications of the cross-sectional survey (chapters 5 and 6) must be interpreted in light of the limited sample size, the length of time since initial prescription, as well as recall difficulty and potential bias. As discussed in chapter 6, a future prospective investigation utilizing a sample of newly diagnosed asthma patients, would likely overcome some of the limitations resulting from the current analysis. A larger scale prospective design was logistically and financially infeasible for this project.

7.5 Knowledge translation

Knowledge translation (KT) is a process that includes the, "synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system".(305) Although the creation of research evidence is a necessary component for the translation of knowledge into clinical implementation strategies, research alone is not sufficient.(306) Health systems regularly under-use research evidence and fail to apply the findings to clinical practice, which results in health system inefficiency as well as preventable mortality and morbidity across a range of conditions.(306,307) Developed to investigate strategies to promote integration of

interventions within the context of telemedicine, the normalization process theory proposes that in order for an intervention or practice to become entrenched as a core component of an organization, the intervention must first be implemented, embedded and then integrated and sustained over a period of time.(308) A term used by Carl May is that of "collective action" – or the enacting of a practice among members of the institution. This concept recognizes the fact that behavioral change is not simply the adoption of intention at the individual level, but that there are social structures within or external to the institution that also play an important role.(309) The recommendations posed in this chapter attempt to promote collective action through increased understanding and awareness about the complex nature of adherence as well as the proposed role for SDM.

To date, much of the evidence that supports the use of SDM has failed to be implemented into routine care. Despite this, knowledge translation interventions have been developed for implementation of SDM into clinical settings. For example, decision aids have been shown to increase patient knowledge, reduce decisional conflict, and promote patient participation in the decision making process.(26) Promoting physician and patient knowledge about the value of SDM as well as the associated benefits, may facilitate the uptake of such existing interventions so that they can be routinely applied into clinical practice.

While recognizing the limitations of this work, I present three clinical implications that are geared toward physicians and other healthcare providers treating asthma

patients. Their purpose is to facilitate and increase in communication between healthcare professionals and asthma patients, while promoting a focus on implementation of SDM into clinical care.

7.5.1. Efforts to increase adherence among asthma patients are likely to benefit from individualized and ongoing discussions, through the use of SDM interventions

The results of chapters 4 and 6 show that variation in adherence cannot be adequately captured using population-level analyses. Given the lack of similar analyses by other investigators, it is difficult to compare the results of these findings, within the context of asthma.(177,178) While the current results show that both demographic and disease-related variables explain some of this variation, the concept of adherence is not one that can be easily predicted or explained.

The implication of this finding is not that it is a frivolous effort to try to explain and predict adherence, but rather that efforts geared toward improving adherence ought to be considered at the individual patient level. Therefore, physicians and other caregivers aiding in the decision-making process must understand the value of ascertaining patient-reported rationale for non-adherence and barriers to adherence on an individual and ongoing basis.

7.5.2 The use of both physician and non-physician care givers in ascertaining patients' disease and medication-related inaccurate beliefs or concerns may help to increase treatment adherence

Two specific findings from the online survey suggest the potential benefits associated with engaging patients about their disease and medication-related beliefs and concerns. Firstly, consistent with the existing literature, results of the survey show that it is not uncommon for patients to hold misconceptions about their medications, as well as concerns about the use of controller therapy.(32,33) Furthermore, the presence of concerns and beliefs about the need for controller medication are shown to be associated with poorer adherence (chapter 6). This conclusion is substantiated further by previous evidence suggesting that patients who are more knowledgeable about their disease management, and those who hold realistic expectations tend to have improved outcomes, across a range of chronic diseases and surgical conditions.(310,311) Therefore, engaging patients in an ongoing basis about their disease and medication-related beliefs and concerns is likely to improve patient knowledge, and subsequent adherence. This requires open and continued discussions between patients and their physicians or other care providers, a strategy that has been promoted elsewhere with regard to chronic disease management.(312) If healthcare providers treating asthma patients do not initiate these discussions, uncertainties regarding these individual level predictors of non-adherence will likely remain.

Secondly, results of the survey show that patient reported exposure to asthma educators explained an increase in treatment adherence, even when controlling for beliefs and concerns about asthma and the need for controller medication. This finding has implications for the potential role of more systematically engaging non-physician caregivers in the regular clinical care of asthma patients. As discussed in chapter 6, these findings are preliminary, and more research is required to determine the characteristics of patients being exposed to educators. However, these findings do suggest that perhaps the onus for SDM implementation ought to extend beyond that of the treating physician.

7.5.3 Awareness of the potential benefits associated with SDM may help to increase SDM uptake and improve health outcomes

The results of the systematic review (chapter 2) illustrate that physicians tend to be more supportive of engaging patients who are willing and able to participate, as well as those who have an understanding of their condition. The implication here is that physicians may select whom to engage in SDM, based on a set of perceived patient-characteristics. A potential consequence of this selection process is that there may be a sub-set of patients who not being approached to engage in the decision-making process.

Results of the online survey show that patients with a greater preference for participation in the decision-making process tend to be younger, with a higher average annual household income (chapter 6). These results are consistent with

existing literature showing that vulnerable populations such as the elderly, immigrants and those with lower SES are less likely to report an interest in SDM.(313) Given the outcomes that are suggested in the literature related to involvement in decision-making, the potential under-utilization of patient engagement may have undue negative impacts on a specific subset of asthmatics.

An implication of this finding is that there is the potential for systematic bias related to those who are and are not being engaged in their decision making processes.(8) As Légaré and colleagues point out, we ought not to engage only those patients for whom it is easier to communicate with.(8) While it may be a challenge to engage those who prefer a passive role, doing so may result in a systematic inequity of care. Previous evidence suggests that that patients who have taken an active role in their healthcare decisions benefit in terms of physical and social functioning as well as quality of life, even among those who reportedly prefer a passive role.(314) Further to this, a recent systematic review reported that SDM interventions directed toward disadvantaged populations (e.g. those with lower literacy levels) were shown to increase preference for a collaborative approach to decision making, among other outcomes.(315) The review also highlights the finding that certain SDM interventions may in fact have a greater impact on outcomes for disadvantaged individuals, compared with high literacy and SES patients.

A potential solution to this challenge is to ensure that patients are made aware of the valuable role they play in the decision-making process. Moreover, patients who

fear that they lack the content knowledge to participate in the process, or fear being labeled a "difficult" patient for seeking active engagement, should be informed of the important role that their personal value and preferences can play in determining the optimal treatment option.(316) Doing so may increase communication, trust and self-efficacy among patients who have misconceptions about their expected or preferred role in the encounter. As proposed in the chapter 3 theoretical framework, patients who have a greater sense of self-efficacy regarding their disease and treatment options are more likely to adhere to the given treatment plan. If patients are more willing to participate and have an understanding of the important role that they play, they may be more likely to reap the benefits of active engagement.

Although patient and physician awareness of the value of SDM is imperative for implementation, a further challenge may serve as a barrier to acting on this awareness – that of the patient's perception of the power dynamic within the clinical encounter.(317,318) This perception is informed by the opinion that physicians hold the legitimate knowledge, and patients are reliant on their physicians to make decisions and provide care.(319) As stated at the beginning of this thesis, there has been a shift away from the perception that "doctor knows best" and that patients lack valuable knowledge to contribute to the decision-making process. However, recent evidence shows that patients may still find it difficult to voice their opinions within the medical encounter.(317) Furthermore, the power dynamic between physicians and their patients may be challenging to overcome, even through increased physician training.(320)

Interventions such as group medical visits have been proposed in an effort to promote patient centered care in certain clinical scenarios such as chronic disease management and mental health.(321) In comparison to one-on-one medical encounters, group medical visits have been shown to make patients feel safer and supported,(322) which may aid in mitigating the power differential. Group medical visits may work in concert with the previous recommendation to integrate non-physician care givers into the SDM implementation process, by considering nurse and nurse-lead group visits.(323)

7.6 Furthering this research agenda

Based on the results of this thesis, it can be concluded that there is a clear role for SDM in asthma management, but uptake has been inconsistent in BC. Therefore, further research is required to specifically address optimal and specific strategies for implementing SDM in routine asthma care. Furthermore, as has been stated previously, much of the literature regarding SDM has focused exclusively on the patient-physician relationship,(299) suggesting that it is the responsibility of treating physicians to become trained in SDM competencies, implement SDM and do so within time and resource constraints. However, the results of this thesis show that further investigation into the potential health and economic impact of more formal engagement of non-physician caregivers in SDM uptake is warranted.

7.7 Conclusions

This research has provided a description of the state of SDM in asthma as well as the potential outcomes associated with increased patient engagement. The results of this dissertation can be used to inform future research designed to further explain variation in adherence to controller medication among asthma patients, at the individual level. In addition, this project provides the groundwork to further address issues related to SDM implementation, with a specific focus on calling for a broader integration of health professionals to aid in uptake efforts. Healthcare providers treating asthma patients may use these findings to further understand the value of increasing communication with their patients and utilizing non-physician educational resources.

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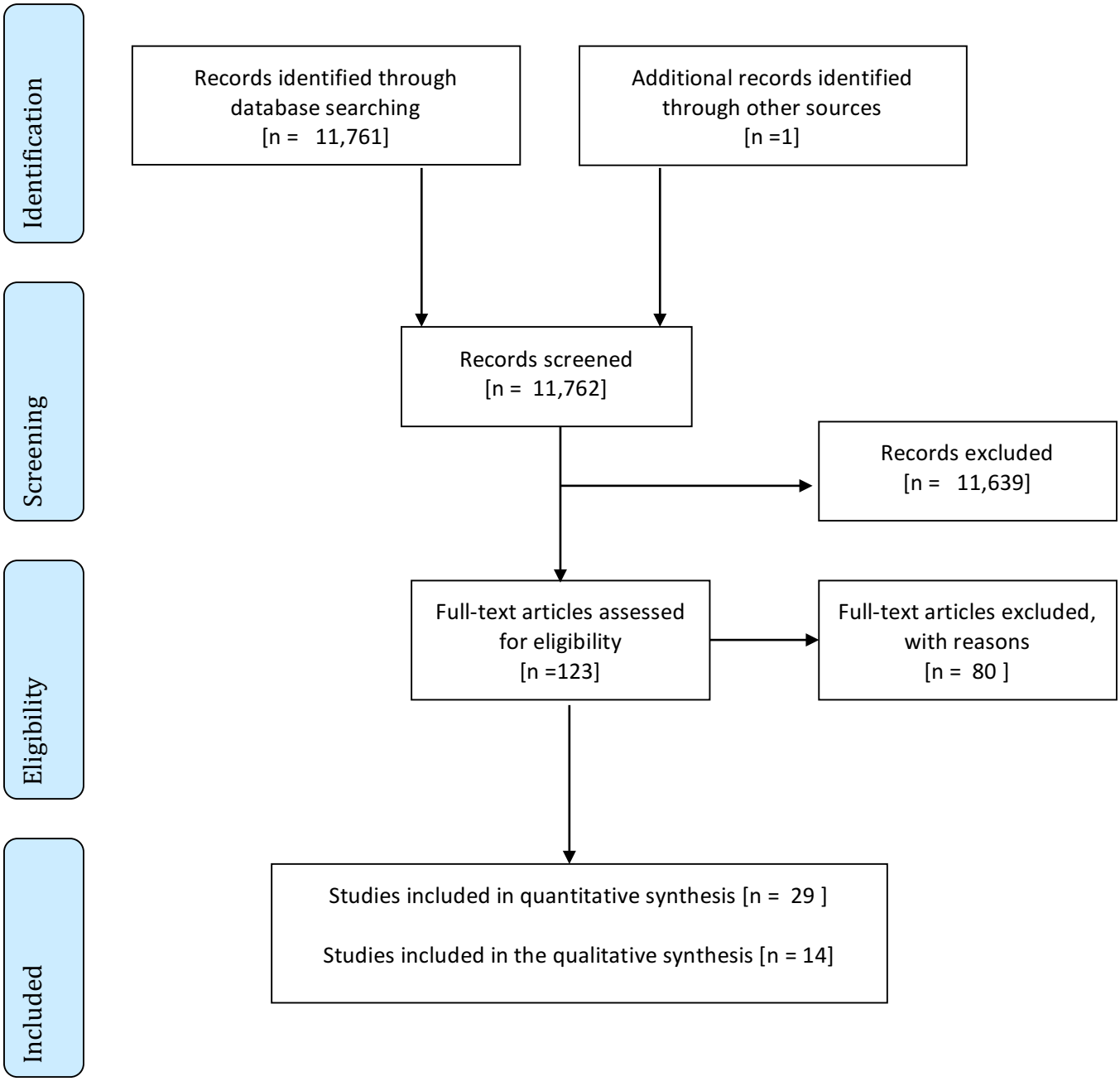
Appendices

Appendix A: Medline search strategy

1. shared decision making.mp.
2. (patient$ adj3 participation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
3. Patient Participation/
4. Patient Education as Topic/mt [Methods]
5. Patient-Centered Care/
6. Communication/
7. (patient centered or patient centred).mp.
8. Physician's Practice Patterns/
9. exp Attitude/
10. exp Physicians/
11. 9 and 10
12. Professional Practice/
13. Physician-Patient Relations/
14. "Attitude of Health Personnel"/
15. (attitude$ or belief$ or opinion$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
16. (physician$ or general practitioner$ or GP).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
17. 15 and 16
18. editorial/
19. letter/
20. comment/
21. 18 or 19 or 20
22. animals/ not (animals/ and humans/)
23. decision making/ or choice behavior/ or consensus/ or "dissent and disputes"/ or refusal to participate/ or negotiating/ or uncertainty/
24. 2 and 23
25. 6 and 23
26. 7 and 23
27. 10 and 23
28. 1 or 3 or 4 or 5 or 24 or 25 or 26
29. 8 or 11 or 12 or 13 or 14 or 17 or 27
30. 28 and 29
31. limit 30 to yr="2000 -Current"*
32. limit 31 to english language

33. 32 not 21
34. 33 not 22
* The search strategy was developed to include all references from 2000 to current. However, only those references published after 2006 were screened for inclusion in this review.

Appendix B: PRISMA 2009 flow diagram (324)



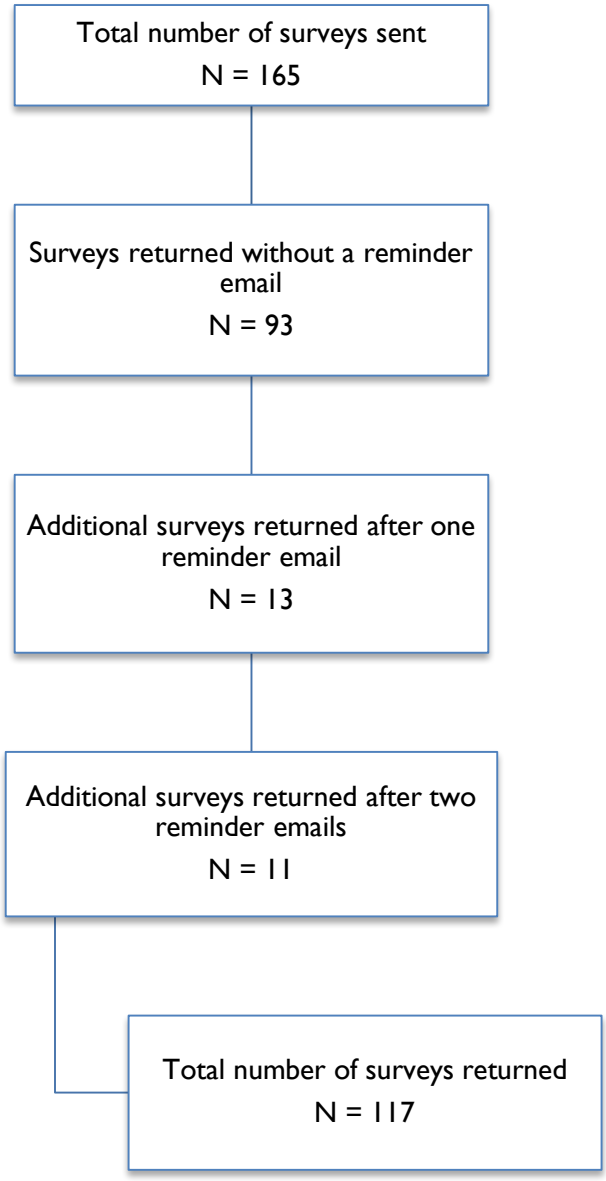
Appendix C: Studies that have used administrative data sources to address us of asthma controller medication use

First author, date author	Controller medications	Adherence measure	Explanatory variables obtained through administrative databases
Sadatsafavi, 2015 (117)	ICS, long acting beta agonist (LABA), leukotriene receptor antagonist (LTRA), systemic corticosteroids (SCS)	Medication possession ratio (MPR)	• Age • Sex • Number of asthma related hospitalizations in the year preceding the index date • Number of SABA canisters received in the year preceding index date • Number of ICS canisters received in the year preceding the index date • Charlson comorbidity index
Blais, 2011 (184)	ICS mono-therapy	Proportion of prescribed days covered (PPDC)	• Sex • Area of residence • Social assistance status • Number of outpatient visits for asthma • Number of outpatient visits for all causes • Number of prescribing physicians for asthma medications • Number of pulmonary function tests • SABA use per week (Exacerbations and control.) • Number of oral corticosteroid prescriptions (Exacerbations) • Number of asthma related ED visits (Exacerbations) • Number of asthma related hospitalizations (Exacerbations) • Prescribing physician speciality (GP, respirologist, paediatrician) • Comorbidities
Sadatsafavi, 2013 (121)	ICS, LTRA, LABA	Proportion of days covered (PDC)	• Asthma-related hospitalization

First author, date author	Controller medications	Adherence measure	Explanatory variables obtained through administrative databases
			• An asthma-related outpatient visit • Total number of asthma-related medication dispensations • Number of oral corticosteroid dispensations • Asthma-related direct medical costs (outpatient visits, hospitalizations and medications)
Marceau, 2006(178)	ICS, LABA	number of prescriptions of either a combination or a concurrent therapy filled during the first year of treatment.	• Number of ICS prescriptions filled in the year preceding cohort entry (Disease severity) • Number of prescriptions OCS prescriptions filled in the year preceding cohort entry • Number of ICS prescriptions or ICS filled in the year preceding cohort entry • Number SABA prescriptions filled in the year preceding cohort entry • Filled prescription of an oral corticosteroids, or a visit to an ED or a hospitalization for asthma (Exacerbations) • Age • Sex • Receipt of social assistance • Area of residence • Number of medications filled in the year preceding cohort entry • prescribed daily dose of ICS at treatment initiation (Disease severity) • Asthma related GP-visits in the year preceding cohort entry (Disease severity) • Asthma related hospitalizations in the year preceding cohort entry (Disease severity) • Asthma related ER admissions in the year preceding cohort entry (Disease severity)

First author, date author	Controller medications	Adherence measure	Explanatory variables obtained through administrative databases
			• at least 1 prescription of antileukotrienes in the year preceding cohort entry (Disease severity) • at least 1 prescription of theophyliene in the year preceding cohort entry (Disease severity)

Appendix D: Impact of participant follow up



Appendix E: Survey variable definitions

Heading	Question	Variable type	Initial Coding
Demographics	What is your household's income range, (before tax)?	Categorical/ Continuous	0: no income or less than 20,000 1: 20-39,999 2 40-59,999 3: 60-79,999 4: 80 or more
	What is the highest level of schooling you have completed?	Categorical	0: primary school 1: middle school 2: high school 3: some college 4: four year college/university
	The following is a list of common health problems. Please indicate if you currently have the problem (even if the problem is under control with treatment)	Categorical *Will also be categorized in terms of number of comorbidities (e.g. 0 versus at least one, or N number of comorbidities	1: heart disease 2: high blood pressure 3: lung disease 4: diabetes 5: ulcer or stomach disease 6: kidney disease 7: liver disease 8: anemia or other blood disease 9: cancer 10: depression 11: osteoarthritis or degenerative arthritis 12: back pain 13: rheumatoid arthritis
	What is your gender?	Categorical	0: female 1: male 2: other (text box provided to specify gender)
	What is your age?	Numeric/	

Heading	Question	Variable type	Initial Coding
		Continuous	
	Please select the racial or cultural group(s) to which you belong.	Categorical	1: White/ caucasian 2: South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.) 3: Chinese 4: Black 5: Filipino 6: Latin American 7: Arab 8: Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.) 9: West Asian (e.g., Iranian, Afghan, etc.) 10: Korean 11: Japanese 12:Other, please specify
Asthma (education/control/ Healthcare use)	What age were you when you were told you had asthma?	Numeric/ continuous	
	Have you seen a specialist for your asthma?	Categorical	0= no/ I cannot remember 1= yes
	Has anyone shown you how to use your inhaler?	Categorical	0= no/ I cannot remember 1= yes
	Who has shown you how to use your inhaler?	Categorical *will also be categorized as "no teaching" versus "any teaching"	1; my family doctor 2: my asthma specialist 3: a nurse 4: my asthma educator 5: a friend 6: family member 7: other (text box provided)

Heading	Question	Variable type	Initial Coding
			8: I do not use an inhaler
	Did you ever get a written action plan for managing your asthma?	Categorical	0= no/ I cannot remember 1= yes
	Have you ever had teaching about your asthma from an asthma educator?	Categorical	0= no/ I cannot remember 1= yes
	In the past year, have you visited a doctor due to your asthma?	Categorical	0= no/ I cannot remember 1= yes
	In the past year, how many times have you visited a doctor due to your asthma?	Continuous	
	In the past year, have you visited an emergency department due to your asthma?	Categorical	0= no/ I cannot remember 1= yes
	In the past year, how many times have you visited an emergency department due to your asthma?	Continuous	
	In the past year, have you been hospitalized due to your asthma?	Categorical	0= no/ I cannot remember 1= yes
	In the past year, how many times have you been hospitalized due to your asthma?	Continuous	
	Are you currently being prescribed asthma controller medication?	Categorical	0= no 1= yes 2= I am unsure
	What is the name of the asthma medication(s) that you are currently	Open	

Heading	Question	Variable type	Initial Coding
	being prescribed?		
	Have you filled your most recent controller medication prescription?	Categorical	0= no/ I cannot remember 1= yes
	When you were first prescribed your controller medication, did your doctor provide you with a sample of the medication?	Categorical	0= no/ I cannot remember 1= yes
	Did you take the medication samples that your doctor provided you?	Categorical	0= no/ I cannot remember 1= yes
	Have you ever heard of an asthma action plan, before today?	Categorical	0= no/ I cannot remember 1= yes
	Were you involved in developing your asthma action plan?	Categorical	0= no/ I cannot remember 1= yes
	When was your current action plan first given to you?	Date – categorical	
	When was your asthma action plan last updated?	Date – categorical	
	Do you recall the first time your doctor prescribed the asthma controller medication that you are currently being prescribed?	Categorical	0= no 1= yes
	When were you first prescribed the asthma controller medication that you are currently being prescribed?	Date	
	Are you currently being prescribed rescue	Categorical	0= no 1= yes

Heading	Question	Variable type	Initial Coding
	medication?		
	What is the name of the rescue medication(s) that you are currently being prescribed?	Open text	
	Do you recall the first time your doctor prescribed the asthma rescue medication that you are currently being prescribed?	Categorical	0= no 1= yes
	When were you first prescribed the asthma rescue medication that you are currently being prescribed?	Date	
Participant feedback (Final survey question)	Is there anything else you would like to share with us on this topic?	Open text	
Self-reported measure of adherence. See Table 2	I follow my asthma medication plan	Categorical	1: I agree completely 2: I agree mostly 3: I agree somewhat 4: I disagree somewhat 5: I disagree mostly 6: I disagree completely
	I forget to take at least one dose of my inhaled steroid each day		
	My asthma is mild and does not require regular preventative medication		
	My inhaled steroid causes side effects		
	I am concerned about the side effects of my inhaled steroids (item added but is not included in the validated version of the AAAQ)		
	I can't afford my inhaled steroid medication		
	How much effort was	Continuous	0: No effort at all[4]

[4] The original Collaborate scale lists this item as "No effort was made." An error appears in the survey instrument where this item is listed as "No effort at all." The

Heading	Question	Variable type	Initial Coding
Experience with SDM: CollaboRATE See Table 2	made to help you understand your health issue?		1: a little effort was made 2. Some effort was made 3. A lot of effort was made 4. Every effort was made
	How much effort was made to listen to the things that matter most to you about your health issues?		
	How much effort was made to include what matters most to you in choosing what to do next>		
Literacy: 3-SQ See Table 2	1. How confident are you filling out forms by yourself?	Categorical/ Continuous	Extremely Quite a bit Somewhat A little bit Not at all
	2.How often do you have someone help you read hospital materials?		All of the time Most of the time Some of the time A little of the time None of the time
	3. How often do you have problems learning about your medical condition because of difficulty reading hospital materials?		All of the time Most of the time Some of the time A little of the time None of the time
Numeracy: SNS See Table 2	How good are you at working with fractions?	Categorical	1: not good at all 2: 2 3: 3 4: 4 5: 5 6: extremely good

incorrect item was retrieved from a publication using the CollaboRATE scale, but was later revised to list the correct anchor.

Heading	Question	Variable type	Initial Coding
	How good are you at figuring out how much a t-shirt will cost if it is 25% off?	Categorical	1: not good at all 2: 2 3: 3 4: 4 5: 5 6: extremely good
	How often do you find numerical information to be useful?	Categorical	1: never 2: 2 3: 3 4: 4 5: 5 6: Very often
Preference for SDM: PSDMS See Table 2	Who should determine (diagnose) what the likely causes of your symptoms are?	Continuous	1. the doctor[5] 2. mostly the doctor 3. both equally 4. mostly me 5. me alone
	Who should determine what the treatment options are?		
	Who should determine what the risks and benefits for each treatment option are?		
	Who should determine how likely each of these risk and benefits are to happen?		
	Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?		
	Given all the information about risks		

[5] The original PSDM scale includes this item as "the doctor alone." A typo appears in the survey instrument where this item is listed as "the doctor."

Heading	Question	Variable type	Initial Coding
	and benefits of the possible treatments, who should decide which treatment option should be selected?		
Asthma control: ACT See Table 2	1. In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school, or at home?	Categorical	1: all of the time 2: most of the time 3: some of the tome 4: a little of the time 5: none of the time
	2. During the past 4 weeks, how often have you had shortness of breath?	Categorical	1: more than once a day 2: once a day 3: 3 to 6 times a week 4: once or twice a week 5: not at all
	3. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?	Categorical	1: 4 or more nights a week 2: 2 or 3 nights a week 3: once a week 4: once or twice 5: not at all
	4. How would you rate your asthma control during the past 4 weeks?	Categorical	1: not controlled at all 2: poorly controlled 3. somewhat controlled 4. well controlled 5. completely controlled
	5. During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as albuterol)?	Categorical	1: 3 or more times per day 2: 1 or 2 times per day 3: 2 or 3 times per day 4: once a week or less 5: not at all

Appendix F: Construction of select variables based on pre-validated instruments

Category	Method of calculation/ Cutoff	Predicted distribution
AAAQ: self reported adherence	Anything other than "I agree completely" constitutes non-adherence (261) Each item assigned 0/1 scoring. No summary score is calculated	Based on previous testing of this item, approx. 42% are categorized as non-adherent(261)
CollaboRATE: Patient reported exposure to SDM	This survey uses CollaboRATE 5 (with a 5 point likert scale) 1) Continuous outcome: sum scores on the 3 items on the original scale from 0 to 12 (266) 2) Binary outcome (CollaboRATE topscore): A patient is coded as 1 if they responded "every effort" to each of the 3 items. All other patients are coded as 0.(266)	
Preference for SDM: PSDMS	To determine preferred role, mean scores are computed separately for the PS and DM dimensions and placed into one of three classifications: • hand over (mean score on that dimension <3) • share (mean score between 3 and 3.99) • keep (mean score > 4). These classified PS and DM scores are then used to place respondents into one of three categories. • Passive patients wish to hand off both PS and DM • autonomous patients want to	Approx. 48% prefer a shared role, 50% a passive role, and the remaining 2% an autonomous role (269)

Category	Method of calculation/ Cutoff	Predicted distribution
	retain some control of both PS and DM (keep PS, and share or keep DM) • shared patients want to hand off or share PS but share or keep DM (269)	
Literacy: 3-SQ	Each of the three items is assigned a score of 0-4 Each of the three items will be tested separately.(276)(278)	
Numeracy: SNS	Each item is rated on a 1-6 point likert scale (with only two anchors at each end. A summary score between 3 and 18 is calculated.(280)	
Asthma control test	All items scored on 1-5 scale, added up to create a total score out of 25. 5-19: Your asthma symptoms may not be well controlled 20-25: Your asthma symptoms may be well controlled Item will also be tested as a continuous variable (5-15)	Previous investigations using mild asthma patients estimate well controlled asthma at 48%, 29% somewhat controlled, and 23% poorly controlled.(325) Among the general population of asthma patients in BC, poor control is estimated to be present in approximately 63%.(105)

Appendix G: Re-definition of selected variables for the bivariate and multivariate analysis, based on original variable distribution

Variable	Original distribution	Re-definition for the purposes of analysis
Ethnicity	82% "white/Caucasian" ethnicity Small cell sizes on most other ethnicities	1= white 0 = non-white
Education	69% four-year college/ university Small sample sizes for primary to high school	1 = four year college/university 0 = less than 4 year college/ university
Comorbidities	Wide-ranging distribution for individual comorbidities. Will investigate as per number of comorbidities reported per patient as a potential indicator of treatment complexity.	0 = 0 comorbidities 1 = 1 comorbidity 2 = 2 comorbidities 3 = 3 or more comorbidities
Numeracy (created as a categorical and numeric variable)	Highly negatively skewed Not appropriate for parametric testing Median numeracy score of 16. Re-categorized per distribution into tertiles.	1 = 3-14 2 = 15-17 3 = 18
Asthma Control	Highly negatively skewed Not appropriate for parametric testing Median ACT score of 22 Select previously defined threshold of 20, for analysis	Well controlled (ACT score => 20) = 1 Not well controlled (ACT score < 20) = 0
Who should determine (diagnose) what the likely causes of your symptoms are? Who should determine what the treatment options are? Who should determine what the risks and benefits for each treatment option are?	Very small sample sizes for the "me" and "mostly me" items. Given the skewed distribution, will categorize as shared/active approach preferred versus passive approach preferred for the analysis	1 = Mostly me/Both equally 0 = Mostly the doctor/ the doctor

Variable	Original distribution	Re-definition for the purposes of analysis
Who should determine how likely each of these risks and benefits are to happen?		
I forget to take at least one dose of my inhaled steroid each day My asthma is mild and does not require regular preventative treatment My inhaled steroid causes side effects I can't afford my inhaled steroid medication I am concerned about the side effects of my inhaled steroid	Small sample sizes for certain items. Given the skewed distribution, will categorize as general agreement versus general disagreement for the analysis	1 = I agree (completely, mostly, somewhat) 0 = I disagree (somewhat, mostly, completely)

Appendix H: Missing data

Item	N missing	% Missing
Income	6	5%
Literacy (Reading)	1	<1%
Age at Asthma Diagnosis	2	1.7%
Problem Solving Decision Making Scale (Who should diagnose?)	2	1.7%
Adherence	1	<1%
Adherence barrier (forget to take medication)	2	1.7%
Adherence barrier (side effects)	1	<1%
Adherence barrier (concerned about side effects	1	<1%
Adherence barrier (cost)	1	<1%
Age	2	1.7%
Asthma Control (Work)	1	<1%
Asthma Control (Symptoms)	1	<1%

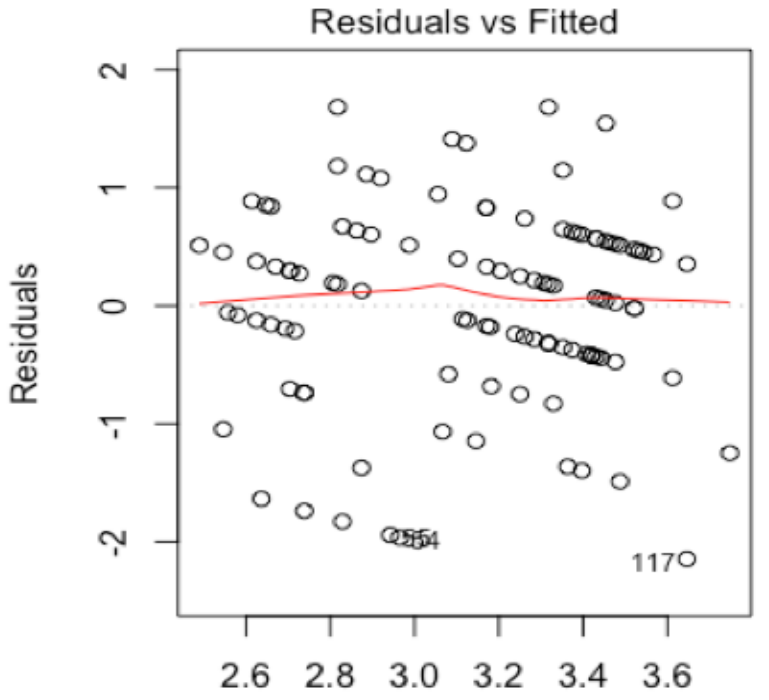
Appendix I: Multivariate linear regression diagnostics

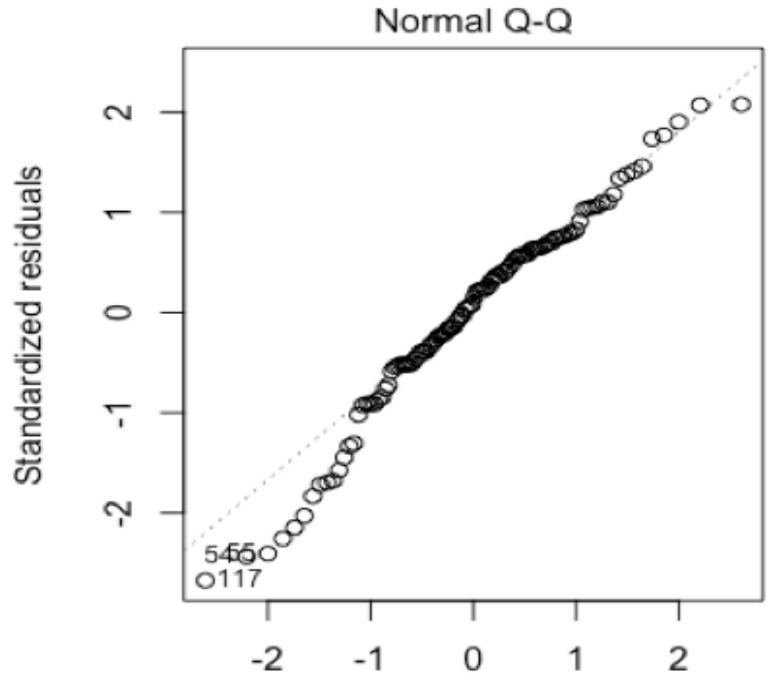
Adjusted R-squared = 0.1254. Age and income explain approximately 12.5% of the variability in role preference for the decision-making process.

Model p-value for the F-statistic = 0.0002855. The multivariate model is statistically significant. The slope is not equal to 0.

Residuals vs. Fitted plot: Indicates that the relationship between age, income and role preferences is approximately linear.

QQ-plot: The model is approximately normally distributed.


Residuals vs Fitted
Residuals
2
1
0
-1
-2
117
2.6
2.8
3.0
3.2
3.4
3.6


Normal Q-Q
Standardized residuals
2
1
0
-1
-2
117
-2
-1
0
1
2

Appendix J: Multivariate logistic regression diagnostics

Tests for goodness of fit:

Pseudo R^2 = 1- residual deviance/null deviance

= 1- (97.694/ 118.056) = 17.3

Conclusion: The multivariate model explains approximately 17.3% of variation in adherence.

Pearson's X^2 = sum (Pearson's residuals)^2 = 84.83572 (p = .113)

Null hypothesis = the fitted model is correct.(216)

Conclusion: Fail to reject the hypothesis that the fitted model is correct.