

**Need for Navigation and Utilization of Cancer Patient Navigators (CPNs) among  
Breast Cancer Patients in Nova Scotia**

**by**

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**Submitted in partial fulfillment of the requirements  
for the degree of Master of Science**

**at**

**Dalhousie University  
Halifax, Nova Scotia  
July 2019**

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## **Dedication**

For the Cancer Patient Navigators who serve Nova Scotians in their time of need.

Also for my Auntie Wendy, who was a shining example of serving others with skill, care and humility, and of balancing rich personal and professional lives. Rest in peace.

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## **Abstract**

**Background:** The Cancer Patient Navigator (CPN) program aims to reduce burdens of care coordination, emotional stress and logistical challenges on cancer patients in Nova Scotia (NS). There is concern that some patients with higher need for navigation are not accessing CPN.

**Methods:** This was a sequential mixed methods study. Interviews and a Delphi survey of CPNs in NS identified factors that increase patients' need for navigation. In a population-based cohort of NS breast cancer patients, we analyzed the association between CPN use and the factors identified from interviews.

**Results:** CPNs identified sociodemographic factors (especially low socioeconomic status [SES]) as important influences on need for navigation. However, we observed no association between SES and CPN use, even after adjustment for need variables.

**Conclusions:** Despite the expectation of greater CPN use among patients of low SES, this was not observed. This suggests that certain patients with higher need are not accessing CPN.

## List of Abbreviations Used

ACG	Aggregated Clinical Group
ADG	Aggregated Diagnostic Group
CIHI	Canadian Institute for Health Information
CPN	Cancer Patient Navigator/Navigation
DAD	Discharge Abstract Database
DA	Dissemination Area
DHA	District Health Authority
HA	Health Authority
MSI	Medical Services Insurance
NS	Nova Scotia
NSCR	Nova Scotia Cancer Registry
NSHA	Nova Scotia Health Authority
OR	Odds Ratio
SES	Socioeconomic Status



## **Acknowledgements**

I have deep gratitude toward many people who have helped me through this process. To my thesis committee, thank you so much for your constant example of patience, professionalism and respect. You have devoted many hours (sometimes with very tight deadlines!) to help me understand every step and ensure that this project was conducted to the highest quality possible. In our meetings, I really appreciated your collegiality—every suggestion and correction was conveyed in a constructive and respectful manner that I hope to pay forward to all of my future colleagues. To my co-supervisor Dr. Robin Urquhart, I couldn't have dreamed of a better mentor. You have trusted me and believed in me far more than I have done for myself, which has inspired in me so much self-confidence and the realization that one day (not so far away), I too will be a valuable, contributing member to the research community. Your generosity and kindness have been incredibly important to establishing an open and fruitful dialogue. To my co-supervisor Dr. George Kephart, thank you for your unbridled enthusiasm for research and for pushing me to dream bigger with this project—you keep me young! Thanks to you, this project was able to dig deeper than I thought my MSc. thesis ever could.

To my parents (Jim and Karen), siblings (Katie, Cam and Malcolm) and Alysia, you have been there for me every hour of the days that I thought I'd never make the next deadline, and for every victory when I actually made it. I thank you for your understanding and optimism, it has meant so much to me. Thank you for every goofy joke and sympathetic therapy session; they all helped to keep me going long after I thought I'd reached my limits. It has taken a village, including many more friends from the CH&E department, the Tupper building and beyond, to raise this thesis and I count myself incredibly lucky to have you all in my life.

Thank you also to the Cancer Patient Navigator Program. Krista, Gordon and their team have been so willing and enthusiastic to participate and advise in any way we asked, it has been a wonderful experience. To the navigators who directly participated in data collection: thank you so much for sharing your stories and experiences, I am absolutely in awe of the difference you make in the lives of patients every day, and I hope this project can help you do this even a little bit. You are there for patients when they are going through one of the hardest experiences they will ever face, with kindness, empathy and advice for all.

Thank you also to Margaret and Cynthia, for patiently guiding me through the important, but complex processes of research ethics and data access—these are some of the most practical skills that I've gained, and I'm confident knowing I learned from the best. Your time answering questions and reviewing my nonsensical first drafts are thoroughly appreciated.

Finally, I would like to thank my funding sources: the Maritime SPOR SUPPORT Unit and the Beatrice Hunter Cancer Research Institute (with the help of the QEII Foundation and The Breast Cancer Society of Canada). Also, to the Canadian Institute for Health Research for funding the CanIMPACT study (the original study that used this project's dataset). Without their support this research would not be possible. Also, to Health Data Nova Scotia of Dalhousie University for making the data for this project available. Note that although this research analysis is based on data obtained from the Nova Scotia Department of Health and Wellness, the observations and opinions expressed are those of the authors and do not represent those of either Health Data Nova Scotia or the Department of Health and Wellness.

## **Chapter 1: Introduction**

Breast cancer has the highest incidence of all cancer types, excluding non-melanoma skin cancers, among women in Nova Scotia and Canada, with almost 800 new cases diagnosed in the province annually (1). The journey through breast cancer diagnosis and treatment can be a long and complex one, involving not only medical interactions with oncologists and surgeons, but also a myriad of logistic and social issues, ranging from financial instability (due to inability to continue working) to care of dependents (adult or child) and travel to treatment centers. For a patient already coping with the physical and emotional stress of a cancer diagnosis, the added burden of navigating the health care system while concurrently making important treatment-related decisions can be overwhelming.

Additionally, many cancer care services in Nova Scotia (NS) are centralized in the two provincial cancer care centres (in Halifax and Sydney). Given that a large proportion of the population in NS is rural, many patients will have to travel up to five or six hours for cancer-related appointments. Previous work has estimated that the large majority of breast cancer patients in NS will travel to Halifax at least once during their cancer journey (2). This distance may cause patients living farther from a cancer centre to feel isolated or “fall through the cracks”, as they may not have as much opportunity to interface with their cancer care team.

In 2002, Cancer Care Nova Scotia (now the Cancer Care Program, Nova Scotia Health Authority [NSHA]) initiated a cancer patient navigator (CPN) service to provide an informed guide throughout the cancer journey (3). CPNs in this program are oncology nurses whose roles include (a) providing emotional support to patients and families and organizing logistic needs around receiving cancer treatment and navigating the health

care system, (b) coordinating the health care teams providing cancer care and (c) acting as a source of information on cancer pathology (3). Program evaluations suggest the program has been successful in fulfilling these three patient-oriented goals, as well as promoting continuity of care and better coordination throughout the cancer care system (3,4).

Patient use of CPN depends entirely on their referral to the program. The main sources of referrals are other health care providers, the patients themselves, or family members (3). The most common source is by far other health care providers, who make nearly two-thirds of all referrals, followed by self-referrals and family member referrals (3). For breast cancer patients, these referrals most often take place after they have breast resection surgery, but before starting adjuvant chemo- or radio-therapies (personal communications with CPNs). The average time from a patient's cancer diagnosis to their referral to CPN was 49 days in the program evaluation performed in 2004 (3). The same evaluation noted that patients would benefit from referral earlier in their cancer journey, as close to diagnosis as possible (3).

Although all cancer patients may benefit from using navigation services, this is unrealistic in our real-world system of constrained resources. Thus, the navigation program should be especially targeted to individuals of relatively higher need for navigation (although the program will always be available to anyone who seeks it out). However, to our knowledge, there has been very little systematic investigation of to identify individuals with higher need. Thus, our first aim is to identify a set of patient factors that can be used to identify individuals who have higher need for navigation.

Knowing these factors and being able to operationalize and measure them quantitatively will allow us to reasonably predict whether an individual has higher or lower need of navigation. However, some factors likely associated with higher need (e.g., low income, low education level, lack of a family doctor) may also act as barriers to accessing many health care programs, including navigation. These are grounds to examine whether patients with higher predicted need for navigation are observed to actually use the navigation program. This has never been explored, to our knowledge. We evaluate here whether there is evidence that patients with higher predicted need for navigation use (or don't) the CPN program, and how this varies regionally across NS.

One of the greatest values of this study is to highlight patient groups that have high expected need for CPN but are not using it. This would likely reflect a deficit in the process of patient referral to CPN. By highlighting potentially underserved patient groups, the CPN program can send tailored messages to individuals responsible for referral (cancer-related health care providers, primary care providers, cancer centre staff, etc.) to promote referrals in these potentially underserved groups.

## **Chapter 2: Literature Review and Rationale**

### **2.1 Previous Studies of Patient Navigation**

Patient navigators (also called case managers, nurse navigators, etc.) are found throughout the United States (5), Australia (6), and the UK (7), as well as in a number of Canadian provinces (3,8,9). Navigation can be provided by a variety of individuals, such as lay persons, social workers, peer volunteers and nurses (as with CPNs in NS) (10). Nurses are especially well-suited for the navigator role due to their formal training in disease pathology, as well as practical insider knowledge of the treatment options and care pathways in their local jurisdictions (11). Because of their wide-ranging clinical experiences, they have been exposed to many different patient situations and seen the range of challenges patients face (11). In addition, because they interface directly with patients, nurses are exposed to the day-to-day challenges of disease in patients' lives and the personal strain of illness (11). This experience helps them to be both empathetic and practical when dealing with their patients during navigation (11).

In NS, CPNs typically divide their services into three categories: (a) psychosocial and practical assistance, (b) coordination of care and (c) informational support.

Psychosocial and practical services usually address the personal circumstances of the patient; for example, if a patient does not own a car, a CPN can help arrange transportation to appointments that are not local. Another of these activities is helping patients manage their financial difficulties, particularly with paying for medications that are not delivered in-hospital (e.g., anti-nausea to combat side-effects of chemotherapy, oral chemotherapies). Financial assistance has been identified by CPNs as the most common type of assistance that they provide (3). Psychosocial support from CPNs to patients struggling emotionally or psychologically with their diagnoses and treatments is

arguably one of the most important functions of the program. Emotional stress, fear and anxiety around cancer diagnosis are the most commonly reported issues by patients using the CPN program (3). Coordination of care involves helping patients keep track of where and when each of their appointments will take place, as well as ensuring that every health care provider on the patient's care team has the most up-to-date information about the patient's progress. Informational navigation services involve the provision of information on the biology of cancer, as well as the various treatment options and their corresponding side effects and practical considerations. Providing this information sets realistic expectations for each stage of a patient's journey and helps to manage their apprehension. Managing a patient's needs goes beyond in-person or telephone meetings with the patient. CPNs' responsibilities also require them to interface with contacts in the health authority, hospitals, government and community, as well as to keep up with administrative tasks (3).

Most of the evidence around cancer patient navigation has focused on its effectiveness in improving systems-level cancer outcomes, such as receipt of breast cancer screening, time to diagnostic confirmation (12), timeliness of treatment initiation, receipt of guideline-level treatment and post-treatment surveillance mammography adherence (13). Other studies have examined patient-reported outcomes such as quality of life (11,14) and patient satisfaction (11,14–16). These studies were performed in a variety of populations, often with a purposeful focus on populations who have been historically disadvantaged in cancer outcomes. Examples include patients of low socioeconomic status (SES), ethnic minority and older ages (16–19). These studies report that disadvantaged patients (older ages (16,17), immigrants (18), ethnic minorities (16),

low income (16), socially isolated (16), or greater burden of comorbidity (19)) tend to derive greater benefit from navigation than their advantaged counterparts (higher SES, white race, younger age, etc.). These benefits are seen in a number of health system indicators (time to diagnostic confirmation and time to treatment initiation) and quality of life outcomes (16–19). Clearly, the cancer patient navigation community is aware that certain patient populations have particularly high need for and greater capacity to benefit from navigation services. Thus, rather than investigating program effectiveness, this study focused on a step “prior” to program effectiveness—that is, this study aimed to identify the patient sub-population(s) who likely have the greatest need for a navigation program. To our knowledge, only one study has purposefully explored factors that increase a patient’s need for navigation (20). There remains a dearth of investigation in this area, and particularly in the context of the Canadian health care system.

## 2.2 Factors Associated with Need and Use of Navigation Services

Variation in how much any given patient uses a health care service is a reality, and not necessarily a negative one—not every patient has the same need for a service, nor the same desire for it. A more reasonable comparison would be between a patient’s need and/or desire for health care services and their health care use. First, we will discuss inequalities in the context of typical treatment-oriented health care services (for example, radiotherapy) before moving on to inequalities in use of navigation services. For most treatment-oriented health care services, it is completely appropriate for patients with more severe illness to use more services than patients who are less ill. Similarly, variation due to patients’ autonomous decisions (“preferences”) is also appropriate when patient preferences are expressed voluntarily through an informed process (21,22). Medical need and patient preference are acceptable reasons for differences in health care service



utilization. However, concerns may start to arise if certain other factors (with no connection to their medical need or informed preference for a service) are influencing a patient's use of health care services. For example, in the case of a hypothetical radiotherapy service, appropriate care may involve greater use of treatment for patients with more aggressive or severe disease, and less use among patients with less progressed disease. However, if patients' receipt of appropriate care is impeded by their low income, lack of transportation, or place of residence, we may have cause for concern. Factors that raise concerns due to their impact on a patient's service use are often "social" or non-medical factors, such as social isolation, minority status or low education level (23).

Whether we should be concerned about the impact of a factor on use of health care services depends on the service of interest. In many ways, the context of patient navigation services is different from the above hypothetical cancer treatment service example. While a cancer treatment service aims to directly treat illness or injury, patient navigation is designed intentionally to address all manner of medical and social disadvantages. The goal of navigation is that patients will use treatment-oriented services without undue influence from non-medical factors (low income, social isolation, greater distance from treatment services, etc.). Thus, in the context of patient navigation, it would actually be desirable to see differences in use of navigation services based on non-medical factors. These social factors likely indicate a patient who stands to gain markedly from navigation services. For example, while differences in use of treatment services based on income level (and not medical need) may raise concern, differences in use of patient navigation based on income level could be entirely appropriate. If a patient is of low income, for instance, a navigator can make them aware of financial assistance for

travel and accommodations while they receive radiotherapy in one of the two radiotherapy clinics (Halifax or Sydney), and help the patient complete the necessary paper work. Similarly, if a patient has no personal mode of transportation, has difficulty understanding new information or lives alone, a navigator can help them obtain a bus pass so they can attend support group meetings. While we can intuitively identify some of these non-medical factors, there are potentially many more factors not well-established in the literature. As mentioned previously, to our knowledge, only one study has made a purposeful investigation in this area (20) and there is a need for further investigation. The first objective of this work was to undertake a similar study. Below, we summarize a number of potential factors that indicate their potential importance based on the literature review.

#### 2.2.1 Sociodemographic Factors

**Age at cancer diagnosis.** We hypothesize that age has a non-linear or “U-shaped” relationship with navigational need. There is evidence to support that both older and younger patients have unique needs compared to middle-aged patients. Increased age is strongly associated with lower receipt of cancer treatment (24–27). A study on NS colorectal cancer patients found that older age was associated with significantly less receipt of chemo- and radio-therapies (27). While it is reasonable to expect that some older patients and their health care providers may decide voluntarily not to pursue treatment, there are a number of other possible influences on treatment decisions. Older patients may be less able to coordinate the logistics of their cancer care, such as transportation to and from doctor’s appointments, care of dependents (such as spouses and grandchildren) and extended recovery time compared to younger patients (16,24). Age is also associated with several other potentially important characteristics discussed

below, such as comorbidity and social deprivation (28). Navigators are well-equipped to address these issues; they can find resources for transportation and coordinate a clear plan to satisfy the needs of the patients' dependents, allowing patients to focus on their own treatment and recovery. In fact, nurse-led navigation has been shown to improve access to adjuvant treatments such as chemotherapy and radiotherapy (16), and timeliness of diagnosis and treatment among older women with breast cancer (17). Younger breast cancer patients (<40 years old) may also have greater navigational needs. Women who are not yet middle-aged are more likely to have dependent children and to be employed. These are particularly important considerations when patients' ability to work may be severely diminished by cancer symptoms and treatment side effects (29). A patient navigator can help patients organize care for their dependents and access financial resources to help carry them through their cancer journey.

**Low income.** Studies of cancer patients have found that low socioeconomic status (of which income is the primary driver) is associated with poorer access to high quality treatments (30) and low income specifically is associated with poorer access to homecare services, even in publicly financed health care systems (31). In a universal health care system with no patient cost at the point of service, such as for physician and hospital services in Canada, income should not be a direct barrier to accessing care. Indeed, there is evidence for a survival advantage among low-income Canadian breast cancer patients over low-income American breast cancer patients, likely due to greater health care access among Canadians (32). However, even though Canadian patients do not pay for hospital-based treatments, there are still other costs to receiving cancer treatment. Patients report financial difficulties from lost wages (due to taking time off of work), travel to another

city and accommodations to receive treatment, medications to manage side effects of cancer treatment, cancer-directed oral chemotherapies, home care services, and psychosocial care (ranging from formal psychologist appointments to informal vacations or gifts to reduce stress) (33). Financial strain was identified by patients in the CPN program as sometimes exceeding even the stress of the cancer diagnosis (3). Patient navigators can help patients learn about the resources that exist to support them, such as unemployment insurance and charitable organizations that support patients struggling under financial strain. The first ever patient navigation program (in Harlem, NY) was, in fact, started to serve low-income cancer patients (5).

**Low education level.** Low education level has been associated with poorer access to specialized care and as a result, poorer survival (34). One explanation may be that highly educated patients are more aware of treatment options and better able to self-advocate, pushing for access to higher quality care and partnering in the decision-making process with their health care provider (34). In addition, individuals with higher education are better able to manage symptoms and modify health behaviours to support recovery (34,35). CPNs support care advocacy for patients who lack the skills and information to do so alone, striving for every patient to receive the highest quality of care.

A related concept to education level is that of health literacy, or an individual's ability to understand information around their illness and treatment (36). This includes reading instructions on medication bottles, preparing for medical tests (e.g. fasting for 12 hours prior) and understanding the information that health care providers communicate to them verbally (37). As of 2014, it has been estimated that 50.3% of adult Nova Scotians have inadequate literacy skills (38,39). There is evidence that these statistics reflect

patients ability to understand information in a real world setting: in a rural US cancer population, over 50% of patients report that they did not understand all of the information that was given to them by cancer clinic staff (40). For these patients, the navigator helps prepare them for upcoming cancer-related appointments, helping them to know what to expect from each health care provider and what information that they should expect to receive. Navigators can also spend more time educating patients with low literacy so that they are fully informed when they make treatment-related decisions.

**Low social support.** Social support is another potential determinant of need for navigation services. Socially isolated individuals have less flexibility in their living situation—when their ability to take care of themselves lapses, there is no immediate household member and few friends in the community who can compensate and supplement their work- and life-related responsibilities. Social isolation is also intrinsically linked to several other characteristics discussed in this section: older age and geographic distance from health care services (41). Thus, patients with low social support stand to gain substantially from the personal contact, support and resources provided by patient navigation, compensating for the limited social network. Indeed breast cancer patients who live alone have been found to experience greater benefit from navigation than their non-socially isolated counterparts (16).

**Greater geographic distance.** Greater distance between a patient's place of residence to the location of health care services has been linked to differential patient treatment patterns in studies on breast cancer patients in Canada and the United States (25,42). This has been confirmed among NS cancer patients as well (27). Olson and colleagues found that total mastectomy was much more common among rural women in

British Columbia than partial lumpectomy because the latter must be accompanied by subsequent rounds of radiotherapy, which are not available in rural community hospitals (42). This is largely thought to be driven by the patient's desire for less travel to urban treatment centres. In this situation, a navigator could advise a patient of treatment options, balancing geographic context with the medical guidelines for treatment. They may also help the patient coordinate the logistics of travel to/from and accommodation in an urban centre for radiotherapy, or to connect with community resources that already exist to satisfy these needs. A survey of Australian breast cancer patients found that rural women were more likely to use a nurse navigator than their urban counterparts (43). Although the authors were unable to explain this definitively, it may have to do with patterns of referral to navigation and the greater availability of nurse navigators in rural areas.

**Responsibility for dependents.** Some cancer patients have responsibility for the well-being of either children or other adults in their lives. Common examples include parenting and caring for a parent, spouse or sibling. A previous study on cancer patients in NS found that having responsibility for dependents was a factor that influenced surgeons' decision to refer patients for adjuvant chemotherapy (44). Surgeons recognize that this influences how willing or able a patient is to access adjuvant chemotherapy and may attempt to connect these patients with more supports to enable them to access an oncologist (44). For instance, patients with caring responsibilities have reported that they require caregiving support not only during appointments with their oncologist or during a chemotherapy session, but also during the recovery phase after each chemotherapy administration (45). However, the ability for a surgeon to connect their patients with

useful resources varied and would likely be better coordinated by a patient navigator, who is devoted to gathering and dispensing this knowledge. Patients with caregiving responsibilities have also reported that information and psychosocial support in advance of and concurrent to treatment is crucial to preventing stress from reaching crisis levels (45). The CPN role can detect emotional strain earlier and connect patients with caregiving responsibilities to relevant resources. Thus, caregiving responsibilities may represent a legitimate source of increased need for navigation services.

### 2.2.2 Clinical Factors

**Higher cancer stage at diagnosis.** Cancer stage is a general measure of the severity of cancer diagnosis, based on several characteristics of an individual's disease including tumour size, lymph node involvement and metastasis. Patients diagnosed at a later stage face poorer prognosis and oftentimes higher-risk treatment options and therefore may have different goals for their treatment (46,47). Moreover, women diagnosed with late-stage cancer may have a further increase in risk of mortality the longer they wait before beginning treatment (48). Navigators can address these unique and formidable challenges, providing information on not only the biology of the disease, but also on treatment duration, intensity and side effects (3). This discussion of practical, patient-relevant topics may ensure that the patient is receiving care that aligns with their personal values and that they are prepared for any symptoms and discomfort associated with illness or treatments. Indeed, evaluations of nurse navigation have shown evidence of greater patient satisfaction and knowledge of treatment in this setting (49–51).

**Greater comorbidity.** Greater burden of comorbidity has been associated with cancer care issues such as a slower journey through cancer diagnosis (19) and treatment choice (52,53). Slower progress is likely due to the extra resources and time required to

manage multiple conditions. Patients may require stabilization of their comorbidities before they can continue with treatment, which may require more tests and appointments that cause further delays (19). The effect of comorbidity on treatment choice occurs due to the extra consideration that the cancer care team must consider how comorbidities and their management will interact with cancer treatment (52–54). These considerations can further be compounded by the strong association between comorbidity and age.

Navigators can help patients better manage their co-morbid conditions in addition to their cancer diagnosis. Ideally, better comorbidity management will allow individuals to focus more on recovering from their cancer.

One particularly consequential class of comorbidity is psychiatric (9), which may severely limit a patient's ability to self-manage their illness and treatment (55). Ludman et al (2015) hypothesized that patients with psychiatric comorbidity (specifically, depression) stand to gain more benefit from navigation than patients without this comorbidity, though the results were inconclusive due to small sample size (55).

**Receipt of chemotherapy or radiotherapy.** Treatment-related decisions are an often-addressed area in navigator encounters (3). Before treatment, a patient's needs are often informational. They want to know about treatment effectiveness and side effect profiles, which navigators can explain in an accessible manner, such that patients are not overwhelmed with technical details (56). Navigators also factor in patient's personal details and integrate information on practical concerns. In NS, radiotherapy is only offered in Halifax or Sydney and so patients living outside of these sites have extra challenges to address related to transportation and local accommodation. After treatment with either radiation or chemotherapy has commenced, patients may require further



informational support when side effects start to occur, and psychosocial and practical support to deal with these side effects (56). Common treatment-related side effects include fatigue, hair loss, nausea/vomiting, skin rashes/irritation, weight loss and mouth/dental problems (57). These can be painful to endure, and so the needs of a patient from her navigator are not only in self-management of symptoms, but also in emotional support to ease the psychosocial consequences of a cancer diagnosis and its treatment.

### 2.2.3 Health System Factors

**Low continuity of care with primary care physicians.** The role of primary care physicians in cancer care has been unclear or small (58). Primary care physicians have indicated that they lack information to help their patients (58) and that they would prefer more communication from the oncology team (59). Patients have reported that they prefer an oncologist to be their main point of medical contact throughout the cancer journey (60). However, primary care physicians have expressed willingness to participate in management of non-cancer comorbidities, treatment side effects and psychosocial support throughout the cancer care period and beyond into the survivorship phase (58). Considering this overlap with the responsibilities of CPNs, it is possible that if a patient has a strong relationship with their primary care physician, they will have reduced navigational needs.

### 2.3 Study Rationale

Any of the above-listed factors could be legitimate sources of need for navigation services. This study will examine whether these higher-need groups have relatively greater observed use of CPN than their lower-need counterparts. For instance, if patients of lower income level were observed to use more navigation services, then this would align with our expectations and would not raise concern. However, if patients of higher

income level (or other “advantaged” positions, such as higher education level or higher level of social support, etc.) were observed to use more navigation services than their higher-need counterparts, then this could raise concern as it would be contrary to our expectations. Patients of lower income levels (or lower education level, etc.) likely have more ways in which patient navigators could assist them, and so if they had less use of navigation in spite of this fact, we should be concerned that these patients are not receiving optimal care.

While CPN program stakeholders are aware that gaps in the referral process for CPNs may cause some patients to miss out on their services (3), it is difficult to measure the impact of these gaps. The primary reason for this is that there is currently scarce evidence to identify groups that have higher need for navigation and simultaneously less ability to access it. This study identifies a comprehensive list of factors that can be used to identify such groups, and thus guide health care providers and others in their referral decisions. Ideally, this would improve the rate of referral for patients with higher need for navigation, and also help the CPN program monitor these trends.

There remains a paucity of data describing navigated cancer patients in the Canadian, and particularly NS, context. While program evaluations of the NS CPN service have been undertaken (3,4), these have primarily been qualitative studies cataloguing and summarizing the views of program stakeholders. Importantly, the program has recorded data on all CPN encounters since its inception and recent upgrades to its database now permit its linkage to other administrative health databases. This is unique in Canada and allows the first comprehensive quantitative investigation of CPN use in Canada.

### **Chapter 3: Research Objectives**

1. Identify what patient factors are important in determining navigational need in the NS breast cancer population from the perspective of CPNs;
2. Determine whether the patient factors identified in Objective 1 are associated with observed use of CPN; and
3. Examine whether the associations measured in Objective 2 show regional variation across the province of NS.

## **Chapter 4: Methodology**

### **4.1 Study Design**

This is a sequential mixed methods study employing interviews, Delphi process and statistical analysis of a patient cohort. First, we conducted interviews with the CPNs currently practicing in NS to gather their views on factors that increase cancer patients' needs for navigation services. Once we had a comprehensive list of factors, we sought to determine whether these views were consistent across CPNs and whether we could improve consensus among these views through an electronic survey. The results of the interviews and Delphi survey were combined to inform what factors would be most useful or interesting to investigate in the statistical analysis. Here, we examined a group of Nova Scotian breast cancer patients and whether any of the identified factors were associated with use of CPN using logistic regression modelling.

### **4.2 Qualitative Methodology**

#### **4.2.1 Interviews**

Experts views on factors that have an important impact on patients' need for navigation were obtained through semi-structured interviews with CPNs in Nova Scotia. The author (SM) and co-supervisor (RU) met to draft the interview guide (Appendix 1). Further elaboration of the interview guide and the included list of hypothesized factors were discussed by the entire committee (RU, GK, YA, TY). The overall sequence of questions in the guide was adhered to across interviews, though some modifications were made in later interviews (61). The guide was used to start conversations, but particularly in later interviews, CPNs were allowed to discuss whatever they felt was relevant. Generally, interview questions asked about the CPN's perception of their role and the factors surrounding a patient and their cancer experience that would increase their need for navigation services (as perceived by CPNs).

The author and co-supervisor (SM and RU) initially approached the CPN program manager to obtain permission and help with CPN recruitment. Initially, all 8 CPNs in the program were targeted for recruitment to the study. CPNs were e-mailed by the program manager with a brief study description and contact information. Interested CPNs reached out directly to SM to schedule a telephone interview. Reminder e-mails for recruitment were sent directly from SM (with CPN program manager's consent). All interviews were conducted by SM. They were recorded with the interviewee's consent and transcribed verbatim by SM.

We used the framework analysis technique to identify the relevant patient factors discussed in the interviews (62). This method has previously been used in the local context of primary care management in NS (63). It was selected for its balance of simple utility and ability to extract detail from a relatively small number of interview transcripts. The author (SM) and one of the author's co-supervisors (RU) reviewed interview transcripts for the presence of a set of "codes" (here, the patient factors that increase need for navigation). The two reviewers met to guide the selection of codes for the remaining transcripts (analyzed by SM only). SM and RU created an analytic framework operationalized as a matrix in which each code appeared as a column, and each "case" (interviewee) appeared as a row. When a particular code was mentioned in a given case, we demarcated the corresponding cell in the matrix and recorded significant quotes. The end result of this process was a table that catalogued all identified factors, and the frequency by which they were identified. This analysis was conducted using Microsoft Excel 2016 (Microsoft Corporation, Redmond WA). We used an audit trail to track the

sources of quotes and analysis-related decisions. All files were stored on a secure NSHA server.

## 4.2 Quantitative Methodology

### 4.2.1 Delphi Survey

Next, we used a modified Delphi process to obtain consensus on whether each of the factors identified in the interviews were important in determining need for navigation. This method was selected for its validated ability to obtain expert consensus in the context of health services research (64). The same CPNs who completed the interviews were asked (and subsequently agreed to) participate in the survey. This process involved the administration of two rounds of an electronic survey using Opinio software (ObjectPlanet Inc, Oslo, Norway). The survey was designed based on the standard Delphi approach (65). We presented each participating CPN with a list of all factors identified by the literature search and interviews and asked them to rate each on a scale of 1-9 for its importance (1 = not important at all, 9 = extremely important) (Appendix 2). We also asked participants to identify any additional factors they felt impacted a patient's need for navigation services that were unmentioned in the survey and to describe any combinations of two or more factors they perceived to amplify the need for navigation.

After the first round of the survey, we assessed the level of agreement on the ratings using the RAND/UCLA Appropriateness Criteria (65). This method is the standard for analyzing Delphi results, as it has been designed as a part of and by the developers of the official Delphi process, and is well-established as such. This method breaks down the 1-9 rating into three "importance brackets": 1-3 = "unimportant"; 4-6 = "uncertain"; 7-9 = "important". Each individual response is sorted into the appropriate importance bracket. We defined "agreement" as no more than two participants' ratings

falling outside of the importance bracket containing the median value of all ratings (65). For instance, if the median importance score was 8 (“important”), with four ratings of 7 or higher, and two remaining ratings of 4 and 6, then we would conclude that participants agreed that this factor is important. However, if there were only three ratings of 7 or higher, and the three remaining ratings were 4, 4, and 6 then, we could not be certain of participants’ agreement. If at least two responses fell between 7 and 9, and at least two responses fell between 1 and 3 (no matter what the remaining ratings were), then we would conclude that participants disagreed on the importance of the factor. If the calculated agreement level for a factor was uncertain or they disagreed after the first round of the Delphi survey, then we included it in a second survey round along with any factors that were identified de novo in the first round. In addition to the list of factors that did not achieve agreement, we informed participants of the results of the first round in the form of summary statistics (median and range for each factor). We also confidentially reminded each participant of their own individual responses from the first round. Upon completion of the second round, we repeated the measurement of agreement among responses. Once participants’ ratings achieved agreement, we summarized their ratings as a median and range. The importance of each factor was determined by the importance bracket that contained its median rating. If the median rating was “important” (7-9) or “uncertain” (4-6), it moved forward to the quantitative analysis stage of the study. We analyzed and presented Delphi survey results together with interview results, as these two methods were used together to address Objective 1. We used an audit trail to track the results of the surveys and analysis-related decisions. All files were stored on a secure NSHA server.

#### 4.2.2 Study Population and Sources of Data

Our second and third research objectives were to examine the associations between the factors identified from the interviews and Delphi survey and CPN use in NS overall and by region. We addressed these objectives with a descriptive study design using data from an historical (retrospective) population-based dataset of NS breast cancer patients. Our dataset contained all women diagnosed with their first invasive primary breast cancer accrued from January 1<sup>st</sup>, 2007 to December 31<sup>st</sup>, 2012 in NS. We excluded non-residents of NS (lack of access to all relevant administrative data), those with in situ or stage 0 cancers (we are only interested in invasive disease, not pre-cancerous lesions as in stage 0), those with any cancer history except non-melanoma skin cancer (data not collected in NS due to difficulty of tracking treatments outside of oncology) and those with non-solid tumors (we are only interested in breast histologies). We excluded those who resided in the Central Zone of NSHA (formerly known as the Capital District Health Authority [CDHA]) and those who were diagnosed more than 6 months before their regional navigation centre's start date because those individuals did not have the opportunity to use navigation. Navigation is only offered to NS patients who reside in the Western, Northern and Eastern NSHA Zones and was instituted in each region at different times between 2002 and 2011. Importantly, this variable influenced whether or not patients had opportunity to use CPN during their cancer journey. The start date of each regional navigation centre was slightly different, as displayed in Table 1. We excluded participants with a diagnosis date more than 6 months earlier than the regional navigation centre's start date, as they likely would not have had the opportunity to use the navigation program during their cancer journey. Patients were excluded based on their



DHA of residence at the time of diagnosis, however, jurisdiction is reported as zone for the remainder of the study.

Table 1. Start date for each regional CPN centre in NS.

Location of Navigation Centre	Current NSHA Zone	Start Date (year)
South Shore DHA	Zone 1 (Western)	Prior to study period
South West DHA	Zone 1 (Western)	Prior to study period
Annapolis Valley DHA	Zone 1 (Western)	Prior to study period
Colchester East Hants HA	Zone 2 (Northern)	2009
Cumberland HA	Zone 2 (Northern)	2009
Pictou County HA	Zone 2 (Northern)	Prior to study period
Guysborough Antigonish Strait HA	Zone 3 (Eastern)	Prior to study period
Cape Breton DHA	Zone 3 (Eastern)	2011

All breast cancer diagnoses were identified using ICD codes C50.0-9 (Appendix 3) from the Nova Scotia Cancer Registry (NSCR). Patient-level records were linked to administrative health data from various sources, including MSI Physician Billings, MSI Insured Patient Registry, MSI Licensed Provider Registry, CIHI Discharge Abstract Database, census data based on patient geography (Postal Code Conversion File, PCCF+ Version 5J), OPIS (scheduling database for medical and radiation oncology services in NS), the NS Breast Screening Program Database and ONCONav (database containing data on all encounters with CPNs since inception of the program). The data linkage diagram is shown in Appendix 4.

#### 4.2.3 Dependent Variable

**Use of CPN services (Individual-level).** Patients were categorized based on whether or not they had ever used CPN services. We considered a patient to have used navigation if they had at least one encounter between January 1st, 2007- December 31<sup>st</sup>, 2014. However, if the patient’s first date of CPN use was more than one year after diagnosis, or more than 3 months prior to diagnosis, we did not classify them as a “CPN

user” because use of CPN outside of this window may indicate an encounter related to a different cancer diagnosis or a data entry error.

#### 4.2.4 Independent Variables

The final list of included factors contained all of the factors that were identified in the literature search (Chapter 2.2) and/or interviews, confirmed by Delphi, and were available in the linked dataset. We defined each included variable as follows:

##### ***Sociodemographic variables:***

**Age at cancer diagnosis (Individual level).** Continuous and categorical (<50, 50-64 and  $\geq 65$  years old) measures of age were derived using date of diagnosis and birth date (month and year) from the NSCR.

**Geographic distance from health care services (Individual level).** Patient geography was operationalized as rural versus urban based on forward sortation area (FSA) of residence at diagnosis. Patients for whom the second character of their FSA was a ‘0’ were classified as rural (66). Any other digit in this position represents an urban location.

**Navigation jurisdiction (Individual level).** Patients were categorized into their corresponding navigation jurisdiction according to the current NSHA zone in which they resided at diagnosis. The CPN program was developed when NS operated with 9 regional DHAs. One navigation centre was implemented in each DHA (except for the CDHA, which contains Halifax). However, the organization of health authorities has since changed to a more centralized models and so we chose to analyze patients according to current NSHA organization (Table 1).

**Income level (Ecological).** Income level was operationalized as neighbourhood income quintile, determined by an individual’s residential postal code at diagnosis. This

data was derived using the PCCF+ (Postal Code Conversion File Plus) using data from Statistics Canada (2006 census). Quintiles were used to create three levels of neighbourhood income: quintiles 1 and 2 were classified as “low”, quintile 3 was classified as “middle”, and quintiles 4 and 5 were classified as “high”. We used neighbourhood-level as a proxy for individual-level data because individual-level was not available. The neighbourhood-level measure has been used in previous studies of cancer care in Nova Scotia to find trends in screening for cervical cancer among individuals living in areas of different income levels (67).

**Material deprivation (Ecological).** Material deprivation was operationalized as the neighbourhood-level Material Deprivation dimension of the Canadian Marginalization Index using data from the 2006 Canadian census (68). Patient assignment to neighbourhood was based on their residential postal code at diagnosis. The Material Deprivation dimension of the Canadian Marginalization Index is a composite of several indicators (Table 2) (68). Briefly, they are education level, single-parent family status, government transfer receipt, unemployment, low-income status and quality of housing. Quintiles of neighbourhood material deprivation were divided into three categories: quintiles 1 and 2 were classified as “least deprived”, quintile 3 was classified as “middle” and quintiles 4 and 5 were classified as “most deprived”. We used neighbourhood-level data as a proxy for individual-level data because individual-level was not available. Other Canadian studies have used this measure in the context of population health research (69), including in NS (70) to examine health inequalities among individuals living in areas of different deprivation levels.

Table 2. Variables used to calculate the Material Deprivation dimension of the Canadian Marginalization Index (68).

Indicators	Description
Education level	Proportion of the population aged 25+ without a high-school diploma
Single-parent families	Proportion of families who are lone parent families
Government transfer recipient	Proportion of the population receiving government transfer payments
Unemployment	Proportion of the population aged 15+ who are unemployed
Low-income	Proportion of the population considered low-income (according to Statistics Canada low income cutoff value)
Quality of housing	Proportion of households living in dwellings that are in need of major repair

***Clinical variables:***

**Cancer stage at diagnosis (Individual level).** Cancer stage was determined using the NSCR to assign the TNM 6<sup>th</sup> edition stage (I, II, III, or IV). Otherwise, stage was defined as “unknown” or “not applicable”.

**Comorbidity (Individual level).** Burden of comorbidity was quantified using the ACG Johns Hopkins system (59,71,72). This variable is reported as the number of ADGs to which an individual belongs, based on linked administrative data in window between 30 and 6 months prior to diagnosis. This window reflects a patient’s health status prior to their cancer diagnosis over two and a half years, capturing any changes to health status within the recent past. Patients were divided into categories based on the number of ADGs to which they belonged: 0-3, 4-6, 7-9 and 10+.

**Evidence of cancer recurrence (Individual level).** We defined cancer recurrence as local or regional cancer recurrence or distant metastasis as evidence by patterns of receipt of chemotherapy/radiation therapy or breast surgery within 27 months of initial cancer diagnosis. This algorithm was developed for a previous study of health care use among breast cancer patients in NS (59).

**Death within follow-up (Individual level).** Date of death was recorded if the patient died within the study period (January 1<sup>st</sup>, 2007 to December 31<sup>st</sup>, 2014).

**Receipt of chemotherapy (Individual level).** Patients were classified into binary groups based on whether or not there was evidence that they had received chemotherapy in the time period between 2 weeks pre-diagnosis and 9 months post-diagnosis. The algorithm to detect receipt of chemotherapy was developed for a previous study of health care use among breast cancer patients in NS (59).

**Receipt of radiotherapy (Individual level).** Patients were classified into binary groups based on whether or not they received radiotherapy within the 12 months after diagnosis date.

**Chemotherapy-related toxicity (Individual level).** Patients were flagged if they experienced at least one of the following: neutropenia, fever, infection, GI toxicity, or other systemic treatment-related issues in the 6 months following their chemotherapy start date.

***Health system variables:***

**Continuity of care with primary care physician (Individual level).** Continuity of care was calculated using the UPC (Usual Provider of Care) Index as follows, based on a previous study of cancer care in Canada (59):

$$\text{Continuity of Care} = \frac{\text{Number of visits to Usual Provider}}{\text{Total number of visits to any primary care physician}}$$

where “Usual Provider” is the most frequently used primary care physician (physician specialties General Practitioner [GP] and Community Medicine [COMD]) recorded in the

MSI Physician Billings database. This results in a value for continuity of care ranging between 0 (no continuity) and 1 (perfect continuity). Visits were counted in the window beginning 30 months prior to cancer diagnosis and ending 6 months prior to diagnosis to assess the relationship of the patient with their usual provider before the initiation of their cancer journey. As published previously (59), we considered any value for continuity of care less than or equal to 0.75 to indicate low continuity and above 0.75 to indicate high continuity of care.

**Diagnostic interval (Individual level).** The diagnostic interval was calculated as the number of days that elapsed between the date of the first breast cancer-related index contact (Appendix 5) and diagnosis date as captured by the NSCR. Based on the distribution of intervals in the cohort, we calculated the 25<sup>th</sup>, 50<sup>th</sup> and 75<sup>th</sup> percentiles and divided patients into four groups based on these cut-off values: 0-24<sup>th</sup> percentile (shortest waiting period), 25-49<sup>th</sup> percentile, 50-74<sup>th</sup> percentile, 75-100<sup>th</sup> percentile (longest waiting period).

**Treatment interval (Individual level).** The treatment interval was calculated as the number of days that elapsed between the diagnosis date (as captured by the NSCR) and the earliest date of: surgery date, chemotherapy start date, or radiotherapy start date. These were the only treatment modality data that were available in our dataset, and so the only modalities that could be incorporated into our definition of treatment interval. If at least one of these three treatment initiation dates occurred before the diagnosis date, the interval was left-censored at a value of '0'. For our purposes, this indicated that there would have been no waiting period between diagnosis date and treatment start date to cause anxiety or concern (thus no source of increased need for navigation). We repeated

the classification according to 25<sup>th</sup>, 50<sup>th</sup> and 75<sup>th</sup> percentiles as for the diagnostic interval variable (above). For most patients, this variable represents the time from diagnosis to surgery and for a minority, the time from diagnosis to initiation of neo-adjuvant chemotherapy. One population for which this variable may be difficult to interpret is metastatic patients, who may not initiate one of the three captured modalities (surgery, chemotherapy, or radiotherapy) until a year or more after diagnosis, and will use biological or hormone therapies (not captured in this variable) in the meantime.

#### 4.2.5 Statistical Analysis

We performed descriptive analysis of CPN user and non-user groups. For each variable, we tested differences in distributions of patients in each group using a  $\chi^2$  test. To model the associations between CPN use and each variable, we used logistic regression models with the outcome of interest coded as ever used CPN (“yes” or “no”). For categorical predictors, the referent group for each odds ratio (OR) calculation was the group with the lowest relative need for navigation (based on expectations established in the CPN interviews). Thus, an OR>1 indicated that higher need patients had higher odds of using navigation than lower need patients. An OR<1 indicated that higher need patients had lower odds of using navigation. Wald tests were used to test joint significance of indicator variables for categorical variables. In order to investigate regional variation (Objective 3), we stratified logistic regression models by regional NSHA zone.

Based on results from unadjusted associations between each need variable and CPN use, more in-depth models were used to further explore the association between SES (neighbourhood income and material deprivation variables), region and CPN use. We first estimated the association between each SES measure and CPN use, adjusted for

other need variables (age and clinical factors: tumour stage, chemotherapy use and radiotherapy use) and region. Then we estimated and tested for need-adjusted interactions between region and SES variables. Likelihood-ratio tests were used to decide which model best described need-adjusted variation in CPN use by SES and region. To help interpret model interaction terms, we calculated marginal predicted probabilities of CPN use, holding age and clinical factors at their mean values (73). All statistical analyses were conducted using Stata version 15.1 (StataCorp, College Station TX). An alpha level of 0.05 was used to assess statistical significance for all tests.

#### 4.3 Ethical Considerations

All study methods were approved by the NSHA Research Ethics Board (File No. 1023809 and 100303). For all components of the study, the most important consideration was for the privacy of participants. In the interviews and surveys, participants provided informed consent for audiotaping and verbatim quotes, but these files were kept confidential with secure storage and access. Further, when using verbatim quotes, CPNs were only identified with a random identifier (“CPN 3”) and any references to location-specific information was removed. In the statistical analysis component, patient privacy was maintained by censoring cell sizes smaller than 5.



## Chapter 5: Results

### 5.1 Interview & Delphi Survey Results

#### 5.1.1 Interviews

In total, 6 of 8 navigators in NS participated in the interviews and Delphi process (Figure 1). One CPN had been in their position for less than one year and thus was not considered to have enough experience to participate. One CPN declined to participate. The two CPNs were from different NSHA zones.

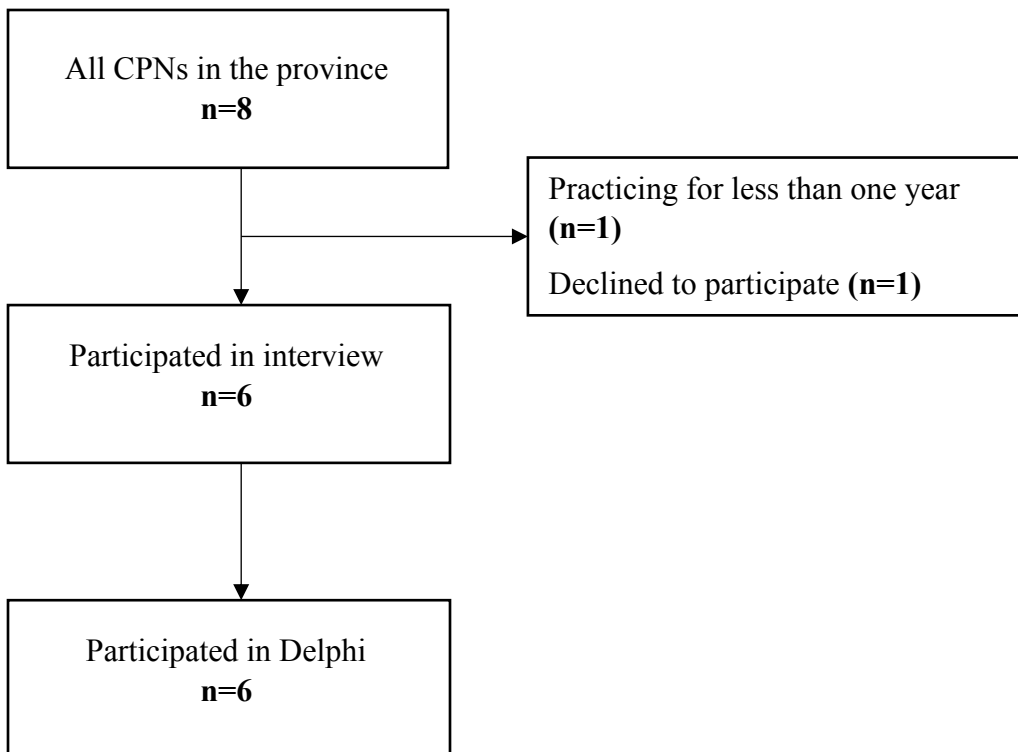


Figure 1. CPN participation in interviews and Delphi survey.

The interviews revealed several new factors and confirmed many hypothesized factors, as having an important impact on a patient's need for the CPN program (Table 3). Factors from the interviews clustered into four categories: sociodemographic, psychological, clinical (with sub-categories of diagnosis- and treatment-related) and health system.

The factors discussed most frequently across interviews were age, socioeconomic status and social support—in fact, these were discussed in every interview. Of the factors discussed by participants without prompting from the interviewer, the most commonly identified factor was low socioeconomic status/income (used interchangeably in the interviews and so considered one concept for the rest of the remainder of the document). In fact, all six interviewees identified this as a factor that would increase a patient’s need for navigation. Also commonly identified were low education level, low social support and high-risk diagnosis (particularly metastatic).

When participants discussed factors, they often described a patient profile that included multiple factors (e.g. young, employed, with child dependants and low income). It seemed uncommon in practice for any one of the factors discussed to occur in isolation. Several combinations were mentioned in particular (Table 3).

Table 3. All individual factors (and combinations thereof) identified through interviews as increasing patients’ need for navigation.

Factor Category	Factors
<b>Sociodemographic</b>	
	Age (younger and older groups)
	Low SES/income
	Low education level
	Currently employed
	Low social supports (family and friends)
	Having dependents (spouse, children, pets)
	Rural geography (longer distance from cancer center)
	Newly moved to their area of residence
	Non-English language spoken at home
<b>Psychological</b>	
	Having psychiatric comorbidity
	High patient anxiety/ subclinical psychological distress
<b>Clinical</b>	
	Having any comorbidity
	Genetic/family history of cancer
<b>Clinical - Diagnostic</b>	
	Higher stage/risk of mortality at diagnosis

	Metastatic at diagnosis
	Tumour detection method (screening vs symptom-led investigation)
<b>Clinical - Treatment</b>	
	Receiving chemotherapy
	Receiving radiation
	Experiencing chemotherapy-related toxicity
<b>Health System</b>	
	No PCP
	Longer diagnostic interval
	Longer treatment interval
<b>Combinations of factors</b>	
	Age*having comorbidities
	Having dependents*receiving chemotherapy/radiation
	Having dependents*low social support
	Receiving chemotherapy*low SES
	Receiving chemotherapy*rural geography
	No PCP*rural geography

Overall, the factors identified most frequently and with most conviction tended to be social factors related to a patient’s living situation. Low income, low social support, low education and longer distance from residence to treatment are prime examples of participants’ views on factors that increase need for navigation services (Table 4). Some of these factors were sometimes mention in combination with one another; that is, these factors often co-occurred within one patient’s situation and would amplify one another’s effects on the patient’s need for CPN services (Table 4).

Table 4. Supporting quotes for social factors identified in CPN interviews as increasing patients' need for CPN services.

Factor	Supporting Quote
Low SES/income	<p>“the stress for them [people of low SES] is, ‘Oh my gosh, I have to drive to Halifax?...’ .... or ‘Medication, is it going to be expensive? I don't have a plan.’” [CPN 6]</p> <p>“definitely the population that can't afford it, I do find they're reaching out a lot more” [CPN 5]</p>

Low social support	<p>“... they might not have very many... friends or family that are close by, so they need that person to connect with...” [CPN 2]</p> <p>“if you're a senior woman but you live alone... or... someone in their early thirties and you're alone, you don't have lots of friends, you family all lives out west... that certainly does make a huge difference as far as... they have no one to support them on that daily basis.” [CPN 5]</p>
Low education level	<p>“they often have a meeting with the physician or are told the cancer diagnosis, but have no idea what that means... So those patients I find, there's an extreme need to go over what those physicians said...” [CPN 5]</p> <p>“Those who are working in... complex jobs and... higher education level-- they understand better... and have more resources to find what they need for information” [CPN 6]</p>
Rural geography (longer distance from cancer center)	<p>“if there is extensive travel to get in to see a physician or specialist, they may opt not to have any investigations or treatment done” [CPN 5]</p>
Low SES/income*(in combination with)* Receiving chemotherapy	<p>“...so patients that are starting chemo, if they don't have prescription drug coverage then they may not have coverage for supportive medications... it pops up as a red flag for me...” [CPN 1]</p>

### 5.1.2 Delphi Survey

CPNs’ ratings of the importance of each of the identified factors are summarized in Table 5. No new factors were identified by CPNs at this stage as increasing need for navigation. Several combinations of previously identified factors were however highlighted as having important impacts on one another’s effect on need for navigation Table 5. Out of 27 items in the Delphi exercise, respondents agreed that 23 were important characteristics that increase a patient’s need for navigation. CPNs rated almost all of the presented factors as being important. The factors with the highest median ratings were those related to SES, social support, psychiatric comorbidity, tumour stage, treatment interval and not having a PCP.

Table 5. Results of Delphi survey establishing consensus among CPNs on the importance of individual factors to patients' need for navigation in both rounds (R1, R2) of the survey.

Factor	R1 Median	R1 Range	R2 Median	R2 Range	Importance
<i>Sociodemographic</i>					
Age	6	5-8	-	-	Uncertain
Low SES/income	7.5	5-9	-	-	Important
Low education level	8	8-9	-	-	Important
Factor	R1 Median	R1 Range	R2 Median	R2 Range	Importance
Being in the workforce	6.5	5-8	7	4-7	Important
Low social support	9	6-9	-	-	Important
Responsibility for dependents	8	7-9	-	-	Important
Living in a community without a community-based cancer clinic or cancer centre	8	1-9	-	-	Important
Greater distance patient lives from a town of significant size (~10,000 people)	7	4-9	-	-	Important
Greater distance patient lives from Halifax or Sydney	7	2-9	7	5-8	Important
Having recently moved to NS	8	5-9	-	-	Important
Immigrant status	6	5-9	7	5-8	Important
Not fluent in English language	-	-	6.5	5-9	Uncertain
<i>Psychological</i>					
Psychiatric comorbidity	8.5	6-9	-	-	Important
Sub-clinical but significant levels of anxiety or depression	8	6-9	-	-	Important
<i>Clinical</i>					
Any pre-existing non-cancer comorbidity	6	4-9	-	-	Uncertain
Multiple/chronic pre-existing comorbidity(ies)	7.5	4-9	-	-	Important
Family/genetic history of cancer	-	-	7.5	6-8	Important
Experiencing cancer recurrence	7	5-9	-	-	Important
Near end-of-life	7	4-8	-	-	Important
<i>Clinical - Diagnostic</i>					
Later tumour stage at diagnosis	8.5	4-9	-	-	Important
Tumour detection method (cancer investigations initiated by screening mammogram or symptoms)	5	3-7	-	-	Uncertain
<i>Clinical - Treatment</i>					
Receipt of chemotherapy	7	6-9	-	-	Important
Receipt of radiotherapy	6.5	6-9	7	6-8	Important

Experiencing treatment-related toxicity	8	7-9	-	-	Important
<i>Health System</i>					
Longer diagnostic interval	8	6-9	-	-	Important
Longer treatment interval	8.5	6-9	-	-	Important
No PCP	8.5	4-9	-	-	Important
<i>Combinations of factors</i>					
Low SES*low social support					
Age*responsible for dependents*low social support*Psychiatric comorbidity*Distance from cancer centre*Transportation					
Low SES*Low education level					
Low SES*higher depression/anxiety					
Low education level*low social support					
Low education level*higher depression/anxiety					
Low social support*higher depression/anxiety					
Greater distance from treatment*low SES					

Four of the items in the Delphi exercise had an “uncertain” rating (age, any comorbidity, speaking non-English language, method of tumour detection). Many of these can be explained by participant descriptions during the interviews. For age, participants expressed uncertainty as to whether different age groups truly had different levels of need for navigation. Different participants expressed that both younger and older age groups had particularly high levels of need for navigation (Table 6) and that the sources of need were different. Additionally, older or younger age tended to co-occur with other factors. For instance, older patients typically have more complicated comorbidity and oftentimes a lower education level. Younger patients, in contrast, tend to have more responsibility for young dependents and are more likely to be in the workforce and have their income jeopardized by their cancer diagnosis. Further, patients younger than 65 years old do not have provincial health insurance for prescription medications. Thus, participants described both of these age profiles as tending to have different types of need, which were not directly a result of their age but rather due to the association of age with several other factors.

Table 6. Supporting quotes for factors that were rated "uncertain" in their importance to increasing need for navigation services.

Factor	Supporting quotes
Age	<p>“...older patients have... more informational and support needs... Younger women that are still in the workforce have a lot of practical needs.” [CPN 1]</p> <p>“women, say, sixty-five, seventy and over... they cope quite well with their disease.” [CPN 6]</p> <p>“that older population, because they've... lived. You know, they've had such a good life that they tolerate things better and are used to coping skills that they've, you know, used throughout their lifetime.” [CPN 6]</p> <p>“... younger patients... have their families to think about...” [CPN 2]</p> <p>“... older patients are more isolated than their younger peers.” [CPN 2]</p>
Comorbidity	<p>“But I don't really feel like it [comorbidity] increases their need for a navigator.” [CPN 1]</p> <p><sup>2</sup> “people with other... chronic illness... they have a few more things that [CPN] can help with” [CPN 6]</p>
Method of tumour detection	<p>“they both have needs, they just have different needs” [CPN 2]</p> <p>“No... but yes, just a tiny bit...[if] they actually found a lump themselves... Their brain has already started thinking ‘well it could be cancer’” [CPN 6]</p> <p>“I almost think those people who find it themselves have at least that little bit of awareness” [CPN 6]</p>
Not fluent in English language	<p>“patients who... only speak one language, ... they're looking for translation or supports to help with... how do they express that in their own language...” [CPN 5]</p>

Non-psychiatric comorbidity was examined through two questions in the Delphi survey. First, we asked whether the presence of any non-psychiatric comorbidity would increase a breast cancer patient’s need for navigation. Secondly, we asked whether the presence of multiple or chronic morbidity/ies would increase a breast cancer patient’s need for navigation. With respect to the first comorbidity item, there was uncertainty towards its importance. Interview discussions on this topic described the management of comorbidities prior to cancer diagnosis as being a better indication of a patient’s need for navigation (Table 6). Further, there was greater certainty that having multiple comorbidities that were not well-managed or were difficult to manage would increase a patient’s need for navigation.

Discussions around tumor detection method were similarly nuanced. Some navigators felt its impact was marginal. One navigator expressed that diagnostic investigations initiated through a screening mammogram (versus symptom-led investigations) could be associated with less need for navigation if a patient had been receiving regular screening mammograms. Regular screening mammograms have a higher likelihood of diagnosing the tumour at an earlier, more treatable stage. However, some CPNs countered that patients whose diagnostic investigations are symptom-led may be less surprised by the diagnostic confirmation and thus more mentally prepared requiring less psychosocial support from navigation (Table 6).

The final factor rated as having an uncertain degree of impact on need for navigation was non-fluence in the English language. In the interviews, one CPN discussed the difficulty that patients who are not fluent in English have in understanding information and communicating their thoughts to health care providers (Table 6). However, this factor was only brought up in a single interview, indicating that this may not be a common patient characteristic for other CPNs.

However, the point was raised that despite the generalized relationships between the factors identified above and need for navigation, a patient's personality was a vital modifier that would change how these factors affect their need for navigation on an individual level. This is demonstrated in the following quote: "It is partly personality, partly learning style... but I'd have to say I can think of a couple patients who have very difficult disease, but they're content, you know? ... Expressing that they know the things they need to know, and then they're not fretting because they don't maybe have that desire to go looking for what else to worry about" (CPN 3).



Overall, CPNs expressed that sociodemographic factors, particularly low income, low social support, low education level, having responsibility for dependents and living far from health care services, were some of the most important factors associated with need for CPN services. Thus, in the statistical analysis we expected to see higher use of CPN among these populations (low SES/low income, etc.) compared to their lower need counterparts (high SES/high income, etc.). Clinical factors such as diagnosis at a later cancer stage (particularly metastatic), receiving chemotherapy and receiving radiotherapy were also identified as having important associations with need for navigation. Thus, we expected that analysis of a cancer patient cohort would show higher CPN use among patients who are diagnosed at later stage, or who receive chemotherapy and/or radiotherapy, compared to patients diagnosed at an earlier stage and/or do not receive chemotherapy or radiotherapy. CPNs also described the overlap between these two categories as amplifying need for navigation—patients who are both low SES and receive chemotherapy will have particularly great need for navigation.

## 5.2 Statistical Analysis Results

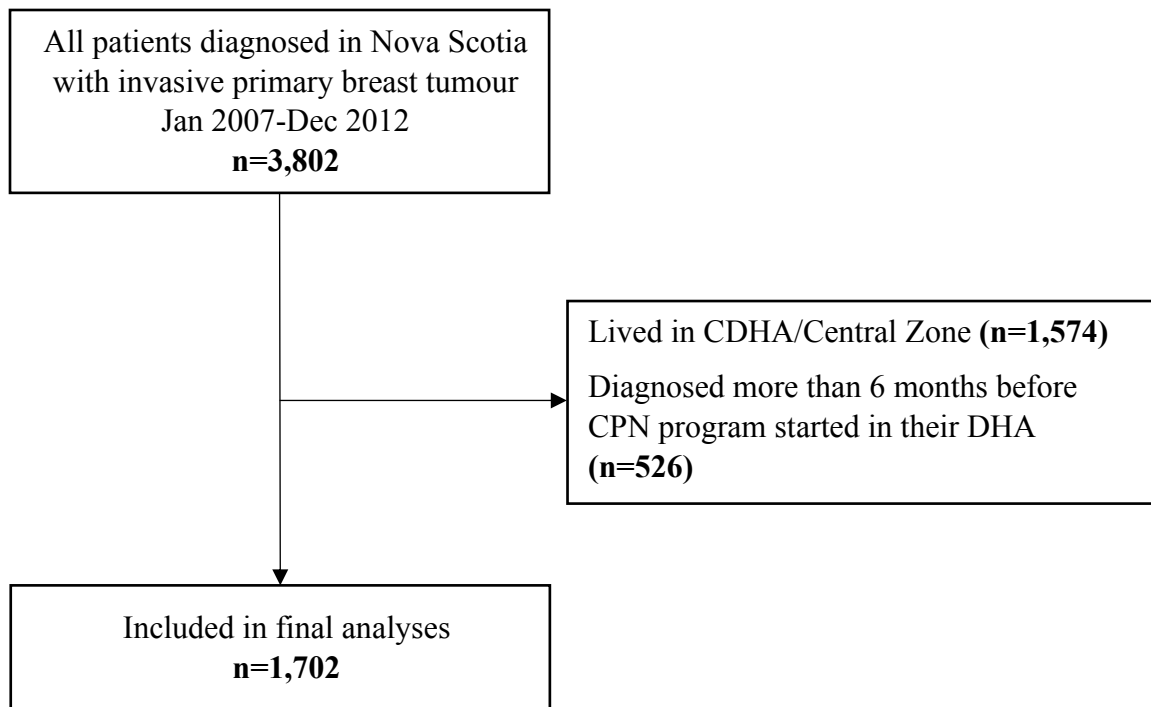


Figure 2. Flow diagram of breast cancer patient cohort used for quantitative analysis.

Overall, 3,802 patients were diagnosed with invasive primary breast tumours between January 1<sup>st</sup>, 2007 and December 31<sup>st</sup>, 2012 in the entire province and met our inclusion criteria. Of these, 41% (n=1,574) lived in the Central Zone of NSHA and 14% (n=526) were diagnosed before a local CPN program had been established in their region, and thus had no opportunity to use CPN during their cancer journey (Figure 2). This resulted in a final study population of 1,702 patients.

CPN interviews established the expectation that patients with certain clinical factors (later tumour stage, receipt of chemotherapy, and receipt of radiotherapy) should have higher CPN use than patients diagnosed at earlier stage and who do not receive chemotherapy or radiotherapy. There was strong evidence that this is the case for receipt of chemotherapy and radiotherapy, with significantly higher proportions of CPN users having used either modality (Table 7). In fact, there were 2.8 times (for chemotherapy

receipt) and 1.8 times (for radiotherapy receipt) greater odds of CPN use (Table 8). These associations were consistent across regional zones (Table 9). The relationship between tumour stage and CPN use was more nuanced. For patients with stages I-III at diagnosis, there was a trend toward increasing CPN use with increased stage, which aligns with our expectations based on CPN interviews (Table 7 and Table 8). However, patients who were metastatic (stage IV) at diagnosis had the opposite of the expected association, with statistically significantly lower odds of CPN use compared to stage I patients (Table 8). Patients with unknown (or otherwise unclassified) tumour stage had an even stronger pattern of low CPN use (Table 7 and Table 8). Each regional zone replicated these patterns (Table 9).

Based on the results of the qualitative component of the study, we expected that patients of low SES/low income would have higher CPN use than patients of higher SES/higher income. However, we did not see any statistically significant association between neighbourhood income and CPN use or material deprivation and CPN use, as seen in the descriptive table (Table 7) and the unadjusted logistic regressions (Table 8). There was a trend for patients of greater neighbourhood material deprivation to have higher CPN use, but the difference was not statistically significant ( $p=0.221$ ). Similarly, there was no significant association between neighborhood income and CPN use ( $p=0.415$ ). However, the trend in ORs for neighbourhood income level was opposite that of material deprivation.

Stratified by zone, we found a lack of evidence for higher CPN use for patients in lower income neighbourhoods. In Zone 2, the lowest income level had significantly lower odds of CPN use than the highest income level (OR=0.65 [0.42, 0.99]), however given

that the Wald test for the overall effect of neighbourhood income was not significant in this zone ( $p=0.134$ ), this must be interpreted with caution. Across all zones, the middle level was not clinically or statistically significantly different from the highest income level, though odds of CPN use trended toward being lower for lower income in two out of the three zones (Table 9).

Interestingly, regionally stratified analyses did reveal some associations between neighbourhood material deprivation and CPN use (Table 9). In Zone 1, material deprivation had a statistically significant association with CPN use ( $p=0.006$ ), and in Zone 3 the association was close to significant ( $p=0.080$ ). In Zone 1, the most deprived level had significantly higher odds of CPN use compared to the middle level ( $p=0.002$ , data not shown), but neither the middle or most deprived levels were significantly different than the least deprived. The same pattern was observed in Zone 3. The most deprived level had significantly lower odds of CPN use compared to the middle level ( $p=0.025$ , data not shown).

Given these results, associations between material deprivation, region and CPN use were examined, adjusting for age and clinical factors (tumour stage, use of chemotherapy and use of radiotherapy). This standardized material deprivation and regional comparisons for compositional differences in age and clinical factors. The association between material deprivation and CPN use remained statistically non-significant after adjusting for age and clinical variables (Model 1, Table 10). After further adjustment for regional zone, the association between neighbourhood material deprivation and CPN use (Model 3) changed, indicating that material deprivation and regional were

associated, and possibly interacted. Indeed, Model 4 demonstrated a statistically significant interaction between regional zone and neighbourhood material deprivation.

To facilitate interpretation of the material deprivation by regional zone interaction model (Model 4, Table 10), we estimated and graphed the marginal predicted probabilities for material deprivation and zone (Figure 3). There was no clear or consistent relationship across zones between material deprivation level and probability of CPN use. However, the overall mean relationship did suggest a slight trend toward higher probability of CPN use among patients with greater material deprivation.

Other variables that had quantitative evidence of CPN use patterns in line with CPN perspectives were having a cancer recurrence and experiencing chemotherapy-related toxicity (Table 7 and Table 8). Both groups had significantly higher odds of CPN use compared to patients who did not have a cancer recurrence or experience toxicity, respectively. Another variable that had quantitative evidence in line with expectations from our qualitative work was rural residence. Based on CPN interviews, we expected patients living in rural areas would have greater need for navigation. While overall there was no statistically significant trend (Table 8), in Zone 3 patients living in a rural area had 2.44 times greater odds of CPN use than patients living in urban areas ( $p < 0.001$ , Table 9).

There were two other factors that had the opposite of the expected association with CPN use based on CPN interviews: older age at diagnosis and death. Older patients had significantly lower odds of CPN use compared to middle-aged patients, despite CPNs' perspectives that older patients have higher need for navigation (Table 8). Also,

patients who died had 0.46 times lower odds of CPN use compared to those who did not die (Table 9).

Table 7. Frequency of study cohort characteristics compared between patients who used navigation and those who did not use navigation in the entire province of NS.

	Non-users n (%)	CPN users n (%)	p-value <sup>1</sup>
Number of patients (total n=1,702)	551 (32.4%)	1,151 (67.6%)	
<i>Sociodemographic</i>			
Age category			p<0.001
<50 years old	64 (11.6%)	218 (18.9%)	
50-64 years old	150 (27.2%)	457 (39.7%)	
≥65 years old	337 (61.2%)	476 (41.4%)	
Rural residence			p=0.133
Non-rural	249 (45.2%)	477 (41.4%)	
Rural	302 (54.8%)	674 (58.6%)	
Regional NSHA Zone			p=0.420
Zone 1	271 (32.4%)	565 (67.6%)	
Zone 2	155 (30.6%)	352 (69.4%)	
Zone 3	125 (34.8%)	234 (65.2%)	
Neighbourhood income level			p=0.414
Low	234 (42.5%)	458 (39.8%)	
Middle	120 (21.8%)	241 (20.9%)	
High	197 (35.8%)	448 (38.9%)	
Missing <sup>2</sup>	0	4 (0.4%)	
Neighbourhood material deprivation level			p=0.220
Least deprived	57 (10.3%)	96 (8.3%)	
Middle	86 (15.6%)	162 (14.1%)	
Most deprived	402 (73.0%)	885 (76.9%)	
Missing <sup>2</sup>	6 (1.1%)	8 (0.7%)	
Neighbourhood immigration status tercile			p=0.113
Lowest immigration tercile	539 (97.8%)	1,138 (98.9%)	
Middle tercile	6 (1.1%)	5 (0.4%)	
Missing <sup>2</sup>	6 (1.1%)	8 (0.7%)	
<i>Clinical</i>			
No. of comorbid ADGs			p=0.307
0-3	124 (23.2%)	271 (23.2%)	
4-6	156 (29.2%)	386 (33.1%)	
7-9	145 (27.2%)	308 (26.4%)	
10+	109 (20.4%)	203 (17.4%)	
Evidence of cancer recurrence			p<0.001
No	303 (55.0%)	556 (48.3%)	
Yes	145 (26.3%)	504 (43.8%)	
Missing <sup>2</sup>	103 (18.7%)	91 (7.9%)	
Death within follow-up period			p<0.001
No	423 (76.8%)	1,011 (87.8%)	
Yes	128 (23.2%)	140 (12.2%)	

	Non-users n (%)	CPN users n (%)	p-value <sup>1</sup>
<i>Clinical - Diagnostic</i>			
Tumour stage			p<0.001
<i>Stage I</i>	263 (47.7%)	517 (44.9%)	
<i>Stage II</i>	154 (28.0%)	397 (34.5%)	
<i>Stage III</i>	41 (7.4%)	165 (14.3%)	
<i>Stage IV</i>	44 (8.0%)	51 (4.4%)	
<i>Unknown or N/A</i>	49 (8.9%)	21 (1.8%)	
Detection method			p=0.320
<i>Screening</i>	209 (37.9%)	458 (39.8%)	
<i>Symptom-led</i>	277 (50.3%)	677 (58.8%)	
Missing <sup>2</sup>	65 (11.8%)	16 (1.4%)	
<i>Clinical - Treatment</i>			
Received chemotherapy			p<0.001
<i>No</i>	442 (80.2%)	684 (59.4%)	
<i>Yes</i>	109 (19.8%)	467 (40.6%)	
Received radiotherapy			p<0.001
<i>No</i>	368 (66.8%)	615 (53.4%)	
<i>Yes</i>	183 (33.2%)	536 (46.6%)	
Experienced chemotherapy-related toxicity			p<0.001
<i>No</i>	533 (96.7%)	1,063 (92.4%)	
<i>Yes</i>	18 (3.3%)	88 (7.7%)	
<i>Health System</i>			
Continuity of care with usual provider			p=0.840
<i>Low</i>	125 (22.7%)	274 (23.8%)	
<i>High</i>	385 (69.9%)	823 (71.5%)	
Missing <sup>2</sup>	41 (7.4%)	54 (4.7%)	
Length of diagnostic interval			p=0.441
<i>(Shortest) 0-24<sup>th</sup> %ile</i>	108 (19.6%)	204 (17.7%)	
<i>25-49<sup>th</sup> %ile</i>	105 (19.1%)	244 (21.2%)	
<i>50-74<sup>th</sup> %ile</i>	137 (24.9%)	326 (28.3%)	
<i>(Longest) 75-100<sup>th</sup> %ile</i>	145 (26.3%)	339 (29.5%)	
Missing <sup>2</sup>	56 (10.2%)	38 (3.3%)	
Length of treatment interval			p=0.879
<i>(Shortest) 0-24<sup>th</sup> %ile</i>	120 (21.8%)	300 (26.1%)	
<i>25-49<sup>th</sup> %ile</i>	116 (21.1%)	310 (26.9%)	
<i>50-74<sup>th</sup> %ile</i>	100 (18.2%)	240 (20.9%)	
<i>(Longest) 75-100<sup>th</sup> %ile</i>	117 (21.2%)	279 (24.2%)	
Missing <sup>2</sup>	98 (17.8%)	22 (1.9%)	

<sup>1</sup>  $\chi^2$  test for independence

<sup>2</sup> Missing values not included in  $\chi^2$  test

Table 8. Unadjusted estimates of the associations between each patient factor and use of CPN using logistic regression for the entire province of NS.

	OR (95% CI)
<i>Sociodemographic</i>	
Age (ref. 50-64 years)	<sup>a</sup> p<0.001
<i>&lt;50 years</i>	1.12 (0.80, 1.56)
<i>≥65 years</i>	0.46*** (0.37, 0.58)
Rural residence (ref. non-rural)	<sup>a</sup> p=0.144
<i>Rural</i>	1.17 (0.95, 1.43)
Regional NSHA Zone (ref. Zone 1)	<sup>a</sup> p=0.421
<i>Zone 2</i>	1.09 (0.86, 1.38)
<i>Zone 3</i>	0.90 (0.69, 1.17)
Neighbourhood income level (ref. high)	<sup>a</sup> p=0.415
<i>Middle</i>	0.88 (0.67, 1.16)
<i>Low</i>	0.86 (0.68, 1.08)
Neighbourhood material deprivation level (ref. least deprived)	<sup>a</sup> p=0.221
<i>Middle</i>	1.12 (0.74, 1.70)
<i>Most deprived</i>	1.31 (0.92, 1.85)
Neighbourhood immigration status tercile (ref. lowest tercile)	<sup>a</sup> p=0.126
<i>Middle tercile</i>	0.39 (0.12, 1.30)
<i>Clinical</i>	
No. of comorbid ADGs (ref. 0-3 ADGs)	<sup>a</sup> p=0.308
<i>4-6 ADGs</i>	1.14 (0.86, 1.51)
<i>7-9 ADGs</i>	0.94 (0.71, 1.25)
<i>10+ ADGs</i>	0.88 (0.64, 1.20)
Evidence of cancer recurrence (ref. no)	<sup>a</sup> p<0.001
	1.89*** (1.50, 2.39)
Died within follow-up period (ref. no)	<sup>a</sup> p<0.001
	0.46*** (0.35, 0.60)
<i>Clinical - Diagnostic</i>	
Tumour stage (ref. Stage I)	<sup>a</sup> p<0.001
<i>Stage II</i>	1.31* (1.03, 1.66)
<i>Stage III</i>	2.05*** (1.41, 2.97)
<i>Stage IV</i>	0.59* (0.38, 0.91)
<i>Unknown or N/A</i>	0.22*** (0.13, 0.37)
Detection method (ref. screening)	<sup>a</sup> p=0.320
<i>Symptom-led</i>	1.12 (0.90, 1.38)
<i>Clinical - Treatment</i>	
Received chemotherapy (ref. no)	<sup>a</sup> p<0.001
	2.77*** (2.18, 3.52)
Received radiotherapy (ref. no)	<sup>a</sup> p<0.001
	1.75*** (1.42, 2.17)
Experienced chemotherapy-related toxicity (ref. no)	<sup>a</sup> p<0.001
	2.45** (1.46, 4.11)
<i>Health System</i>	
Continuity of care with usual provider (ref. high)	<sup>a</sup> p=0.840
<i>Low</i>	1.03 (0.80, 1.31)



	OR (95% CI)
Length of diagnostic interval (ref. 0-24 <sup>th</sup> percentile)	<sup>a</sup> p=0.442
25-49 <sup>th</sup> percentile	1.23 (0.89, 1.71)
50-74 <sup>th</sup> percentile	1.26 (0.93, 1.71)
75-100 <sup>th</sup> percentile	1.24 (0.91, 1.68)
Length of treatment interval (ref. 0-24 <sup>th</sup> percentile)	<sup>a</sup> p=0.880
25-49 <sup>th</sup> percentile	1.07 (0.79, 1.44)
50-74 <sup>th</sup> percentile	0.96 (0.70, 1.32)
75-100 <sup>th</sup> percentile	0.95 (0.70, 1.29)

<sup>a</sup> Wald test p-value

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

Table 9. Unadjusted estimates of the associations between each patient factor and use of CPN using logistic regression, by NSHA zones.

	Zone 1	Zone 2	Zone 3
	OR (95% CI)	OR (95% CI)	OR (95% CI)
<i>Sociodemographic</i>			
Age (ref. 50-64 years)	<sup>a</sup> p<0.001	<sup>a</sup> p=0.046	<sup>a</sup> p<0.001
<50 years	1.14 (0.69, 1.86)	0.96 (0.55, 1.68)	1.48 (0.65, 3.35)
≥65 years	0.42*** (0.30, 0.59)	0.61* (0.40, 0.93)	0.41*** (0.25, 0.67)
Rural residence (ref. non-rural)	<sup>a</sup> p=0.452	<sup>a</sup> p=0.857	<sup>a</sup> p<0.001
Rural	0.89 (0.65, 1.21)	1.04 (0.71, 1.51)	2.44*** (1.53, 3.90)
Neighbourhood income level (ref. high)	<sup>a</sup> p=0.381	<sup>a</sup> p=0.134	<sup>a</sup> p=0.182
Middle	0.84 (0.57, 1.24)	0.81 (0.48, 1.37)	1.19 (0.65, 2.18)
Low	1.09 (0.78, 1.52)	0.65* (0.42, 0.99)	0.70 (0.43, 1.14)
Neighbourhood material deprivation level (ref. least deprived)	<sup>a</sup> p=0.006	<sup>a</sup> p=0.231	<sup>a</sup> p=0.080
Middle	0.70 (0.40, 1.24)	1.75 (0.83, 3.69)	2.06 (0.56, 7.52)
Most deprived	1.32 (0.82, 2.12)	1.66 (0.91, 3.02)	0.86 (0.28, 2.57)
Neighbourhood Immigration status tercile (ref. lowest tercile)	<sup>a</sup> p=0.126	no data	no data
Middle tercile	0.39 (0.12, 1.30)		

	Zone 1	Zone 2	Zone 3
	OR (95% CI)	OR (95% CI)	OR (95% CI)
<i>Clinical</i>			
No. of comorbid ADGs (ref. 0-3 ADGs)	<sup>a</sup> p=0.146	<sup>a</sup> p=0.975	<sup>a</sup> p=0.396
4-6 ADGs	1.27 (0.85, 1.91)	0.98 (0.59, 1.63)	1.11 (0.61, 2.02)
7-9 ADGs	0.83 (0.55, 1.25)	1.04 (0.61, 1.77)	1.05 (0.57, 1.92)
10+ ADGs	0.89 (0.57, 1.38)	1.12 (0.60, 2.08)	0.65 (0.33, 1.27)
Evidence of cancer recurrence (ref. no)	<sup>a</sup> p<0.001 1.80** (1.27, 2.54)	<sup>a</sup> p<0.001 2.37** (1.45, 3.86)	<sup>a</sup> p<0.001 2.77*** (1.67, 4.61)
Died within follow-up period (ref. no)	<sup>a</sup> p<0.001 0.38*** (0.26, 0.54)	<sup>a</sup> p=0.082 0.63 (0.38, 1.06)	<sup>a</sup> p=0.026 0.49* (0.26, 0.92)
<i>Clinical- Diagnostic</i>			
Tumour stage (ref. Stage I)	<sup>a</sup> p<0.001	<sup>a</sup> p=0.001	<sup>a</sup> p<0.001
Stage II	1.31 (0.93, 1.85)	1.03 (0.67, 1.59)	1.80* (1.07, 3.02)
Stage III	2.30** (1.34, 3.95)	1.69 (0.86, 3.30)	2.00 (0.89, 4.50)
Stage IV	0.73 (0.41, 1.30)	0.60 (0.22, 1.65)	0.39* (0.16, 0.95)
Unknown or N/A	0.26** (0.12, 0.58)	0.21*** (0.09, 0.49)	0.11** (0.02, 0.51)
Detection method (ref. screening)	<sup>a</sup> p=0.515	<sup>a</sup> p=0.141	<sup>a</sup> p=0.626
Symptom-led	1.10 (0.81, 1.51)	1.35 (0.91, 2.00)	0.89 (0.56, 1.42)
<i>Clinical- Treatment</i>			
Received chemotherapy (ref. no)	<sup>a</sup> p<0.001 4.42*** (3.05, 6.41)	<sup>a</sup> p=0.002 2.11** (1.33, 3.34)	<sup>a</sup> p=0.019 1.73* (1.10, 2.74)
Received radiotherapy (ref. no)	<sup>a</sup> p=0.002 1.61** (1.20, 2.16)	<sup>a</sup> p<0.001 2.31*** (1.52, 3.53)	<sup>a</sup> p=0.038 1.61* (1.03, 2.51)
Experienced chemotherapy-related toxicity (ref. no)	p<0.001 6.62*** (2.37, 18.5)	p=0.592 1.24 (0.56, 2.72)	p=0.633 1.30 (0.45, 3.77)
<i>Health System</i>			
Continuity of care with usual provider (ref. High)	<sup>a</sup> p=0.317 1.19 (0.84, 1.68)	<sup>a</sup> p=0.617 0.89 (0.55, 1.42)	<sup>a</sup> p=0.633 0.89 (0.54, 1.48)
Low			

	Zone 1	Zone 2	Zone 3
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Length of diagnostic interval (ref. 0-24 <sup>th</sup> %ile)	<sup>a</sup> p=0.003	<sup>a</sup> p=0.406	<sup>a</sup> p=0.555
25-49 <sup>th</sup> %ile	1.84* (1.15, 2.95)	0.91 (0.46, 1.79)	0.68 (0.35, 1.31)
50-74 <sup>th</sup> %ile	1.69* (1.11, 2.58)	0.97 (0.52, 1.83)	0.72 (0.36, 1.44)
75-100 <sup>th</sup> %ile	2.17*** (1.43, 3.31)	0.67 (0.36, 1.25)	0.62 (0.32, 1.23)
Length of treatment interval (ref. 0-24 <sup>th</sup> %ile)	<sup>a</sup> p=0.624	<sup>a</sup> p=0.496	<sup>a</sup> p=0.011
25-49 <sup>th</sup> %ile	0.94 (0.61, 1.46)	1.36 (0.77, 2.40)	1.08 (0.58, 2.02)
50-74 <sup>th</sup> %ile	0.84 (0.54, 1.31)	1.56 (0.83, 2.92)	0.74 (0.38, 1.45)
75-100 <sup>th</sup> %ile	1.13 (0.72, 1.77)	1.41 (0.79, 2.53)	0.41** (0.23, 0.75)

<sup>a</sup> Wald test p-value

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

Table 10. Adjusted<sup>1</sup> logistic regression models of material deprivation and regional zone on CPN use.

	Model 1 <sup>a</sup> OR (95%CI)	Model 2 <sup>b</sup> OR (95%CI)	Model 3 <sup>c</sup> OR (95%CI)	Model 4 <sup>d</sup> OR (95%CI)
Neighbourhood material deprivation level (ref. least deprived)				
Wald test p-value	0.043*	-	0.030*	0.001**
<i>Middle</i>	1.06 (0.68, 1.64)	-	1.08 (0.69, 1.68)	0.65 (0.36, 1.18)
<i>Most deprived</i>	1.42 (0.98, 2.06)	-	1.46* (1.01, 2.12)	1.39 (0.84, 2.28)
Zone (ref. Zone 1)				
Wald test p-value	-	0.140	0.121	0.751
<i>Zone 2</i>	-	1.14 (0.88, 1.46)	1.13 (0.88, 1.45)	0.75 (0.35, 1.59)
<i>Zone 3</i>	-	0.84 (0.64, 1.10)	0.82 (0.62, 1.08)	0.93 (0.28, 3.15)
Neighbourhood material deprivation*Zone (ref. least deprived*Zone 1)				
Wald test p-value	-	-	-	0.008**
<i>Most deprived*Zone 2</i>	-	-	-	1.42 (0.63, 3.20)
<i>Most deprived*Zone 3</i>	-	-	-	0.70 (0.20, 2.48)
<i>Middle*Zone 2</i>	-	-	-	2.53 (0.94, 6.80)
<i>Middle*Zone 3</i>	-	-	-	3.39 (0.77, 14.9)

<sup>1</sup>Adjusted for age, tumour stage, use of chemotherapy and use of radiotherapy

<sup>a</sup> Material deprivation on CPN use<sup>1</sup>; <sup>b</sup> Zone on CPN use<sup>1</sup>; <sup>c</sup> Material deprivation and Zone on CPN use (no interaction)<sup>1</sup>; <sup>d</sup> Material deprivation and Zone on CPN use (with interaction)<sup>1</sup>

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

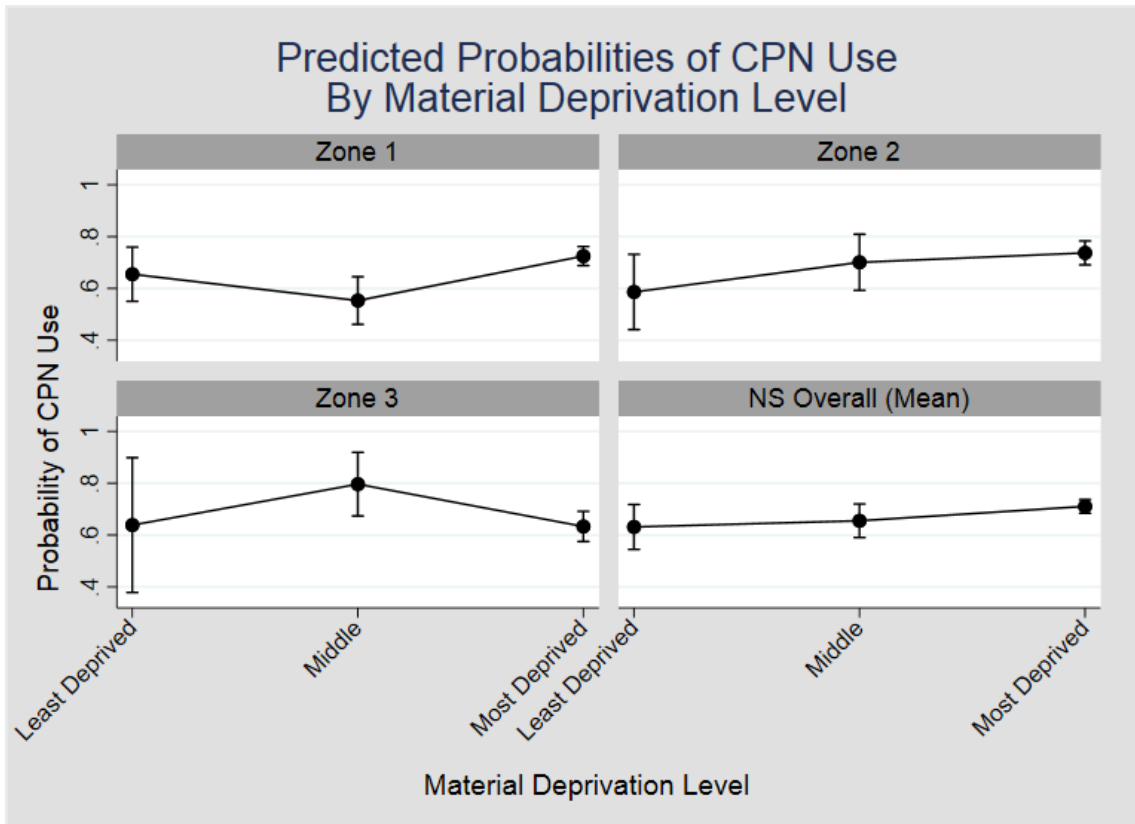


Figure 3. Adjusted marginal predicted probabilities of CPN use by material deprivation level and zone.

## **Chapter 6: Discussion**

This study sought to identify factors associated with greater need for navigation services (from the perspective of CPNs) and to observe whether these associations existed in a population-based cohort of breast cancer patients. The major finding was that despite the CPN-established expectation that sociodemographic factors (particularly low SES) would be strongly associated with need for navigation, we observed little statistical evidence of their association with use of CPN in our breast cancer patient cohort. Another major finding was that clinical factors (i.e. higher tumour stage at diagnosis [except metastatic], use of chemotherapy, use of radiotherapy and chemotherapy-related toxicity) were associated in the statistical analysis with greater odds of CPN use. This was in agreement with the expectations set in the CPN interviews. Interestingly, all four of these factors are related to the treatment phase of cancer, and specifically, the probability of seeking cancer treatment and/or the intensity of treatment. To our knowledge, there have not been any previous observational studies that examined how these factors associated with use of navigation. Overall, these findings highlight patient populations who likely have great need for navigation services but may not be using CPN. From a health system planning perspective, this could help increase awareness of the types of patients who most benefit from referral to CPN and to improve referrals for these patients.

### **6.1 Comparing Findings to Literature**

Sociodemographic factors have been identified as important in the patient navigation context (74) and are associated with particularly great need for referral to navigation (20). Given the evidence that patients of low SES generally have less access to cancer care services (30,47), we suspect that this result is similar in other jurisdictions. Oddly, the two SES measures in this study (neighbourhood income level and

neighbourhood material deprivation level) trended in opposite directions, with low income patients tending to have lower odds of CPN use and low material deprivation patients tending to have higher odds of CPN use. While puzzling, there are at least two possible explanations for the discrepancy. First, since both measures were ecological, and used as proxies for individual measures, it is possible that measurement error led to this discrepant finding. Overall, there were few significant associations, and so the difference in trends may simply be due to chance. The second explanation is due to the fact that income level and material deprivation measure different aspects of a patient's life. Although material deprivation includes income level, it also includes measures of education level, quality of housing, social support (in terms of single-parent families), and other important factors. These additional components, particularly education level (especially in terms of health literacy) and social support are extremely important to consider when estimating an individual's need for navigation services. This more complex approach may be a better representation of SES as a concept, rather than simply income level (75).

Most clinical factors expected by CPNs to increase need for navigation were associated with greater odds of CPN use. This seems to confirm that patients with higher clinical-associated needs are accessing CPN appropriately. An exception to the positive association between greater expected need and greater use was for metastatic patients. The CPN interviews indicated that metastatic patients would have greater need for navigation, and yet the quantitative showed that patients diagnosed with metastatic (stage IV) disease had much lower odds of CPN use than stage I patients. Similarly, older (over 65 years old) patients and patients who died within the follow-up period had lower odds

of CPN use in the provincial population. This trend (lower CPN use by older patients) has also been found specifically among patients who died following a cancer diagnosis (76). These patterns may occur because these patients are less likely to pursue intensive treatment as seen in a study of lung cancer patients (77), reducing their opportunity to be referred to CPN. The trend for lower odds of CPN use among older patients may also be related to economic or practical issues that are less prevalent in this population. For example, older patients receive coverage from the NS Seniors' Pharmacare Program, which provides financial assistance for medications, such as oral chemotherapy, that are not administered in hospital and therefore not covered by provincial health insurance. Moreover, older patients are less likely to be dealing with challenges related to leaving paid employment upon diagnosis or treatment, or returning to employment after treatment. CPNs also described somewhat less emotional stress and greater resilience among older patients, a trend that has been reported before among cancer patients (78). However, there are other aspects of older age discussed in the interviews that could contribute to greater need for navigation, such as reduced mobility, difficulty understanding information, and social isolation. Further, both older patients and patients diagnosed with metastatic cancer have high risk of mortality (79). Though a large role of CPNs surrounds treatment coordination, there could be other roles for CPNs in the end stages of cancer journey, such as referring patients to and helping to coordinate palliative care (80). Navigation can help palliative care services guide patients and their families through the practical and emotional challenges associated with this phase of the cancer journey (80). Navigation may not be necessary in all of these cases and referring patients directly to palliative services may satisfy their needs. However, since there is no



benchmark proportion of patients that should be using navigation for palliative care, it is unclear whether the results of our study indicate an under-use of CPN.

Another interesting result related to accessing cancer treatment is rural residence. Based on interviews, we expected that patients who live in rural areas would have greater need for navigation as there is more travel involved in receiving all types of health care and community services. However, there was no difference in use between urban and rural residence in two of the three zones. An important explanation here may be that Zone 3, where rural use of CPN was higher, is that the zone lies largely in Cape Breton Island, where there is a cancer treatment centre (in Sydney). Sydney residents could have particularly low need for navigation because their cancer treatments are in their hometown, whereas in other zones, both urban and rural residents alike will have to travel extensively to reach the nearest cancer treatment centre.

Only one other study has reported similar work to the qualitative component of this thesis, comprehensively investigating patient factors associated with greater need for navigation services (20). This study, by Krok-Schoen et al, found several demographic and psychosocial factors were associated with experiencing more barriers to care (20). Examples included non-white race, unemployed/retired, lower education level, lower income, psychological functioning (higher anxiety/depression levels, etc), low social support (from friends and family, etc) and comorbidities (20). Several of these factors overlap with our study's results, notably lower education level, lower income, psychological functioning and low social support. However, the Krok-Schoen study's list of potentially important factors were pre-determined by the study authors, with no factors added based on the participants' personal experiences (20). Further investigations into

important factors based on the experiences of patients and health care providers, and not exclusively on pre-specified lists of hypothesized factors, will increase the comprehensiveness of our understanding in this area.

## 6.2 Strengths

To our knowledge, this study represents the first-ever systematic examination of factors that impact need for navigation services in a Canadian context. The qualitative component of the study in particular is a novel investigation into health care providers' perspectives on this topic. Further, the interviews were open-ended and provided unrestricted opportunity to learn about the nuances of patient factors that influence navigation experiences. We were not limited by information in the published literature, nor the quantitative data that was available for us to explore. This allowed us to collect data beyond what could be pre-hypothesized from the literature and learn about factors that we were unable to predict, such as genetic/family history of cancer, having recently moved to NS and subclinical anxiety/depression levels. Moreover, because CPNs observe the complex interactions of these factors, we were also able to examine combinations of factors that co-occur together (such as low income and low social support) that have particularly important impacts on need for navigation.

The major strength of a mixed methods design is the ability to combine quantitative evidence of causal effects or associations, and qualitative information on their causal or associative mechanisms. Having both types of information lends credibility to our arguments for the relationships between each of the patient factors and CPN use. The use of two methodologies also helped us to “triangulate” results. When the interviews and Delphi survey established an expectation of a certain relationship (e.g. patients who use radiotherapy as a treatment modality should be more likely to use CPN)

with a clear mechanism (needing informational preparation, dealing with side effects, helping to coordinate travel to and from cancer centres, etc) and the statistical analysis shows a strong association between patients who use radiation and CPN use, we can be more confident in the interpretation of our data.

Additionally, the quantitative analysis component of the study used a highly comprehensive dataset. The NSCR, from which the study cohort was extracted, is a population-based registry containing information on every breast cancer patient diagnosed in the province of NS. This eliminated the threat of selection bias, as we captured every member of this population in the study cohort. This allows us to reasonably generalize our results to all breast cancer patients in the province.

Finally, there were very little missing data in our linked administrative data. Some variables had no missing data whatsoever, such as age, comorbidity and tumour stage at diagnosis. For variables with missing data, the rate of missing data never exceeded 15%. In fact, none of the rates of missing data exceeded 10%, except for the variable that indicated whether there was evidence of cancer recurrence following the initial primary diagnosis. With these low rates of missing data, the risk of selection bias due to significant data not missing at random is low.

Over the course of this project, we have had access to key decision makers in Nova Scotian patient navigation policy environment, such as the Director of the CPN program, the CPNs themselves and the program database manager. Moreover, the CPN team had input into the project and received updates of the project as it progressed. This gave us greater assurance that our findings are reasonable and trustworthy, and are not

only consistent with CPNs' observations, but also helpful to their practice moving forward.

### 6.3 Limitations

There are, of course several notable limitations to this study that we should acknowledge. Particularly, there were limitations in our measurement strategies for some of the potentially important patient characteristics. For instance, several factors (income level, material deprivation, immigration level, etc) were only available at an ecological (or neighbourhood) level. Given the puzzling lack of association between the ecological SES measures and CPN use, it is possible that this limitation had a serious impact on this study's results. Studies comparing aggregate and self-reported individual data found that neighbourhood-level variables are less sensitive in predicting health outcomes and that the two are not always well correlated (81,82). Aggregate data are also noticeably less robust when applied to rural populations compared to urban (83). One reason for this is that many neighbourhood-level variables are calculated by census dissemination areas (DAs), which are geographically smaller in condensed urban areas and thereby more homogeneous than in rural DAs. This is a particular concern in this study, as a sizeable proportion of this cohort was rural and may have been one of the reasons for the lack of statistically significant association between patient SES level and CPN use.

Another limitation of variable measurement was in the case of measuring comorbidity. While the Johns Hopkins ACG® System has been validated in the Canadian context (59,71,72), it was not originally designed for research purposes. Rather it was designed for health administrators to predict resource use based on the severity or number of unique comorbidities (72). Thus, ADGs tend to be constructed to contain conditions that have a similar degree of resource use, rather than true clinical similarity. Studies

comparing multiple comorbidity measures in a Canadian cancer population have found that ACG is mediocre in predicting health outcomes compared to other measures such as the Charlson Comorbidity Index (84). This is not to say that the etiology does not factor into ADG assignment. ADGs do sufficiently distinguish, for example, psychosocial conditions from ear, nose and throat conditions. However, ADGs reflect the comorbidity burden from a hospital perspective and not from the perspective of a patient and the resources required to manage comorbidity in the community.

Another limitation of comorbidity measurement is that the ACG® System and other administrative variables rely entirely on the accuracy of MSI physician billings and the CIHI DAD. Because these data sources are not constructed with research as their primary purpose, there can be flaws in the way a health care visit is described (e.g., in the number and order of assigned diagnostic codes). This may mean that not all relevant medical conditions will be recorded with every health care visit. As with all studies involving administrative data, our conclusions from these data must be interpreted with caution.

The measurement of treatment interval also had some notable limitations. It was measured as the time elapsed from diagnosis date to the first of: surgery date, chemotherapy start date, or radiotherapy start date. It did not include any information on other common types of therapies such as hormonal or biological therapies. A particular population that was likely affected by this omission was metastatic patients, who may be on a course of hormonal or biological therapy for a year or more before using any of the three modalities included in the treatment interval measure. This would have led to an overestimation of treatment interval particularly among metastatic patients.

There is also a possibility of misestimation due to the measure of continuity of care. The UPC Index calculation does not include emergency department visits and so may not accurately portray a patient's experience with primary care. Adding emergency department visits would likely increase the denominator of the index and reduce the calculated value. This is of particular concern in NS, where patients have been reported to wait for 4 or more days for urgent primary care appointments and so frequently use the emergency department as an alternative to a family physician (85). As such, the UPC Index as calculated in this study may represent an overestimation of continuity of care and particularly so for patients who rely on emergency departments as a major source of primary care.

Besides the measurement of the factors in our statistical analysis, also important was the inability to include all of the patient factors identified by the interview and Delphi components in the statistical analysis. CPNs identified a wide variety of factors perceived to increase a patient's need for navigation. However, not all of these factors were available in the study dataset, such as responsibility for dependents and social support (family and friends). As a result, the quantitative analysis was not able to observe whether certain groups with greater need for navigation actually used navigation services.

Within the quantitative analysis, we stratified the logistic regression models by NSHA zone in order to examine regional variation. While novel, these analyses must be interpreted with particular caution, as the number of patients in each zone is not very large (varies from x to x). This is particularly important in Zone 3 (Eastern Zone, containing the former Guysborough-Antigonish Strait HA and Cape Breton DHA), where there was no CPN in the Cape Breton DHA until late in the study period. Limited

population sizes reduce the statistical power of the quantitative analysis and thus reduce the reliability of

A limitation of using the CPN perspective of patient need for navigation is that we would not have captured the experiences of any groups of patients that are consistently unable to access navigation. The CPNs' perspectives are based on their experiences with the navigated population of cancer patients, not the non-navigated population. If they are indeed completely missing a specific vulnerable segment of the population, this experience was not reflected in our results and we would not have been able to examine the associations between these unknown factors and use of navigation. However, given that the patterns of patient referrals and access in each jurisdiction are likely diverse, we assume that we achieved adequate coverage of these vulnerable populations. Moreover, because all CPNs are registered nurses, they have clinical experience outside of navigation upon which they would have also inevitably drawn to inform their judgements. Thus, it is unlikely that this issue posed a significant risk to the integrity of our study.

The CPN perspective is also limited by the CPN's understanding of a patient's motivations for using CPN services. CPNs may not know all of the reasons that a patient behind a patient's decision to use or not to use their services, and thus we may not have a comprehensive view of the factors that truly draw a patient to use CPN. This could have been strengthened by incorporating the patient viewpoint into this study's interview and Delphi survey components.

As mentioned by one of the CPNs, a patient's personality and preferences are likely an extremely important modifier on the relationship between any need-associated

factor and CPN use. Some patients may appear to have need for navigation (e.g. have low income, or greater diagnostic severity), yet do not want to use CPN, or at least do not reach out for help. We have no ability to estimate the impact of patient preference on observed utilization in this study. Patient preference stands to be quite substantial in the navigation context, especially due to the emotionally stressful nature of cancer and the difficult treatment-related decisions that some patients must make.

#### 6.4 Study Impact

There has not been adequate effort to understand what aspects of a patient's experience contribute to their navigational needs. This study represents the first Canadian study to explore all patient factors relevant to need for navigation. It illuminated factors that have not yet been studied in reference to cancer patient navigation (e.g. genetic/family history of cancer), as well as confirm our understanding of factors that have previously been studied (e.g. socioeconomic status, tumour stage, etc).

For the CPN program, knowledge on specific patient factors important to determining navigational need can help identify vulnerable populations who are currently not accessing CPN services. This may lead to interventions to improve access, including changes in referral patterns, program advertisement, or provider education to increase awareness of the program.

#### 6.5 Future Research

This study provides an important foundation on which to further investigate access to and need for navigation. Yet, future research must seek to examine the use of navigation in more depth than the datasets permitted in this study. For example, we were only able to examine whether an individual had ever used navigation—there was no distinction between individuals who used navigation only once and those that regularly



contacted their CPN over the course of their diagnosis and treatment, and/or beyond. It would be useful to determine whether the factors identified in this study are associated with degree of use of navigation and not simply a binary “ever versus never” outcome. Further, if we had a variable describing degree of navigation utilization, we could compare groups of “high users” and “low user” and examine what factors are associated with each of these. These descriptions could help us better understand how patients access navigation and what makes them more likely to use/comfortable using navigation services.

Another direction for future work would be to replicate the qualitative investigations of this study in other jurisdictions across Canada. Because the NS CPN program is small, we were limited in how many individuals we could interview and how much diversity of views we could include. We could greatly increase the richness of our dataset (interviews) and the strength of agreement (Delphi panel) by including more navigators from across the country. This would ensure that our list of patient factors that increase need for navigation is much more comprehensive and generalizable across the country.

One perspective which was completely absent from this study was that of patients. It would be extremely valuable to know what factors influence a patient’s need for CPN from their own perspective. Additionally, if a general cancer population was investigated, we could investigate patient preference for using CPN. This could help further identify patient groups who do not use CPN and establish the reasons for this.

## 6.6 Conclusions

The most important factors to consider in estimating an individual's need for CPN services are most likely sociodemographic factors, especially low SES, and clinical factors (such as tumour stage or types of treatments). In a cohort of breast cancer patients, clinical factors associated with higher need for navigation were associated with greater use of CPN. However, no such relationship was seen with sociodemographic factors (particularly low SES). These findings suggest that the low SES patients may benefit from greater targeting for referral to CPN.

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## Appendix 1

### Interview Guide

#### *General Discussion of Cancer Patient Navigator Role*

1. Tell me about your role as a CPN
  - What are your responsibilities to a patient?
  - What do you find you actually spend most of your time doing? Does this fit with your expectations or do you think you should be spending more time doing other activities?

#### *Patient Description*

2. Describe a typical client to me.
  - What type of patient is most often referred (not necessarily most time spent on one patient, but most patients are this type)?
3. Based on your experience, what things increase a patient's need for navigation services?
4. Do you get the sense that you see the majority of patients diagnosed in your geographic area?
5. Are you concerned that you are not seeing any particular patient groups/types that you think could stand to gain from your services?
6. What type(s) of patients individually require the most attention/time?
  - Age: do you expect that as age increases, importance to need increases? Or would you expect need for navigation to change differently according to age group?
  - Material deprivation: do patients from lower income households have more needs?
  - Social deprivation: do patients who live alone/don't have adult children/don't have other family members or friends nearby have more needs?
  - Education level: Do patients with less formal education/who are less literate have more needs?
  - Geographic distance: Do patients who live farther from Halifax or Sydney have greater needs? Patients who live further from the navigation centre?
  - Stage of cancer at diagnosis: Do patients diagnosed at an earlier stage have more or less needs than those diagnosed at later stages, on average?
  - Comorbidity: Do patients with a greater burden of comorbidity (that is, more comorbid diagnoses or more severe comorbid diagnoses) have greater needs than patients with a smaller burden of comorbidity?
  - Chemotherapy: Do patients receiving chemotherapy have more needs than those who do not receive chemotherapy? Are these largely practical needs vs emotional vs informational? Or a mix of many types of needs?

- Radiotherapy: Do patients receiving radiotherapy have more needs than those who do not receive radiotherapy? Are these largely practical needs vs emotional vs informational? Or a mix of many types of needs?
  - Dependents: Does it make a difference whether the patient has an adult dependent vs child?
  - Relationship with primary care physician/family doctor.
5. Based on your experience, what types or groups of patients benefit most from your support?

## Appendix 2

### Delphi Panel Questionnaire

#### Cancer Patient Navigation- Delphi Survey

##### Survey Questions

We ask that you rate each characteristic for its importance on a scale of 1-9 (1 = not at all important to 9 = very important).

Importance = In your experience, does the characteristic reflect an important characteristic that increases a breast cancer patient's need for navigation?

For another way to think about this, consider two breast cancer patients who are identical in every way, except on [characteristic]. Is this difference alone an important difference in need for navigational services?

(Optional) Please add any comments in the text box below if you think it would be helpful to explain your reasoning, or you wish to clarify the question. If you are satisfied with the clarity of the question and your response, you do not need to write anything in the text box.

##### 2. Age of patient

1 Not important at all	2	3	4	5 Uncertain importance	6	7	8	9 Extremely important	N/A
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Optional)

##### 3. Patient education level

1 Not important at all	2	3	4	5 Uncertain importance	6	7	8	9 Extremely important	N/A
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Optional)

##### 4. Socioeconomic status

1 Not important at all	2	3	4	5 Uncertain importance	6	7	8	9 Extremely important	N/A
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Optional)

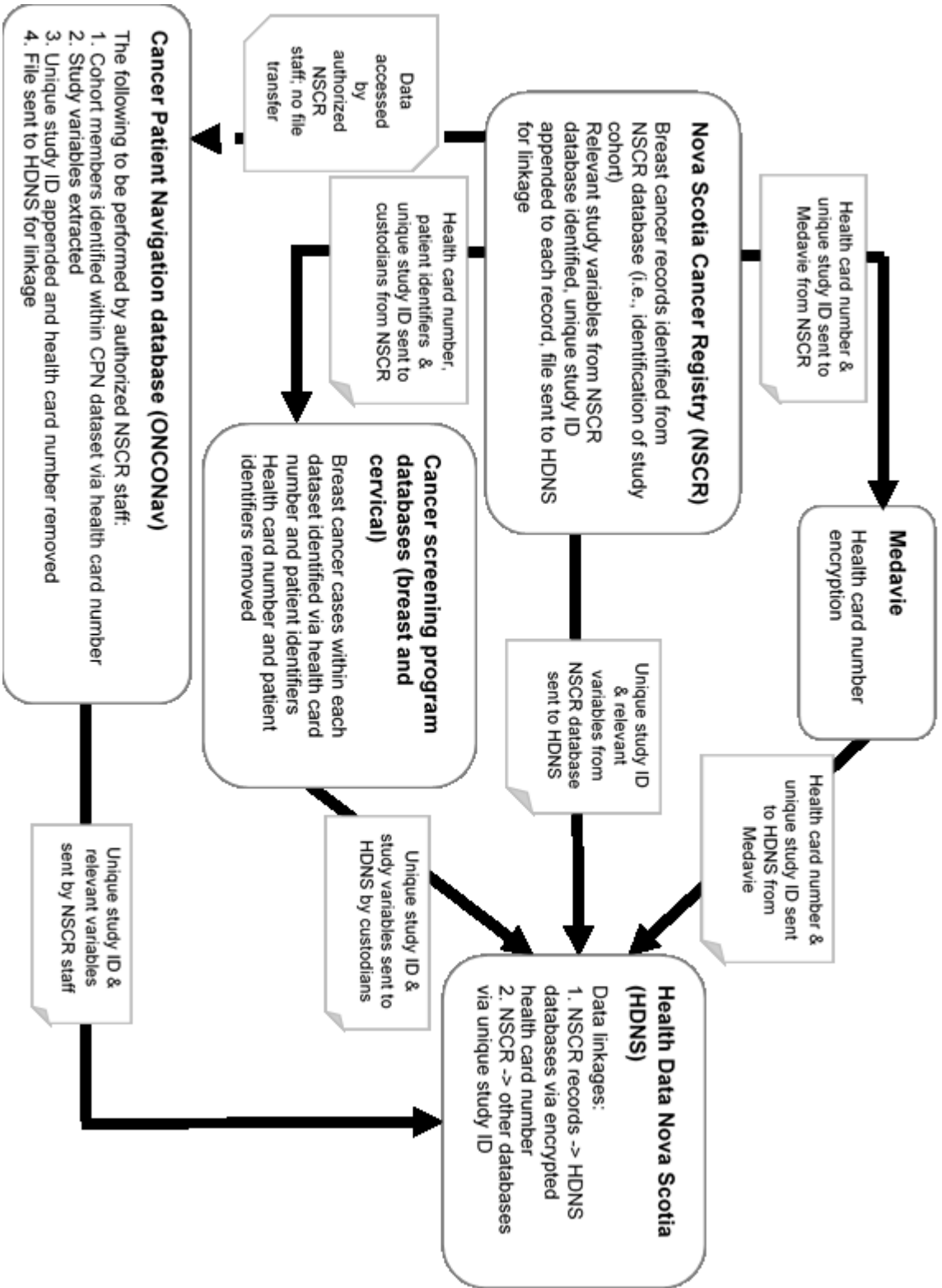
&tc... Survey continues as such for all included factors.

### Appendix 3

#### Breast cancer diagnosis codes (ICD-O-3) for inclusion in cohort

ICD-O-3 Code	Description
C50.0	Nipple
C50.1	Central portion of the breast
C50.2	Upper-inner quadrant of the breast
C50.3	Lower-inner quadrant of the breast
C50.4	Upper-outer quadrant of the breast
C50.5	Lower-outer quadrant of the breast
C50.6	Axillary tail of breast
C50.8	Overlapping lesion of breast
C50.9	Breast, NOS (excludes Skin of breast C44.5); multi-focal neoplasm in more than one quadrant of the breast

**Appendix 4**  
**Diagram of linkage process among administrative data sources**



## **Appendix 5**

### **Detailed information for definition of diagnostic interval variable**

The first breast cancer-related index contact = Within the six months prior to the diagnosis date from the NSCR, the first contact was defined as follows, hierarchically.

- a) Screening tests: The date of the earliest screening mammogram if one took place, regardless of the order of other diagnostic procedures that occurred, in the NSBSP.
- b) Diagnostic investigations: The earliest of the booking date of the first diagnostic mammogram, ultrasound, or breast MRI prior to diagnosis date from within the NSBSP. ('booking date' is a field within the NSBSP database)
- c) PCP visit: If booking date in b) is missing, use the date of the most recent visit to the patient's primary care doctor before the first diagnostic test.
- d) Breast cancer-related visits: If no screening or other imaging test exists, index contact will be identified using the earliest breast cancer related diagnosis code present in either MSI Physician Billings, or CIHI DAD (Appendix 3).