A systems analysis approach to colorectal cancer screening access in the Northwest Territories

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Abstract

Introduction

The Northwest Territories as a rural and remote region of Canada has higher colorectal cancer rates and lower uptake of colorectal cancer screening compared to the rest of the country. Understanding the complex health system processes involved in screening is necessary to develop informed solutions to improve screening access amongst marginalized populations. A systems approach to describe and understand the health care processes and system-level factors influencing colorectal cancer screening access was undertaken.

Methods

Semi-structured interviews with health care providers (N=29) involved in colorectal cancer screening in all health authorities within the Northwest Territories (N=8) were performed from September to December 2015. Interview transcripts were analyzed using qualitative content analysis methods within a Collaborative Information Behaviour (CIB) and Continuity of Care framework. Exploratory models of colorectal cancer screening processes were developed and translated into quantitative parameters for simulation modelling.

Results

Colorectal cancer screening access was defined by patient health care interactions supported by foundational information processes. Eighteen models of colorectal cancer screening access within the territory were identified, with varying complexity in care access seen across communities. Screening access problems included screening initiation, colonoscopy scheduling, screening recall and information silos, and were influenced by multiple contextual factors including a transient health work force, social health determinants, and patient travel. Qualitative models were translated into a system dynamics (SD) design framework for development of further quantitative modeling.

Conclusions

Colorectal cancer screening access in the Northwest Territories is a complex process comprising patient interactions and information processes linking primary care and hospital care processes, which are influenced by challenging contextual factors in the rural and remote health care environment. In developing screening access solutions the foundational role of information support and the need for system trade-offs in restructuring health system processes are necessary considerations. Optimizing information processes through the utilization of health informatics tools such as standardized referral forms and EMRs may also support health system transformation to improve screening access across the Northwest Territories. Understanding and evaluating system trade-offs may be best achieved using a combination of qualitative and quantitative modeling through future application of SD modeling research.
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1. Introduction

1.1 – Study overview

Colorectal cancer is the second leading cause of cancer related death in the Northwest Territories, with patients presenting at a more advanced stage and experiencing poorer long-term outcomes compared to the rest of Canadians (Northwest Territories Department of Health and Social Services [NWT DHSS], 2014). Colorectal cancer screening can improve colorectal cancer related mortality by preventing and treating early stage cancers (Fry, et. al., 2008; Tinmouth, Lansdorp-Vogelaar & Allison, 2015). While territorial colorectal cancer screening guidelines were implemented in 2011, only 20% of eligible individuals between 50-74yo were screened in 2011 and 2012, and screening rates are lower compared to other Canadian jurisdictions despite a higher need (NWT DHSS, 2014; Singh, et. al., 2015). Understanding the factors contributing to poor colorectal cancer screening access in the NWT is necessary to develop targeted solutions to improve screening rates.

To enable colorectal cancer screening access, the NWT has the challenge of coordinating the multidisciplinary health care processes involved in screening within a rural and remote health care system. Within the territory, colorectal cancer incidence is higher in the primarily indigenous, small, remote communities within the territory, and Dene patients experience poorer colorectal cancer outcomes compared to non-aboriginal patients, similar to other rural and remote indigenous populations (NWT DHSS, 2014; NWT DHSS 2015; Asmis, et. al., 2015; Condon, Barnes, Armstrong, Selva-Nayagam & Elwood, 2005; Hill, Sarfati, Robson & Blakely, 2013). Inequitable cancer outcomes among indigenous and marginalized patients may represent an emergent property of the health system, requiring an understanding of the sociocultural
aspects of care access as well as contributions of structural health system barriers to address these inequities (Hill, et. al., 2013; Mandelblatt, Yabroff, & Kerner, 1999). While it is recognized that the complexity of cumulative health care processes may contribute to inequities in care access impacting patient outcomes among marginalized populations, the mechanisms are poorly understood (Hill, et. al., 2010b; Hill, et. al., 2013; Mandelblatt, Yabroff, & Kerner, 1999).

Systems analysis examines the interrelationships between health care processes and their influences to understand how they influence system-level outcomes. (Kannampallil, Schauer, Cohen & Patel, 2011; Sturmberg, O’Halloran & Martin, 2012; Coiera, 2011). Systems analysis can be used to develop process and simulation models to guide health policy and health service delivery planning (Complex Systems Modelling Group [CSMG], 2010; Mandelblatt, Yabroff & Kerner, 1999). The first step in systems analysis involves conceptualizing the problem by understanding the processes involved (Roberts, et. al., 2012; Rad, Benyoucef & Kuziemsky, 2009; Kuziemsky, 2016). Qualitative methods can be applied in the initial stages of systems analysis where an in-depth understanding of processes is required (Creswell, 2013).

Approaching the problem of colorectal cancer screening access within the NWT through systems analysis will provide an in-depth understanding of the health system interrelationships influencing screening access through the development of an exploratory process model to capture health system complexity. Building a greater understanding of these health system interrelationships within colorectal cancer screening access may support equitable screening access within the NWT and similar rural and remote populations to improve patient outcomes by identifying targeted areas for health system transformation.
1.2 - Research purpose and objectives

This study aims to understand how current health care processes and system-level factors within the Northwest Territories [NWT] health care system influence patient access to colorectal cancer screening.

To achieve this, the following research objectives will be pursued:

(1) Conceptualization of colorectal cancer screening access to identify and describe the health system components, interrelationships and contextual factors involved.

(2) Construction of exploratory process models depicting the health care processes involved in colorectal cancer screening access in the NWT.

(3) Translation of exploratory process models into a system dynamics design framework
2. Literature Review

2.1 – Literature review overview

The literature review will introduce and discuss the relevant literature that informs systems analysis research of colorectal cancer screening access in the Northwest Territories. It describes foundational concepts from the health systems and screening literature, as well as identifies key literature gaps within established knowledge.

2.2 - Systems analysis approach in health care transformation

Health care systems are described as complex adaptive systems, as there is a high degree of interconnectedness between components combined with a high degree of unpredictability across these relationships, resulting in the system-level behaviours of self-organization, coevolution and emergence beyond the sum of the component parts (Kannampallil, et. al., 2011; Lipsitz, 2012). Systems analysis, the practice of examining the contextual interrelationships among health care processes and their influences, may provide insights into the health system that are not readily apparent when studying system components in isolation (Kannampallil, et. al., 2011; Sturmberg, et. al., 2012; Coiera, 2011).

With rising health care costs and an aging population, Canadian policy-makers and health care organizations are citing the need for health care transformation to target care access, quality of care, and cost to ensure sustainability of the health care system (Canadian Medical Association [CMA], 2010a; Ministry of Health and Long Term Care [MOHLTC], 2014; Health Council of Canada [HCC], 2013). There is consensus that change is needed, but little consensus
on how to achieve it (HCC, 2013). The accumulation of medical advancements and their associated random practice variations without the removal of irrelevant or outdated processes has resulted in resistance to change within health care systems (Coeira, 2011). In an era of complex interventions, complex patients and complex health care systems, improved organizational function and patient outcomes may be achieved through the rearrangement and synthesis of health care processes such as process bundling in clinical care pathways (Coeira, 2013, 2015). Systems analysis may support health care transformation by understanding system interrelationships and how they may be restructured and aligned to optimize patient outcomes.

Continuity of care is defined as “the degree to which a series of discrete healthcare events is experienced as coherent and connected, and consistent with the patient’s medical needs and personal context” (Haggarty, et. al., 2003). It can occur through the flow of information (informational continuity), patient care management across multiple providers (management continuity), and through building of long-term relationships between patients and their health care providers (relational continuity) (Haggarty, et. al., 2003). Continuity of care is considered a cornerstone of health care access and quality, making it a foundational component of health care transformation (CMA, 2010a; HCC, 2013). Continuity of care provides a framework for conceptualizing health care interactions over time and understanding continuity of care within health care processes may inform the development of targeted health care transformation initiatives.

Systems analysis combines qualitative systems thinking with quantitative system dynamics modelling to understand and predict complex system behaviours through the use of
computer simulation (CSMG, 2010). Qualitative modelling is a critical first step in systems analysis, as complex processes must be clearly understood before they can be effectively translated into a formal process model or system dynamics model (Rad, et. al., 2009; Roberts, et. al., 2012; Kuziemsky, 2016). Qualitative and quantitative health system modelling is increasingly being used to support decision-makers in understanding complex health care problems to develop health transformation solutions (Jun, Ward, Morris & Clarkson, 2009; CSMG, 2010; Mandelblatt, 2012; Cooke, et. al., 2007).

A systems analysis approach of understanding and describing complexity within the health care system was used to inform the literature search strategy, as well as frame the research question and study requirements.

2.3 - Literature review search strategy

To describe the problem of colorectal cancer screening access within the Northwest Territories as a rural and remote patient population with a high proportion of indigenous patients, SCOPUS and MedLine databases were searched for relevant colorectal cancer screening literature using combined search terms of ‘cancer’ or ‘colorectal cancer’ combined with ‘rural and remote’, ‘indigenous’, ‘Inuit’, ‘First Nations’ or ‘Northwest Territories’, as well as ‘colorectal cancer screening’ combined with ‘Canada’. Abstracts of articles were reviewed and articles addressing cancer incidence among First Nations, Metis or Inuit in Canada, or indigenous patients within a similar health care context, specifically New Zealand and Australia, were reviewed in full. Reference lists within these articles were reviewed for additional relevant or foundational literature not identified in the initial database search. All articles with references
specific to the Northwest Territories were included in the literature review. Literature on colorectal cancer among rural and remote, and indigenous populations in New Zealand and Australia published within the past 10 years were reviewed and relevant articles included. Literature from American Indian populations was not included due to the contextual differences in health care delivery between the United States and Canada, particularly the impact of insurance status on care access among marginalized populations within the US.

Grey literature from First Nations and Inuit organizations and provincial and territorial colorectal cancer organizations in Canada was identified through a Google search of ‘First Nations’ or ‘Inuit’ or ‘Northwest Territories’ and ‘cancer’ or ‘colorectal cancer’. The Northwest Territories Department of Health and Social Services website was consulted for relevant territorial documents.

In identifying systems analysis approaches to understanding colorectal cancer screening access, SCOPUS and MedLine databases were also searched for relevant health systems and system dynamics literature by combining search terms of ‘health systems’ and ‘indigenous’, as well as ‘system dynamics’ and ‘screening’. As a recognized foundational component of care access, databases were also searched using combined terms of ‘continuity of care’ with ‘colorectal cancer screening’ or ‘screening’.

2.4 - Colorectal cancer screening access as a complex health systems problem

Health care processes, structural and system-level factors, and patient factors all impact access to cancer care and the ability of marginalized patient populations to participate in
screening (Hill, et. al., 2013; Mandelblatt, et. al., 1999). Colorectal cancer screening within the Northwest Territories involves multidisciplinary health care processes delivered within the structural and system-level factors of a rural and remote health care system, embedded in a unique sociocultural context with a strongly indigenous cultural identity (Figure 1). As a result, facilitating colorectal cancer screening access to improve screening uptake is highly complex, as many of the individuals involved are spread over a large geographical area and are influenced by many contextual factors.

Figure 1. Complexity of colorectal cancer screening

Cultural context is an important consideration in colorectal cancer screening within the NWT, as approximately 50% of the population is First Nations, Inuit, or Metis, many of them residing in smaller, more remote communities (NWT DHSS, 2011). Cultural norms and societal values have a significant influence on when indigenous and other marginalized patients present to primary care and how they engage with screening programs (Mandelblatt, et. al., 1999; Macdonald & Trenholm, 2012; Martini, et. al., 2011; Kalahdooz, et. al., 2014; Inuit Tapiirit Kanatami [ITK], 2008; Cancer Care Ontario [CCO] 2012). Unfortunately, historical
marginalization of indigenous peoples in Canada through practices of residential schools and relocation may contribute to a mistrust of health care services, impacting patients’ willingness to access care (Marchildon & Torgerson, 2013). In addition, cancer terminology within indigenous languages in the NWT is limited, imprecise, and often understood as untreatable and incurable (Pauktuutit, 2013; NWT DHSS, 2015). The lack of culturally reflective cancer resources may limit indigenous patients’ engagement in screening programs (Pauktuutit, 2013; Kalahdooz, et al., 2014). Sociocultural factors impacting colorectal cancer screening among indigenous communities within the NWT are currently under investigation (Sharma, 2015).

Within a complex system, system inputs are transformed into system outputs, with overall system behaviours emerging through interaction between system components during the transformation process (Coeira, 2015). Colorectal cancer screening can be conceptualized as the transformation of an eligible unscreened patient input into a screened patient output through interaction with health care processes (Figure 2).

![Figure 2. Conceptualization of colorectal cancer screening system](image-url)
Health care processes that contribute to patient transformation from unscreened to screened in colorectal cancer screening involve coordinated interactions between patients, multiple health care providers, diagnostic procedures and laboratory processes. The complexity of health care process coordination in the NWT is significant, as patients are often required to travel for procedures or specialist care, and coordination of laboratory testing or pathology review is more complex than settings where all required facilities and expertise are within close proximity (Kalahdooz, et. al., 2014). The health care processes and system-level factors involved in transforming patients who have not accessed screening to patients who have successfully accessed screening within the NWT are currently not well understood. Understanding the complexity of these processes and how they interact may provide a crucial foundation for improving colorectal cancer screening uptake in the NWT.

Continuity of care provides a framework for conceptualizing health care processes over time (Haggarty, 2003). It is recognized as a crucial foundation for screening access, particularly in promoting resource allocation to support health equity among vulnerable populations including indigenous cancer patients (Miranda et. al., 2012; Slater, et. al., 2013). In addition to supporting health equity goals, continuity of care may also support appropriate use of diagnostic testing and procedures, as well as support uptake of FIT testing in colorectal cancer screening (Romano, Segal & Pollack, 2015; Fenton, et. al., 2008). Continuity of care may also be applied as a quality indicator in colorectal cancer prevention programs (Serra-Sutton, Serrano, Carreras, 2013). Understanding the health care processes involved in colorectal cancer screening access within a continuity of care framework may identify opportunities for health care transformation that supports equitable health outcomes among patients across the Northwest Territories.
2.5 - Health care in the Northwest Territories

The Northwest Territories (NWT) is politically, geographically and culturally distinct compared to other Canadian jurisdictions. The territory operates through consensus government and has eleven official languages including English, French, Cree, Tłęcho, Chipewyan, South Slavey, North Slavey, Gwich’in, Inuvialuktun, Inuktitut, and Inuinnaqtun. 50% of the population is indigenous, and multiple land claims and self-governance agreements have been signed or are in negotiation across the territory. The population is approximately 44 000 people spread across 33 communities. The territorial capital is Yellowknife; 46% of residents live in Yellowknife and 22% of residents live in regional centres of Inuvik, Fort Smith and Hay River, with the remaining 32% of residents spread across small, predominantly indigenous, communities with populations <1000 (NWT DHSS, 2011). The NWT has a stable population with a median age of 40.6 years and a growing population of seniors, influencing the number of patients eligible for colorectal cancer screening (Statistics Canada, 2012).

The NWT health care system consists of six regional Health and Social Services Authorities (HSSAs), the Tłęcho Community Services Agency, and the Stanton Territorial Health Authority (NWT DHSS, 2015b). Specialist care is provided primarily in Yellowknife at the Stanton Territorial Hospital, with the Stanton Territorial Health Authority also providing outreach elective surgical services to Inuvik and Hay River (NWT DHSS, 2015b). Family Physicians with Enhanced Surgical Skills (FP-ESS) provide surgical care, including endoscopy services, at the Inuvik Regional Hospital (NWT DHSS, 2015b). Any tertiary-level specialist services unavailable in Yellowknife are provided through Alberta Health Services, primarily in Edmonton, requiring patients to travel to access complex care (NWT DHSS, 2015).
The landmass of the Northwest Territories encompasses a total of 1.17 million square kilometres. Road access is limited, and there is a high reliance on air travel for transportation, particularly for medical care. The territory’s widespread geography has a significant impact on health care system costs, with a per capita expenditure of $8,923/year compared to the Canadian average of $4,915/year (Ellsworth & O’Keefe, 2013).

2.6 - Colorectal cancer in the Northwest Territories

Colorectal cancer rates are 1.6 times higher for men and 2 times higher for women in the NWT compared to the general Canadian population (NWT DHSS, 2011; NWT DHSS, 2014). It is the second most common cancer diagnosed in the NWT, the second leading cause of cancer death in the territory, and is the most common cancer seen in smaller, predominantly indigenous, communities (NWT DHSS, 2014). 50% of these patients present with advanced stage disease (stage 3 or 4), greatly impacting their long-term outcomes (Hechenbleikner, et. al., 2014; NWT DHSS, 2014).

Ethnic differences in cancer incidence between Dene, Inuit, Metis, and non-Aboriginal patients are seen in the NWT (NWT DHSS, 2014). Colorectal cancer is the most common cancer among Dene men and women, who experience poorer long-term cancer outcomes compared to non-aboriginal patients (NWT DHSS, 2014). Colorectal cancer is also the most common type of cancer among Inuit men and the third most common cancer among Inuit women (NWT DHSS, 2014). Epidemiological studies of Inuit across Canada demonstrate that colorectal cancer presents at a much younger age and higher stage, with poorer long-term outcomes.
compared to Canadian averages (ITK, 2008; Asmis, et. al., 2015). This suggests there may be unique genetic or environmental risk factors for colorectal cancer amongst both Dene and Inuit, increasing the potential impact of colorectal cancer screening in these populations. Differences in colorectal cancer incidence and outcomes between non-aboriginal and aboriginal patients in the NWT make screening access an important health equity consideration.

2.7 - Colorectal cancer screening in the Northwest Territories

Colorectal cancer is amenable to screening interventions, as it is generally a slow growing cancer with well-defined progression through the adenoma-carcinoma sequence (Fry, et. al., 2008). While patients with a family history of colorectal cancer or a known genetic cancer syndrome are at higher risk of developing colorectal cancer, age is the predominant risk factor for developing spontaneous colorectal cancer in the general population (Fry, et. al., 2008; Hechenbleikner & Wick, 2014). The need for colorectal cancer screening within the Northwest Territories can be expected to increase over time with the territory’s growing population of seniors.

Population-based fecal occult blood testing (FOBT) colorectal cancer screening programs with guiac FOBT (gFOBT) or Fecal Immunochemical Testing (FIT) supported by follow up colonoscopy have been shown to decrease colorectal cancer incidence and improve colorectal cancer related mortality within a population (Mandel, et. al., 1993; Hardcastle, et. al., 1996; Tinmouth, Vogelaar-Lansdorp & Allison, 2015). Professional associations and societies involved in colorectal cancer screening have developed evidence-based clinical practice guidelines for colorectal cancer screening and surveillance including the Canadian Association
of Gastroenterologists, American Cancer Society, Canadian Taskforce on Preventative Health Care (Leddin, et. al., 2004; Winawer, et. al., 2006; Canadian Task Force on Preventative Health Care, 2016). These guidelines have informed the development of provincial and territorial recommendations and programs for colorectal cancer screening across Canada. Unfortunately, despite well-established screening guidelines and follow-up recommendations for colonoscopy in many jurisdictions, including formal screening outreach programs, lower rates of colorectal screening uptake and poorer cancer outcomes are often seen amongst indigenous and rural and remote patient populations in Canada, Australia and New Zealand (CCO, 2012; Honein-AbouHaider, et. al., 2013; Nishri, Sheppard, Withrow & Marrett, 2015; Martini, et. al., 2008; Ward, Javanparast & Wilson, 2011). Contextual differences in care settings such as proximity to health services and transportation availability, as well as cultural influences such as community attitudes towards fecal screening tests and the perception of incurability of cancer have been identified as contributors to low colorectal cancer screening rates among indigenous patients (Ward, et. al., 2011; Kalahdooz, et. al., 2014; Martini, et. al., 2008).

In the Canadian setting, colorectal cancer outcomes and screening rates have been examined among First Nations and rural and remote populations in Ontario. Nishri et. al. (2015) identified a discrepancy in five year survival between First Nations and Non-aboriginal patients of 38.2% compared to 52.6%, and observed widening of this gap over time. Among rural and remote populations in Ontario, Honein-AbouHadar et. al. (2013) compared colorectal cancer screening rates before and after the introduction of ColonCancerCheck (CCC), Cancer Care Ontario’s formal screening outreach program, and observed improvements in both rural and urban screening rates over time with persistently lower screening uptake among rural
populations, approximately 3% less than their urban counterparts. No colorectal cancer screening research specific to indigenous populations in Ontario has been conducted to date (CCO, 2012).

In an effort to improve colorectal cancer outcomes within the territory, the NWT Department of Health and Social Services (DHSS) implemented clinical practice guidelines for colorectal cancer screening in 2011. For average risk patients, the guidelines recommend initiation of FIT at age 50 and repeat testing every 1-2 years with follow-up colonoscopy for patients with positive FIT results. Colonoscopy screening is recommended for patients identified as increased risk due to a genetic cancer syndrome, inflammatory bowel disease, or a family history of colorectal cancer, defined as one first degree relative diagnosed <60 years of age, or two first degree relatives diagnosed at any age (NWT DHSS, 2011). The guidelines also outline recommendations for follow up surveillance for patients who undergo colonoscopy. While there is currently no organized territorial program for colorectal cancer screening in the Northwest Territories, guideline recommendations closely resemble pan-Canadian recommendations by the Canadian Association of Gastroenterology, and Canadian Task Force on Preventative Health Care (Leddin, et. al., 2004; Canadian Task Force on Preventative Health Care, 2016).

In 2011 and 2012 only 20% of eligible patients participated in colorectal cancer screening, and screening rates in the NWT are lower than in other Canadian jurisdictions (NWT DHSS, 2014; Singh, et. al., 2015). The combination of high incidence and advanced presentation among colorectal cancer patients underscores the importance of improving access to screening across the territory, particularly within smaller indigenous communities where
colorectal cancer is the most common cancer diagnosis and second leading cause of cancer death (NWT DHSS, 2014). Improving colorectal cancer screening rates through increased screening access has been identified as a strategic priority in the 2015-2020 Northwest Territories Cancer Strategy, developed by the Northwest Territories Department of Health and Social Services in consultation with local health organizations and communities (NWT DHSS, 2015c). Further research is required to fully understand and address low colorectal cancer screening rates and poor colorectal cancer outcomes within the Northwest Territories and other rural and remote populations.

2.8 - Systems analysis and modelling in colorectal cancer screening

Disparities in cancer outcomes and screening rates between indigenous and non-indigenous populations are also seen among rural and remote indigenous populations in New Zealand and Australia (Hill, et. al., 2010; Condon, et. al. 2005; Kalahdooz, et. al., 2014). Screening disparities are also seen among low socioeconomic status [SES] populations, as well as urban and rural populations (Wardle, et. al., 2016; Honein-AbouHaider, et. al., 2013; Ward, Javanaparast & Wilson, 2011). Multiple contextual and sociocultural barriers to screening participation have been identified, including long-distance travel difficulties, fear of leaving home, health system mistrust, limited cancer terminology, perpetuation of cancer myths, and poor social acceptance of FOBT (Shahid, Finn, Bessarab & Thompson, 2011; Kelly, Dwyer, Willis & Petarsky, 2014; Treloar, et. al, 2014; Slater, et. al., 2013, Javanaparast, Ward, Carter & Wilson, 2012; Martini, et. al., 2011). The development of culturally responsive health systems is recognized as a critical component of overcoming persistent diagnostic and screening inequities among marginalized populations (Hill et. al., 2010; Hill et. al., 2013; Condon et. al., 2005;
Javanaparast, et. al., 2012; Kalahdooz, et. al., 2014; Slater, et. al., 2013; Gupta, et. al., 2014, Mandelblatt, 1999).

The complexity of health care processes, combined with structural and system-level, in addition to patient factors, may present significant barriers to cancer screening access among marginalized populations (Mandelblatt, et. al., 1999; Shahid, et. al., 2011; Hill, et. al., 2013; Gupta, et. al., 2014). Due to the complexity of cumulative health care processes, inequities in health care outcomes among marginalized patients may reflect an emergent property of the health system, which cannot be understood in isolation (Hill, et. al, 2010b; 2013). While sociocultural barriers and patient factors have been described, the contribution of health care process and system-level factors to disparities in colorectal cancer screening is not well understood. Understanding the complexity of the health system processes involved in colorectal cancer screening access within the rural and remote environment of the Northwest Territories may support the development of system-level solutions.

Fitness for purpose describes the ability of a system to achieve its stated objectives and is heavily influenced by system complexity (Coeira, 2015). Healthcare systems in their current state have not been designed as a coherent system, and instead represent an aggregation of multiple different processes with multiple adaptations and services added over time. This complexity may limit opportunities to improve system performance and health care organizations often do not have a clear understanding of how their activities contribute to their peak fitness, or ability to meet their stated outcomes, necessitating management of complexity and process restructuring to achieve desired outcomes (Coeira, 2015). In the case of colorectal
cancer screening, improving screening rates requires an understanding of how health care processes support or impede screening access so they can be aligned to promote improved screening access, particularly among marginalized patient populations.

Managing health system complexity requires an understanding of the processes involved, followed by measurement and subsequent implementation and management of targeted system changes (Coeira, 2015). Conceptualization of the problem is a critical first step in systems analysis modelling, as a clear, in-depth understanding of a process is necessary in order to effectively model it (Roberts, et. al., 2012; Rad, et. al., 2009). Qualitative methods are well-positioned to explore problems and describe processes and can inform development of models that reflect the system in question (Creswell, 2013; Yin, 2013).

Once a model of the health system in question has been developed, subsequent quantitative measurement can inform system transformation. System dynamics modelling provides an approach to quantifying qualitative models generated from a broader systems thinking approach, to then predict and measure potential impacts of health care transformation initiatives (CSMG, 2010). System dynamics models can be used to quantify relationships within complex systems by modelling components and their interrelationships as stocks, or variables that accumulate or deplete over time, and the flows that increase and decrease the defined stocks (Coeira, 2015; CSMG, 2010; Sherwood, 2002). Computer simulation software can be used to run system dynamics models under varying initial circumstances to predict the behaviour of the complex system being modelled. System dynamics models can be used to provide quantitative predicted outcomes of proposed system adaptations (Coeira, 2015; CSMG, 2010).
System dynamics modelling has been applied to colorectal cancer screening to inform the development of and assess the impacts of screening programs (Cooke, et. al., 2007; Hosking, et. al., 2013). Cooke, et. al. (2007) developed modeling frameworks to assess the morbidity and mortality impacts of a colorectal cancer screening program in Alberta, Canada, based on the disease trajectory of cancer development. They advocated for the use of such models to direct policy decisions and inform cost-benefit analysis of screening by Alberta Health Services, although application and quantitative findings were not described (Cooke, et. al., 2007).

In comparison, Hosking, et. al. (2013) developed a model measuring supply factors, enablers to screening, and demand factors, barriers to screening, impacting colorectal cancer screening rates to compare potential impacts of proposed interventions to increase screening uptake, including increasing number of providers and/or facilities, reducing patient no-shows, public awareness campaigns, and redistribution of rural services. They identified that a combination of supply (increased uptake) and demand (decreased barrier) interventions were most effective, but that supply interventions alone such as increased public awareness activities were potentially more effective than demand interventions alone (Hosking, et. al., 2013). Limitations of both of these modeling efforts are that they are based on colorectal cancer screening guidelines and disease outcome literature and do not identify or address unique contextual factors or local health system processes impacting screening. While they are able to provide quantitative measurements, the complexity of the health system processes involved is not described or captured.
A combination of qualitative and quantitative modelling can provide decision-making support for policy-makers and clinicians in health service delivery planning by providing a more complete picture of local processes and contextual factors in combination with quantitative measurements (Jun, et. al., 2009; Mandelblatt, et. al., 2012; CSMG, 2010). This combined modeling approach makes it possible to develop quantitative models that appropriately reflect the reality of the system, which is a necessary foundation for accurate predictive modeling (Rad, et. al., 2012; Coeira, 2015). This approach may be used to inform health system transformation initiatives to support increased, equitable access to colorectal cancer screening across the NWT and improve patient outcomes.
## 2.9 – Literature summary

Table 1. Literature summary of colorectal cancer screening in the Northwest Territories from a systems perspective

<table>
<thead>
<tr>
<th>What we know</th>
<th>What we don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Colorectal cancer screening results in early detection and prevention of cancer. However, patients in the Northwest Territories have poor colorectal cancer screening rates despite high cancer rates compared to other Canadians.</td>
<td>1) What unique health care processes and system level factors are involved in colorectal cancer screening access within the Northwest Territories?</td>
</tr>
<tr>
<td>2) Health disparities among marginalized populations may represent an emergent property of the health care system. Improving outcomes among these patient populations including rural and remote, and indigenous patients requires an understanding of the health care processes contributing to patient outcomes.</td>
<td>2) How do health care processes and system-level factors within the Northwest Territories interact to enable or restrict colorectal cancer screening access?</td>
</tr>
<tr>
<td>3) Modeling provides a necessary foundation for health system transformation initiatives that support the system to achieve desired outcomes. Qualitative and quantitative modelling of colorectal cancer screening processes can provide decision-making support to policy makers.</td>
<td>3) How can models of health care processes and system level factors in colorectal cancer screening access be developed to inform health system transformation initiatives?</td>
</tr>
</tbody>
</table>
3. Methods

3.1 – Methods overview

The study methods section summarizes the research purpose and objectives, outlines the qualitative research methods used and describes the research methodology in relation to the research purposes and objectives.

3.2 – Research purpose and objectives

This study aims to understand how current health care processes and system-level factors within the NWT health care system influence patient access to colorectal cancer screening. To achieve this, the following research objectives will be pursued:

1. Conceptualization of colorectal cancer screening access to identify and describe the health system components, interrelationships and contextual factors involved.
2. Construction of exploratory process models depicting the health care processes involved in colorectal cancer screening access in the NWT.
3. Translation of exploratory process models into a system dynamics design framework.

3.3 – Qualitative approach overview

A qualitative approach was undertaken to understand the health system processes involved in colorectal cancer screening within the Northwest Territories. Qualitative research is an integral research method when a problem or issue needs to be explored, when a detailed understanding of an issue is required, and when understanding context is important (Creswell, 2013). At the time of this study, the health system processes and contextual factors contributing to low colorectal cancer screening rates are not well understood. An exploratory qualitative
approach was considered most appropriate to describe and understand colorectal cancer screening processes and their influential contextual factors.

3.3.1 – Conceptual framework

According to Reddy (2010), Collaborative Information Behaviour (CIB) in health care is triggered by high problem complexity, lack of immediate information access, lack of domain expertise, and fragmentation of information resources, all of which are present in the setting of rural and remote multidisciplinary colorectal cancer screening in the NWT. Reddy’s (2010) model provides a framework for describing information seeking behaviour of a health care team, categorizing health care processes in the form of health system agents, interactions and information problems and their resulting system behaviours within the system context. Reddy’s (2010) emphasis on system context is a critical consideration in rural and remote health care delivery within the NWT. Haggarty’s (2003) Continuity of Care model identifies three types of continuity contributing to patient care over time. These include informational continuity, the use of information from past events to inform care interactions, management continuity, a coherent and responsive approach to managing a patient’s condition over time, and relational continuity, an ongoing therapeutic relationship between patients and providers. Reddy’s (2010) CIB model provides a framework for understanding complex health care processes at the point of care, while Haggarty’s (2003) Continuity of Care model provides a framework for understanding how health care processes contribute to patient care over time. Together, these models provide a framework for conceptualizing complex health care processes over time. This is necessary to understand colorectal cancer screening access in the distributed health care environment of the Northwest Territories, as the health care processes involved are multidisciplinary and occur over an
extended time period, as screening is ideally and ongoing and repetitive process among eligible patients until the age of 74. Table 2 shows the component categories and their definitions within CIB and Continuity of Care (Reddy, et. al., 2010; Haggarty, et. al., 2003).

Table 2. Categories and definitions within Reddy’s (2010) model of Collaborative Information Behaviour (CIB) and Haggarty’s (2003) model of Continuity of Care

<table>
<thead>
<tr>
<th>Collaborative Information Behaviour</th>
<th>Continuity of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health System Agents</strong>&lt;br&gt;People (i.e. – users) and information systems, entities that must interact to address the information problem, number increases with increasing problem complexity.</td>
<td><strong>Relational Continuity</strong>&lt;br&gt;An ongoing therapeutic relationship between a patient and one or more providers.</td>
</tr>
<tr>
<td><strong>Information Problems</strong>&lt;br&gt;Problems encountered within the system context and domain, ranging from simple to complex.</td>
<td><strong>Management Continuity</strong>&lt;br&gt;A consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs.</td>
</tr>
<tr>
<td><strong>Interactions</strong>&lt;br&gt;Interactions between individuals and systems, ranging from direct to conversational. People are engaged as individuals or in some collaborative situation along a spectrum of activity affected by their interactions with other agents.</td>
<td><strong>Informational Continuity</strong>&lt;br&gt;Use of information on past events and personal circumstances to make current care appropriate for each individual.</td>
</tr>
<tr>
<td><strong>System Context</strong>&lt;br&gt;The environment and domain of information problem or need.</td>
<td></td>
</tr>
</tbody>
</table>

3.3.2 – Researcher perspective

As a General Surgery resident and MSc (Health Systems) candidate I have a role within the health care system as a researcher, learner and care provider. As a result, I have baseline knowledge of colorectal cancer screening guidelines and processes to inform the development of a pre-structured case outline. However, I may also identify provider-centric results, particularly focusing on hospital-based endoscopy care, as this is within my scope of practice as a General Surgeon. The participation of a non-clinician researcher (CK) as a thesis supervisor, as well as a
non-surgical clinician (GGA) in the data analysis process may help identify and discuss potential researcher biases. In addition, seeking participant selection from multiple care provider groups and participant feedback from multiple care provider stakeholders may also inform broader data analysis and conclusions.

My position as a resident learner throughout the data collection process helped me to build relationships with health care providers across all groups. Primary care providers and scheduling providers appeared to be comfortable and welcoming, as they could discuss their experiences in medical terms, but were not concerned about having their practice ‘judged’ by a specialist, as I am still a trainee. Endoscopy providers appeared comfortable in discussing their practices, as I shared a common specialist interest as a General Surgery resident.

During the data collection phase, I also provided clinical care in General Surgery as a resident at the Stanton Territorial Hospital in Yellowknife, NT. Experiencing the system processes I was working to describe helped me to understand and clarify the processes described to me during provider interviews. While this personal experience with the Northwest Territories health care system and colorectal cancer screening system may have decreased the objectivity of my data analysis, I also believe it helped me to identify and understand some of the critical processes and challenges within the system first hand. Providers also appeared more willing to share their experiences with me when I informed them of my clinical work, as they expressed the importance of working within the Northwest Territories health care environment in order to truly understand and appreciate the challenges and context.
3.4 – Study permits

Research Ethics Board approval for this study was granted by the Stanton Territorial Health Authority, Beaufort Delta Health and Social Services Authority, Ottawa Health Research Institute (OHRI), and University of Ottawa. Data collection was carried out under 2015 Northwest Territories Scientific Research Licence No 15747 from September 1, 2015 to December 31, 2015 granted by the Aurora Research Institute for pan-territorial data collection.

3.5 – Sampling methods

Purposeful sampling of primary care providers and endoscopy providers involved in colorectal cancer screening across the territory was carried out by key informant identification by Medical Directors from each of the HSSAs. Sampling targets were three primary care providers per primary care HSSA to facilitate data triangulation, as well as inclusion of endoscopists from all three endoscopy sites within the Territory. Snowball sampling from interviewees was also sought, resulting in the inclusion of endoscopy scheduling providers in sampling, as both primary care provider and endoscopy provider participants identified these individuals as having crucial roles in colorectal cancer screening processes. All individuals approached for participation who expressed interest were offered an interview. Informed consent was reviewed and obtained from participants prior to study participation.

Primary care providers included Family Physicians, Nurse Practitioners and Community Health Nurses across the Northwest Territories, depending on the health service structure of each community. Endoscopy providers included General Surgery, Gastroenterology (GI), and Family Physician-Enhanced Surgical Skills (FP-ESS) endoscopists. Scheduling providers included
individuals with both administrative and clinical care support roles in colorectal cancer screening, as these individuals often have dual roles in smaller communities, while these roles are separated in larger communities. Table 2 shows the distribution of participant sampling across territorial health authorities. In health authorities with multiple communities, an effort was made to include primary care providers from different communities.

Table 3. Interview participant sampling by Northwest Territory Health and Social Services Authorities (HSSAs)

<table>
<thead>
<tr>
<th>Primary Care Providers (N=18)</th>
<th>Endoscopy Providers (N=5)</th>
<th>Scheduling Providers (N=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(FPs, NPs, CHNs)</td>
<td>Stanton Territorial Health Authority*</td>
<td></td>
</tr>
<tr>
<td>Fort Smith HSSA</td>
<td>Beaufort Delta HSSA</td>
<td>Stanton Territorial Health Authority</td>
</tr>
<tr>
<td>Hay River HSSA</td>
<td></td>
<td>Hay River HSSA</td>
</tr>
<tr>
<td>Beaufort Delta HSSA</td>
<td></td>
<td>Beaufort Delta HSSA</td>
</tr>
<tr>
<td>Yellowknife HSSA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tłı̨chǫ Community Services Agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sahtu HSSA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dehcho HSSA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Stanton Territorial Health Authority provides outreach colonoscopy services to Hay River HSSA

3.6 – Data collection methods

Data was collected in the form of recorded in-person or phone interviews. Interview questions followed a pre-structured case outline informed by Reddy’s (2010) model of Collaborative Information Behaviour (CIB) and Haggarty’s (2003) Continuity of Care model to facilitate comparison of screening processes between HSSAs (Appendix I). Field notes taken during interviews within the pre-structured care outline, and contact summary forms were prepared following the interview. Verbatim transcripts were generated from the recorded interviews and were de-identified for data analysis. The data collection period ran from September 21, 2015 to December 21, 2015 within the pre-determined study period granted by the
Northwest Territories Scientific Research Licence. At the conclusion of data collection, participants had been sampled from all Health and Social Service Authorities and general saturation of case outline themes had been achieved, with minimal new information or areas of further exploration identified within subsequent interview contact summary forms.

3.7 – Data analysis methods

Data analysis involved coding of verbatim interview transcripts and subsequent content analysis of coded passages following coding methods of Saldana (2012) and qualitative content analysis methods of Miles, Huberman and Saldana (2014). A logbook was used to record data analysis decisions and the progression of analysis in the generation of study results. First round coding was conducted concurrently with the data collection phase, while further code refinement and data analysis occurred following the completion of data collection. Regular analysis meetings between research team members were conducted throughout the analysis process and analysis decisions recorded in the logbook.

3.7.1 – Codebook development

First round coding included both deductive and inductive coding methods using the methods of structural coding and line-by-line descriptive coding described by Saldana (2013) to develop the first iteration of the code book. Structural codes were identified from the CIB and Continuity of Care categories forming the study’s conceptual framework applied to colorectal cancer screening processes identified in the literature review. Descriptive codes were initially developed through line-by-line coding of Hay River – Primary Care Provider 1, and Hay River – Endoscopy Provider 1 transcripts.
Hay River HSSA primary care provider and endoscopy provider transcripts were used to develop the initial code book through the first round coding process, as this was the first complete set of primary care provider and endoscopy provider interviews generated in data collection prior to the inclusion of scheduling providers as study participants. Once structural and descriptive codes were generated to develop a codebook, they were applied to the Hay River primary care provider and endoscopy provider transcripts using holistic coding methods to capture the process component and system interrelationships with other components. The codebook was further refined following holistic coding of the Hay River transcripts.

Initial first round coding of Hay River transcripts was completed by the study’s primary author (CC) and reviewed by the supervisory committee (CK, GGA). The codebook generated from first round coding was applied to Fort Smith primary care provider transcripts by all members of the research team (CC, CK, GGA) to test for coding consistency. Fort Smith HSSA transcripts were selected for coding, as they formed the second complete set of primary care provider transcripts collected. During this process, memos describing preliminary relationships within the data were recorded. The codebook was further refined as additional codes were identified and code groupings modified.

Following first round coding and initial codebook development, holistic coding was applied to the Hay River – Scheduling Provider 1 transcript to complete the Hay River HSSA transcript coding. The codebook continued to be iteratively adapted throughout the data analysis
process. The final codebook is included as Appendix II. Coding of transcripts was managed using NVivo software.

3.7.2 – Health system conceptualization

Data analysis of coded Hay River HSSA transcripts was undertaken using code based conceptually-clustered matrices. Contents of the conceptually-clustered matrices were then used to develop a case summary of system components and interrelationships within colorectal cancer screening access in the Hay River HSSA following the methods of Miles, Huberman & Saldana (2014). Case summary development was conducted concurrently with operational model diagramming described by Saldana (2013) to develop exploratory process models depicting colorectal cancer screening process components and their interrelationships within the Hay River HSSA (see Figure 3).
3.7.3 – **Exploratory process model construction**

In developing exploratory process models to depict health care processes over time, the research team chose swimlane diagrams with lanes representing the different categories of continuity of care as a framework for organizing the CIB system categories to depict their development over time (Figure 4). The decision was made to label Reddy’s (2010) information problems category as decision nodes within colorectal cancer screening, as these decisions may be made collaboratively or by individuals and do not necessarily require resolution of a problem.
Following analysis of the Hay River HSSA transcripts and development of associated exploratory process models, contact summary forms and field notes were reviewed to identify overarching models of FIT service delivery and colonoscopy service delivery processes in use throughout the territory, described in detail in the Results section. A representative subset of HSSAs was then selected to encompass all models identified, which included the Hay River HSSA, Fort Smith HSSA, and Beaufort Delta HSSA (see Table 4). These transcripts were then coded and analyzed following the conceptually-clustered matrix, case summary and operational model diagramming methods described above.
Table 4. Interview transcript subset for in-depth data analysis

<table>
<thead>
<tr>
<th>Hay River HSSA (N=5)</th>
<th>Fort Smith HSSA (N=11)</th>
<th>Beaufort Delta HSSA (N=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Providers</td>
<td>Primary Care Providers</td>
<td>Primary Care Providers</td>
</tr>
<tr>
<td>Endoscopy Provider – STHA</td>
<td>Endoscopy Providers – STHA</td>
<td>Endoscopy Providers</td>
</tr>
<tr>
<td>Scheduling Provider</td>
<td>Scheduling Providers – STHA</td>
<td>Scheduling Provider</td>
</tr>
</tbody>
</table>

Case summaries and exploratory process models were analyzed to identify and describe overall health system relationships, as well as specific screening access problems and influential contextual factors within colorectal cancer screening processes. Primary data and interim analysis documentation including interview transcripts, field notes, contact summary forms, conceptually clustered matrices, and case summary documents were retained by the research team for audit purposes.

3.7.4 – System Dynamics (SD) framework translation

Translation of the exploratory process models of colorectal cancer screening to a system dynamics (SD) framework with data requirements was undertaken following final validation of the process models. Patient stocks and flows were identified within the exploratory process models, and translated to a system dynamics design framework following Sherwood’s (2002) definition of a stock as “any variable that accumulates over time” and a flow as “any variable that increases or decreases a stock” in consultation with an SD expert (Moll, R., personal communication, 2016). Further mathematical modelling and quantitative validation of the SD framework beyond the boundaries of this study is required prior to utilization in formal simulation modelling.
3.8 - Validation

Data subsets included sufficient participants and participant provider role distribution to permit triangulation of data analysis findings. Participant checks of study results were conducted through review of exploratory process models by one to two study participants from each of the Hay River, Fort Smith and Beaufort Delta HSSAs. Community presentations of general study results outlining colorectal cancer screening access problems and contextual factors influencing screening access were also completed as an alternate method of participant validation engaging both study participants and health system stakeholders (see Table 5).

Table 5. Community presentation list

<table>
<thead>
<tr>
<th>Date</th>
<th>Venue</th>
<th>Stakeholder Groups Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 1, 2016</td>
<td>Institute for Circumpolar Health Research, Yellowknife – Research Rounds</td>
<td>ICHR researchers, DHSS public health officers, epidemiologists, aboriginal health officers</td>
</tr>
<tr>
<td>March 3, 2016</td>
<td>Stanton Territorial Hospital, Yellowknife – Medical Advisory Committee (MAC) meeting</td>
<td>Physician and administrative members of the MAC</td>
</tr>
<tr>
<td>March 7, 2016</td>
<td>Inuvik Regional Hospital, Inuvik – Primary Care Rounds</td>
<td>Primary care physicians, Beaufort Delta HSSA administrators</td>
</tr>
<tr>
<td>March 9, 2016</td>
<td>Government of the Northwest Territories Department of Health and Social Services, Yellowknife</td>
<td>DHSS deputy minister, public health officers, epidemiologists, IT services, administrators</td>
</tr>
<tr>
<td>March 10, 2016</td>
<td>Stanton Territorial Hospital, Yellowknife (teleconference to Fort Smith, Hay River) – Educational Rounds</td>
<td>Primary care physicians, STHA administrators</td>
</tr>
</tbody>
</table>
Corrections to process models and study findings were made to reflect participant comments generated by individual and group participant checks. These included the requirement of lab requisitions in provider interface FIT screening, as well as the use of both provider and lab interface FIT screening in Inuvik, which was previously thought to offer only lab interface screening. Following participant review, a final internal review process was conducted by the research team, which involved a review of selected codes, case summaries and exploratory process models for congruence.
4. Results

4.1 – Results overview

The results section identifies and describes the health system components and interrelationships within colorectal cancer screening access and contextual factors influencing these processes. Health care process problems impacting colorectal cancer screening access and possible solutions are also described. Finally, the translation of health care process models to an SD design framework is identified and described.

4.2 – Health system overview of colorectal cancer screening access

Colorectal cancer screening access within the Northwest Territories represents a highly complex system, as it has a large number of components with a high degree of interrelationships among them. The health system interrelationships and components involved in colorectal cancer screening can be grouped into patient interactions and information processes. Patient interactions encompass the relational continuity dimension of the combined CIB/continuity of care framework, while information processes encompass decision nodes, management continuity and informational continuity dimensions. The health system interrelationships and components can also be grouped into primary care processes, which involve FIT screening, and hospital care processes, which involve colonoscopy screening. Conceptualization of health system processes over time allowed for identification of upstream aspects of screening access, or those occurring at earlier points in the screening continuum, as well as downstream aspects, or those occurring at later points in the screening continuum. The ability to conceptualize upstream and downstream interrelationships within the health system was used to understand and describe system complexity within colorectal cancer screening access, particularly the impacts of screening
access problems. Figure 5 shows an overview of these health system relationships represented within the process models.

![Health system overview of colorectal cancer screening access](image)

Figure 5. Health system overview of colorectal cancer screening access

Information behaviour, or the utilization of health care information within colorectal cancer screening, ultimately links all health system components. Information behaviour is generated by interactions between health system components, including health system agents and decision nodes, and forms the health system interrelationships across the continuity of care streams of relational continuity (patient-provider interactions), management continuity (provider-provider interactions), and informational continuity (provider-information system interactions) that make up colorectal cancer screening access. Examining information behaviour within the exploratory process models, it is apparent that health system information processes enable information flow through the health system to support the patient interactions required for colorectal cancer screening access.
Figure 6 shows an example of information behaviour generated from a primary care encounter interaction (relational continuity) between patients and providers (health system agents), subsequently generating the decision node sequence of screening initiation, risk stratification, and FIT initiation. Records of previous care may be obtained from documents (management continuity) retrieved from the health centre chart (informational continuity) that inform the decision node of screening initiation. The decision node sequence generated by the primary care encounter is then documented in the primary care encounter note (management continuity) and subsequently stored in the health centre chart (informational continuity). As demonstrated by this sequence of health care processes, information flow from patient interactions through decision nodes, management continuity, and informational continuity is necessary to enable screening access.

Figure 6. Information behaviour situated within the exploratory process models
In addition to supporting patient interactions within colorectal cancer screening access, information behaviour also forms critical links between primary care and hospital care processes in the form of colonoscopy referrals and final follow-up reports from colonoscopy. Clear, complete information transfer between system components is necessary to enable access along each subsequent step of the colorectal cancer screening continuum.

### 4.3 – Colorectal cancer screening access models

Colorectal cancer screening requires a combination of access to primary care FIT screening and colonoscopy screening. This study identified two models of FIT screening access and six models of colonoscopy screening access which, when combined, resulted in a total of eighteen different models of colorectal cancer screening access currently in place within the Northwest Territories. These models exhibit variable health system complexity, which will be discussed in more detail in subsequent sections.

As a result of the variable complexity among access models, as well as variable combinations of access models within and between communities, colorectal cancer screening access in the Northwest Territories is highly complex and highly variable. Identifying the combinations and permutations of FIT and colonoscopy screening access models by community resulted in a total of eighteen different models of colorectal cancer screening access among patients across the territory. The models of FIT screening and colonoscopy screening access in place in each community depend on the local health care services and are variable across Health and Social Services Authorities, as well as communities within these authorities. A list of the FIT and colonoscopy access models within each community and health authority is outlined in
Appendix III. Exploratory process models depicting colorectal cancer screening access for both FIT and colonoscopy, as well as care access models in the case of post-colonoscopy emergency were developed for the Hay River, Fort Smith, and Beaufort Delta Health and Social Services Authorities, as a representative sample of the two FIT and six colonoscopy screening access models (see Appendices IV-VI). Table 6 provides definitions of each screening access model.

Table 6. Colorectal cancer screening access models

<table>
<thead>
<tr>
<th>FIT screening access models</th>
<th>Lab interface</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care processes</td>
<td>Patients interact with laboratory personnel to receive FIT kit instructions and return kit for processing</td>
</tr>
<tr>
<td>Provider interface</td>
<td>Patients interact with primary care providers to receive FIT kit instructions and return kit for processing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Colonoscopy screening access models</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care processes</td>
</tr>
<tr>
<td>Coupled pre-colonoscopy consultation and colonoscopy appointments</td>
</tr>
<tr>
<td>Appointments are booked concurrently with planned colonoscopy within a 2-3 day timeframe</td>
</tr>
<tr>
<td>Full service outreach</td>
</tr>
<tr>
<td>Consultation appointments and colonoscopy services are offered in the community by a visiting endoscopy provider, no patient travel is required</td>
</tr>
<tr>
<td>Full distance services</td>
</tr>
<tr>
<td>Consultation appointments and colonoscopy services are offered in a single location, patient travel is required to access all services</td>
</tr>
<tr>
<td>Locally-based services</td>
</tr>
<tr>
<td>Consultation and colonoscopy services are offered by providers in the local community, no patient travel is required</td>
</tr>
<tr>
<td>Full distance services (Telehealth)</td>
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<tr>
<td>Consultation appointments offered through telehealth, patient travel is required to access colonoscopy services</td>
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<tr>
<td>Full distance services (Travel)</td>
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<tr>
<td>Separate patient travel encounters are required for consultation appointment and to access colonoscopy services</td>
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<tr>
<td>Partial service outreach</td>
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<tr>
<td>Consultation appointments are offered in the local community by a visiting endoscopy provider, patient travel is required to access colonoscopy services</td>
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4.3.1 – System complexity in screening access

There is variable complexity in colorectal cancer screening access across both FIT and colonoscopy screening access models. Screening access complexity was determined by the number of health system components involved, including health system agents, decision nodes, and management continuity documents involved, as well as the number of interactions required and degree of information behaviour interrelationships between them. Complexity of models increased as the number of health system components and interrelationships increased.

System complexity within FIT screening access was captured according to patient and provider interactions between patients and primary care providers or patients and lab technicians. Within FIT screening, the health system interrelationships required to enable access increased with an increase in the number of providers involved. System complexity within colonoscopy screening access was also captured according to patient and provider interactions, categorized by the coupling or uncoupling of patient and provider interactions at the time of pre-colonoscopy consultation and colonoscopy and the travel required on behalf of patients and endoscopists. Coupled pre-colonoscopy consultation and colonoscopy appointments are scheduled concurrently to occur over a short timeframe (i.e. – single travel encounter) compared to uncoupled appointments, which are scheduled separately over a longer timeframe and may require multiple travel encounters. System complexity in colonoscopy screening access increased with an increased number of providers involved, as well as with increased travel requirements among patients and providers.
4.3.1 – FIT screening access models

Models of FIT screening access reflect variability in how the patient interfaces with FIT testing, either through primary care providers or through laboratory personnel. Exploratory process models of FIT screening access are available in Appendix III. Within the exploratory process models, patients from Inuvik within the Beaufort Delta HSSA, Fort Smith, and Hay River within the Hay River HSSA primarily access lab interface FIT screening. Patients from all other communities within these HSSAs, as well as some patients in Inuvik and Fort Smith access FIT testing directly from their primary care provider.

Within FIT screening access, the lab interface model is more complex, as there are more patient-provider interactions, information behaviour interrelationships, and health system agents involved, compared to the provider interface model where the patient receives the kit directly from their primary care provider (Figure 8).

![Figure 8. FIT screening access models according to structure and complexity](image)
There is variable complexity in FIT screening access across communities, as patients in smaller communities without lab services experience provider interface FIT screening access, compared to patients in larger communities such as Inuvik, Hay River, Yellowknife, and Fort Smith with access to lab facilities who experience lab interface FIT screening access. In larger communities, some patients may experience either lab interface or provider interface FIT screening, depending on the practice of their primary care provider, resulting in variable complexity of screening access among patients in these communities.

4.3.1 – Colonoscopy screening access models

Models of colonoscopy screening access reflect variability in scheduling of pre-colonoscopy consultation and colonoscopy appointments, whether they are scheduled concurrently in a short timeframe (coupled), or scheduled separately over an extended timeframe (uncoupled), as well as travel requirements on behalf of patients and endoscopists (Figure 9).

Figure 9. Colonoscopy screening access models
The exploratory process models depicting these six models of colonoscopy screening access are available in Appendix V. Within the Beaufort Delta HSSA, patients from Inuvik access locally-based colonoscopy, while patients from smaller communities access uncoupled distance (telehealth) colonoscopy, and partial service outreach colonoscopy screening. Within the Hay River HSSA, patients from Hay River access full service outreach colonoscopy screening, while patients from small communities access coupled full distance (travel) services via Hay River. Within the Fort Smith HSSA, patients may access colonoscopy screening through a partial service outreach, coupled full distance travel services, or uncoupled full distance telehealth or travel services based in Yellowknife.

As with FIT screening, the complexity of colonoscopy screening increases with an increased number of involved health system components and information behaviour interrelationships (Figure 10).

Figure 10. Colonoscopy screening access models arranged according to complexity
Locally-based colonoscopy services were found to be the lowest complexity, as no patient travel is required. The full service outreach model of colonoscopy screening currently in use in Hay River is slightly increased in complexity, as interactions between scheduling providers and endoscopy providers are increased, and the process requires travel on the part of the endoscopy provider. The distance (coupled) model where patients must travel but undergo both pre-colonoscopy consultation and colonoscopy within the same travel period is the third least complex model, as only one travel interaction is required. In this model, while coordinating clinic and colonoscopy scheduling is slightly more complex compared to uncoupled models where the pre-consultation and colonoscopy appointments are booked separately, the number of scheduling steps is decreased, decreasing the overall complexity of the process in terms of number of health system agents and steps involved. The uncoupled distance telehealth model is of intermediate complexity, as it requires coordination of separate pre-colonoscopy consultation and colonoscopy appointments, but is considered less complex than the other uncoupled distance models, as it does not require patient travel for the initial consultation. The partial service outreach model is the second most complex model of colonoscopy screening access, as it requires coordination of pre-colonoscopy consultation appointment during a travel clinic by an endoscopy provider within the patient’s home community, in addition to coordination of a separate colonoscopy appointment that requires patient travel. The most complex colonoscopy screening access model identified was the uncoupled distance travel model, which requires scheduling and patient travel for separate pre-colonoscopy consultation and colonoscopy appointments.

Compared to FIT screening access across the territories, variability in the complexity of colonoscopy screening access across the territory is inverted, with larger communities with
locally available colonoscopy services experiencing less complex screening access compared to smaller communities without local colonoscopy access. In smaller communities without local colonoscopy services, complexity of colonoscopy access is still variable, depending on provider practices and availability of telehealth and travel clinic opportunities.

4.4 – Colorectal cancer screening access problems

Through analysis of interview transcripts and exploratory process models, multiple screening access problems were identified. These access problems can be categorized as patient interaction or information process problems, as well as primary care and hospital care process problems. Table 7 shows a categorized matrix of colorectal cancer screening access problems identified. Many screening access problems are interrelated and influenced by contextual issues within the rural and remote health care system of the Northwest Territories.

Table 7. Colorectal cancer screening access problems

<table>
<thead>
<tr>
<th>Patient Interactions</th>
<th>Primary Care</th>
<th>Hospital Care</th>
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<tbody>
<tr>
<td></td>
<td>• Limited Screening Initiation</td>
<td>• Colonoscopy Capacity</td>
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<td></td>
<td>• Inappropriate FIT initiation</td>
<td>• Frequent Colonoscopy No-Shows</td>
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<td></td>
<td>• Unsupported FIT Screening Recall</td>
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<tr>
<td>Information Processes</td>
<td>• Unclear or incomplete colonoscopy referrals</td>
<td>• Highly complex colonoscopy scheduling</td>
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<td></td>
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<td>• Inconsistent colonoscopy recall reconciliation</td>
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<td></td>
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<td>• Inconsistent colonoscopy follow-up communication</td>
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• Multiple disconnected patient charts
4.4.1 - Patient Interactions - Limited screening initiation

Within the Northwest Territories, colorectal cancer screening is opportunistic and dependent on the primary care encounters, as there are guidelines but no formalized territorial screening program. At this time, patients must first interact with their primary care provider to access colorectal cancer screening either through FIT or colonoscopy screening (Figure 10).

“I don’t think that as a territory we’ve been able to offer screening to everybody who should be offered screening [...] it’s been quite, sort of, episodic, if it’s identified in an encounter with a patient, if the patient comes and asks me about it, if the health care provider happens to bring it up, but I don’t think there’s been any consistent way of identifying that in patients.”

Colorectal cancer screening may be initiated by patients or primary care providers, but was identified most often as being initiated by primary care providers in the setting of a primary care encounter for an unrelated issue.

Figure 10. Exploratory process model situating screening initiation decisions within the primary care encounter

Health system complexity within screening initiation is demonstrated by the multitude of influential contextual factors as both barriers and enablers to screening. Colorectal cancer screening initiation is heavily influenced by contextual factors, including a locum practice
environment, high patient acuity, social determinants of health, residential school experiences, and patient education and awareness.

“It very much seems to be on an adhoc basis […] if you have time during the appointment […] it’s very hit or miss […] we’re constantly putting out fires rather than just taking away the matches.”

“I think a lot of it is a history of trauma. Often times when people do have a history of abuse […] they’re a bit more apprehensive”

“tons of social issues […] if people’s basic needs aren’t being met, the chances of them going to a doctor to ask about […] prevention is pretty much slim to none”

“I would imagine in locum environments that we may miss more opportunities to meet the screening guidelines”

A locum practice environment may make screening initiation more difficult due to lack of familiarity with territorial practice guidelines, as well as lack of continuity with individual patients. Poor social determinants of health including job insecurity, housing insecurity, and food insecurity may also present a barrier to screening initiation, as patients may be less interested in preventative care when their basic needs are unmet. Residential school experiences were also identified as a major barrier to colorectal cancer screening initiation, as patients with a history of sexual abuse may have associated triggers.

While many contextual barriers impact colorectal cancer screening initiation, patient education and awareness presents an enabler, particularly in smaller communities.

“It’s also a small community, so when one person gets colon cancer the whole town knows about it […] then they come in the next week”

“we had this blitz going on and we just had tons of people come in”

Communities within the Beaufort Delta were identified as having high levels of cancer awareness and cancer screening awareness. In addition, providers identified quick word of
mouth spread when a community member is diagnosed with cancer as a motivator for patients to present for screening if there has been community education regarding the availability of screening. They also identified the effectiveness of awareness programs with older community members, particularly as they will often share information with their relatives and encourage them to participate in screening.

Screening initiation is a crucial first step in colorectal cancer screening access. The many contextual factors involved make this step highly complex despite the relatively straightforward information behaviour relationships involved. Many of the contextual factors involved are complex in their own right and are not easily resolved. Addressing and managing the contextual aspects of screening initiation within public education materials and awareness campaigns, as well as managing health system factors such as locum-based practices are important considerations in improving colorectal cancer screening access. Managing modifiable contextual health system factors such as longer appointments, as well as enabling information behaviours that prompt screening through the use of informatics tools such as EMR may also support screening initiation within the Northwest Territories. Understanding the potential downstream impacts of increased screening initiation on the health system, such as increases in colonoscopy referrals, increased lab processing, and follow up and management of results is also necessary to enable improved screening access. Additional health system processes and resources may be required to manage increases in patient screening access.
4.4.2 - Patient Interactions – Inappropriate FIT initiation

Inappropriate FIT initiation was identified by endoscopy providers as a problem within colorectal cancer screening, particularly with the use of FIT as a diagnostic test in the primary care setting (Figure 11).

“I would suggest that much of our FIT testing is done for inappropriate reasons in that it’s being used as a diagnostic tool and not a screening tool.”

“There are a lot of FIT tests that are done when they don’t need to be done or shouldn’t be done and the patient should go straight to colonoscopy.”

![Figure 11. Exploratory process model situating FIT initiation decisions within the primary care encounter](image)

Use of FIT was described variably among primary care providers, with some providers describing their use only in the setting of average risk, asymptomatic patients, while others described using FIT to facilitate endoscopy access, perceiving that a positive FIT would support earlier colonoscopy access.

“Generally, it helps your case I feel, if you have a positive FOBT. So if I think I can get one and I think that that will speed them up to colonoscopy, then I’ll do it.”

“If they meet the criteria for higher risk, I usually refer them right away because there can be a long waitlist for a colonoscopy and I’ll write on the referral FOBT pending.”
Inappropriate application of FIT outside of the screening process is of concern, particularly among endoscopy providers, as it may contribute to delayed diagnosis or confusion in endoscopy prioritization decisions due to lack of clarity regarding whether the patient is being referred for screening colonoscopy or symptomatic rectal bleeding.

Increased health system complexity within information behaviour interrelationships is seen in inappropriate FIT screening through the generation of additional requests for clarification of referrals, or unnecessary communications between primary care and endoscopy providers for inappropriate referrals. These information behaviours may also generate additional patient interactions to clarify information not captured in previous documentation, further increasing the complexity of screening access. Decreasing inappropriate FIT initiation may support decreased health system complexity and improved colorectal cancer screening access by focusing information behaviours on appropriate screening initiation and resource utilization.

4.4.3 - Patient Interactions - Colonoscopy capacity

Colonoscopy resources within the territory are limited and there are long wait lists for pre-colonoscopy consultation appointments and colonoscopy appointments, particularly in Yellowknife and Hay River. Due to resource constraints, average risk patients who are eligible for FIT screening and are referred for colonoscopy in Yellowknife or Hay River are often referred back to their primary care provider by the endoscopist with recommendations to initiate FIT screening.

“I’ve gotten pretty strict with sticking with the guidelines. [...] people who definitely need it done are having to wait sometimes more than is ideal, so I don’t think we can be offering screening colonoscopies to everyone who wants one.”
Colonoscopy screening capacity is managed alongside diagnostic colonoscopy and resources must be allocated accordingly. Because screening or surveillance colonoscopy is frequently prioritized as routine, scheduling may be delayed due to prioritization of more urgent or semi-urgent diagnostic colonoscopy. Timely repeat colonoscopy for both screening and surveillance patients is challenging in the resource strained environments of Yellowknife and Hay River.

“Now I’m finding my callback follow-ups are overdue by 2-3 years [...] this is where I’m finding [...] that we’re getting our cancers from”

Colonoscopy capacity is also impacted by clinic capacity for pre-colonoscopy appointments, as patients must be seen in consultation with the endoscopist in clinic prior to undergoing colonoscopy. In addition, colonoscopy scheduling in Yellowknife is managed through the Stanton Territorial Hospital Medical Daycare Unit, which also provides holter monitoring and chemotherapy services. This requires complex human resource management, particularly among nursing staff.

“It’s complex. [...] You would never find a nurse somewhere else who was in the scope room in the morning and doing a stress test in the afternoon and then maybe pushing some chemo or a monoclonal antibody in the afternoon. That’s just not a mix you would see somewhere else”

Capacity is less constrained in Inuvik, and as a result, colonoscopy is offered as a first-line screening test to average risk patients. Due to high cancer rates in the Beaufort Delta and concern of higher incidence of colorectal polyps, there is a question among Beaufort Delta providers as to whether the patient population is truly ‘average risk’ or should be considered at increased risk regardless of family history and other risk factors outlined in the territorial colorectal cancer screening guidelines.

“We have a bit of a lower threshold for offering colonoscopy rather than FIT testing. We are aware that then northern populations and specifically Dene, [...]they have a higher rate of colon cancer than the rest of Canadians [...] So I would be more likely to do a
scope here than to use a FIT test in some populations whereas down south, I might say I’d do FIT.”

“And if we do have a bias here, I think it’s just that we do see so much pathology. [...] So I think because we see that, I think perhaps if there is a bias, it’s probably towards offering endoscopy because we don’t want to miss stuff”

In addition, endoscopists in the Beaufort Delta have a dual role as primary care providers and endoscopists, which may make them more inclined to offer patients colonoscopy as a first line screening test, as they regularly identify many average risk patients with multiple polyps at the time of colonoscopy and are comfortable discussing potential risks and benefits with patients in the primary care setting.

Health system complexity in colonoscopy capacity impacts patient interactions in screening access by limiting opportunities for patients to undergo timely colonoscopy screening. It is influenced by information behaviours in scheduling between clinic and colonoscopy appointments, as well as waitlist management of new referrals combined with repeat screening and surveillance colonoscopy. Colonoscopy capacity has upstream impacts on FIT screening initiation, as patients who are determined to be appropriate candidates for FIT screening are referred back to their primary care provider. The complexity of colonoscopy capacity is also influenced by contextual factors of having care providers with multiple roles, as the availability of these providers must be balanced across multiple health system areas outside of endoscopy. Managing the health system complexity involved in colonoscopy capacity and utilization is a necessary consideration in improving colorectal cancer screening access.
4.4.4 - Patient Interactions - Frequent colonoscopy no-shows

Colonoscopy appointments with last minute cancellations or no-shows have significant impacts on colonoscopy scheduling and capacity, as filling appointments at the last minute is often not possible due to travel and colonoscopy preparation requirements.

“The biggest reason in my mind why we’re not totally caught up is no-shows, it’s by far [...] the biggest barrier to access”

“If they get cancelled the day before, we may have a hard time filling that endoscopy spot”

There are many contextual factors impacting colonoscopy no-shows, including weather, miscommunication, substance abuse, and residential school experiences.

“If you’re booking a colonoscopy in hunting season [...] the guy is not going to come in for a scope because there’s only a little bit of time [for hunting]”

“Often there’s good reasons, you know, the plane didn’t fly out of the community”

“A lot of people have gone through the residential schools and so that’s one of the reasons why they don’t want to go through the colonoscopy”

Because of the multitude of contextual factors impacting colonoscopy no-shows, there are often multiple attempts to rebook patients, with an informal three strikes rule at all sites. If patients requiring colonoscopy cannot be rebooked they will not complete the process of colorectal cancer screening and will be lost to follow up. Patient no shows may put additional strain on managing scheduling, as they contribute to increasing the endoscopy wait list, which must be balanced with scheduling new referrals and surveillance recall.

Figure 12 depicts the patient interactions in which patient no shows for appointments impact screening access. At these points, efforts by scheduling providers within endoscopy units
and specialist clinics, as well as medical travel are required to try and find the patient to avoid rebooking.

Figure 12. Exploratory process model depicting potential for patient no shows within coupled travel distance model of colonoscopy screening access (Fort Smith HSSA)

Colonoscopy no-shows impact health system complexity through the requirement for additional information behaviour interrelationships among scheduling provider activities and decisions in efforts to track down patients, as well as rebook patients for colonoscopy at a later date. These actions have upstream impacts on colonoscopy capacity, in terms of the ability to book patients from the endoscopy waitlist. They also have downstream impacts on completion of colonoscopy screening and management of screening recall, as patients who cannot be rebooked are unable to complete the screening process and effectively access colorectal cancer
screening. These patients return to the unscreened population and must have screening re-initiated at a later date.

Limiting colonoscopy no-shows would improve screening complexity by minimizing the additional information behaviours required for rescheduling and rebooking. However, the contextual factors impacting no-shows including weather and residential school experiences may not be easily modified and likely cannot be eliminated. Complexity of information behaviours in managing colonoscopy no-shows may be a reality of colorectal cancer screening in the rural and remote health care environment of the NWT. Managing and mitigating no-shows to facilitate patient interaction in screening access while managing complex information behaviours involved in rebooking may support improved screening access.

4.4.5 - Patient Interactions - Unsupported FIT screening recall

Within the territory there are currently no formal processes to support patient recall for ongoing FIT screening. Recall is dependent on patients remembering to present for repeat screening or providers remembering to review screening during the primary care encounter. As a result, FIT screening must often be re-initiated every time repeat screening is required.

“For the FIT testing I think it’s a gap in the system”

“We don’t have any kind of recall system for FIT testing [...] which is something I think we need to work on”

“For FIT there’s generally nothing written [...] We just assume that magically every two years someone will tell patients that it should be done”

Some primary care providers will use the reminder function of Wolf EMR to generate reminder tasks for follow up, and some smaller communities keep patient screening lists using binders or
Excel spreadsheets. However, these practices are provider-dependent and vary across communities. Providers who use the EMR reminder tasks regularly or communities with recall systems may be more successful in facilitating ongoing screening compared to communities and providers who do not use these informatics tools.

“I understand that the health centres [in smaller communities] do have a recall system [...] to make sure that for those who are doing FIT testing they’re getting it every one to two years”

“I have used Excel lists for recall lists for a long time”

“If they have a negative FIT there should be something entered into the EMR [...] that prevents gaps being missed a lot”

Figure 12 shows the health system information behaviour for patient-dependent recall, which relies on patients to present to primary care for repeat FIT screening, compared to information-dependent FIT recall where information processes such as EMR recall are in place to facilitate FIT recall. Information-dependent FIT recall practices are reported by providers to be more effective compared to patient-dependent FIT recall.
Health system complexity of FIT screening recall is increased in information-dependent FIT recall processes, with addition of a FIT recall list and the information behaviours required to manage the recall list. However, this also facilitates ongoing information behaviour loops to enable continuous colorectal cancer screening access and future patient interactions for screening access. Without these additional information behaviours there is a high likelihood of patients being lost to follow up or experiencing inconsistent screening recall, as screening must then be re-initiated at the time of future primary care encounters. In this case, increasing the health system complexity may support care access improvements.
4.4.6 - Information Processes - Unclear or incomplete colonoscopy referrals

Colonoscopy referrals provide a major communication link between primary care providers and endoscopy providers and also form the link between primary care and hospital-based screening processes (Figure 14).

“For family docs and gen surg it would be our referral letter [...] that’s how the information gets to them”

“You know that primary care provider often has that whole picture of the patient, not just a referral with a few lines on it”

Figure 14. Colonoscopy referral as information link between primary care and hospital-based care across all exploratory process models

Colonoscopy referrals are generated for patients who have a positive FIT, are considered to be at increased risk for colorectal cancer, or by patient request. Referral contents inform booking prioritization and planning decisions by endoscopists, and incomplete or unclear
referrals negatively impact colonoscopy screening processes. However, it is unclear to some primary care providers exactly what information is required by endoscopists.

“It’s not always clear if this is something we’re seeing them in terms of symptoms or if they are truly asymptomatic people who just had a real, true screening test done [...] the other part is not providing enough background information about co-morbidities and medication because obviously those can impact how you proceed”

“Do they want a hemoglobin with someone who’s bleeding? Well then what will help me get my patient seen faster?”

Specific endoscopy referral forms currently in use in the Beaufort Delta Health and Social Service Authority have helped support clear, complete referral communication between primary care providers and endoscopists.

“The endoscopy referral is very specific, so I can see where that’s the information they need”

Health system complexity is impacted by unclear colonoscopy referrals by the addition of information behaviour loops for clarification of referral contents if required. Unclear referrals also have downstream system impacts on colonoscopy booking and scheduling decisions, as patients may be inappropriately prioritized for screening or diagnostic colonoscopy if the indication for colonoscopy is unclear. Unclear or incomplete referrals may also impact colonoscopy capacity and no-shows, as patients may be scheduled for unnecessary colonoscopy, or their colonoscopy may need to be rescheduled due to the need to cancel or adjust appointments to accommodate medications and medical co-morbidities.

The use of endoscopy referral forms would not greatly impact current screening access complexity, as they would simply replace the existing specialist referral forms. However, the need for clear, accurate referral information to inform colonoscopy initiation and booking
prioritization decisions was identified as critical by endoscopists. With information processes being foundational to patient interactions, improvements in the clarity, accuracy, and completeness of referral form contents are necessary to enable information behaviours between primary care and hospital care processes. Clarity of initial referrals may minimize additional information behaviours generated when clarification of referral contents are required, or when patient care must be adjusted to account for medical co-morbidities that were not clearly outlined in the referral.

4.4.7 - Information Processes - Highly complex colonoscopy scheduling

Colonoscopy scheduling was identified as a highly complex process requiring integration of new referrals, as well as recall screening and surveillance colonoscopy wait lists, and rescheduling missed appointments. Within this process scheduling providers have a crucial role in integrating information behaviours, as shown in Figure 15.

![Figure 15. Exploratory process model demonstrating complexity of scheduling processes and integrative role of scheduling provider](image-url)
In addition to integrating information, scheduling providers have important roles in effectively managing clinic appointment and colonoscopy capacity. Colonoscopy appointment availability needs to be balanced with pre-colonoscopy consultation appointment availability, as well as and medical travel arrangements for patients outside of Hay River, Yellowknife and Inuvik.

“Remembering that patients have lives too, and just because the physician said I want this person booked [...] doesn’t mean the patient’s willing to come at that point in time”

“The medical travel makes a bit more complicated booking because then the booking clerk has to look at where they’re coming from, when does their plane get into town, when should they start their prep”

Scheduling providers also have the challenge of managing recall and surveillance patients while balancing colonoscopy capacity. While these decisions are informed by prioritization decisions by endoscopists, scheduling is ultimately managed by scheduling providers.

“The problem is left up to my discretion a lot of the times. So it’s a big burden to figure out who am I going to scope and who am I not going to scope because if everybody’s listed for one to three months then you have your follow-ups off to the side [...] I just try to do the best that I can”

In Yellowknife, scheduling decisions are more complex because of the multiple provider groups and multiple scheduling providers involved in the Medical Daycare Unit (MDCU) and General Surgery and GI clinics. While in Hay River and Inuvik scheduling processes are integrated by a single scheduling provider, these providers have multiple roles within the hospital, which must be balanced with their scheduling role.

The complexity of scheduling highlights the crucial role of scheduling providers as process integrators within the health system.
“It’s a challenging position to start with [...] it’s an art, it’s not an exact science”

Skilled scheduling providers are necessary to manage the complex information behaviours involved in clinic scheduling, colonoscopy timing and patient travel arrangements. This ability to integrate information for scheduling has significant upstream and downstream impacts on screening access in supporting timely colonoscopy screening access and effective utilization of endoscopy resources.

4.4.8 - Information Processes - Inconsistent colonoscopy recall reconciliation

Colonoscopy recall reconciliation occurs when polyps are removed or biopsies are taken at the time of colonoscopy, as pathology results impact when repeat surveillance or screening colonoscopy is required. Accurate colonoscopy recall requires reconciliation of colonoscopy results and pathology results, with a final recall decision by the endoscopist that integrates information from both.

“With permanent specialists and having the ability to wait until the pathology comes back, you can get more accurate recalls”

When this reconciliation process does not occur, patients may be placed on the waitlist with a shorter or longer recall interval than is appropriate, or may be recalled unnecessarily. Inconsistent recall reconciliation is influenced by locum-based practice and a lack of formal reconciliation processes.

“Just wanting to decide the follow up just then and there, I think you mostly see that among locums. And I think it’s because they feel an urge to not pass something over to the next guy [...] which I really don’t think is appropriate for this”

“we don’t have someone consistent [...] I think that makes it difficult to set standards for things”
In comparison to Yellowknife and Hay River, endoscopists in the Beaufort Delta Health and Social Services Authority use a colonoscopy reporting form to support accurate recall reconciliation.

Figure 16 compares recall reconciliation processes with and without the use of a colonoscopy reporting form to support reconciliation. In Inuvik, where the colonoscopy reporting form is in use, colonoscopy and pathology results are reconciled by the endoscopist and a final recall decision is communicated to endoscopy scheduling providers at the time of reconciliation. In comparison, in Yellowknife and Hay River there is no formal process to support reconciliation and these processes are provider dependent.

“Physicians will do that [reconciliation] on their own, and we appreciate that greatly, but there is no formal process for that [...] it’s work that should be done [...] not just specifically to colorectal cancer screening”

“There’s probably some parts of our system that still do need to be improved and mostly it seems around the follow-up of the biopsies [...] maybe that’s something we have to sort of think of how to do better”

Within current practices in Yellowknife and Hay River, there is the risk of missed reconciliation or miscommunication between endoscopists and scheduling providers. In addition, when contradictory information is provided to scheduling providers or if information is missing it becomes the responsibility of the scheduling provider to follow up on reconciliation to ensure patient recall is appropriately documented and managed. While primary care providers and endoscopists identified that reconciliation decisions should be the responsibility of the endoscopist, this may not be the case within unlinked decision process and the onus for accurate recall reconciliation may be placed on the scheduling provider.
Consistent recall reconciliation significantly impacts health system complexity, as it has information behaviour impacts on colonoscopy recall and the complexity of scheduling. Patients who are inappropriately recalled or are placed on the waitlist unnecessarily must be integrated into colonoscopy scheduling along with new referrals for screening colonoscopy and balanced with diagnostic endoscopy demands. Duplicated or missing recall information also requires additional information seeking by scheduling providers to facilitate ongoing screening access. Processes and tools to support effective recall reconciliation, such as reporting forms, may help
decrease health system complexity and improve colorectal cancer screening access through appropriate colonoscopy recall intervals or timely return to FIT screening.

4.4.9 - Information Processes - Multiple disconnected patient charts

Patient health information throughout the territory is often siloed, increasing the risk of missed or duplicate information, and requiring providers to access multiple information sources to access the information required to support decision making.

“Let’s say I get a referral for somebody for surveillance colonoscopy; I go in Medi-Patient find their last visit [...] so that I can pull up their colonoscopy note [...] I’ll pull up on HealthNet Viewer and see if I can find a pathology [...] it may or may not be there [...] if I can’t find what I need in the computer systems I ask for their paper chart because it’s in their paper chart”

“I get triples of pathologies [...] so I end up having to keep records of which ones I have already received [...] I am looking forward to electronic records so we will not have all these multiple copies”

“There’s a potential for people to be scoped more frequently than necessary, which increases their risk of complications because papers are not always going to the place they’re supposed to go”

Primary care charts may be paper or, in the case of Yellowknife, Fort Smith, Hay River, and Fort Resolution, part of the integrated territorial Wolf EMR system. GI and General Surgery endoscopist clinics in Yellowknife and Hay River, and FP-ESS endoscopy in Inuvik are all paper-based, necessitating faxed communications between primary care and endoscopy providers. HealthNet viewer provides computer-based access to lab results and some dictation documents across the territory. MediPatient at Stanton Territorial Hospital and Inuvik Regional Hospital are used for endoscopy scheduling and waitlist management, but are not integrated with each other or other computer information systems. Wolf EMR is used for endoscopy scheduling and waitlist management in Hay River and is integrated with the primary care chart.
Figure 17 shows the integration of information systems across the territory, with Hay River having the most integration within their Wolf EMR system and the small communities in the Beaufort Delta having the least integration with a paper-based system. The system complexity increases with decreasing levels of information system integration, as information behaviour interrelationships must increase to support access to information across primary care and hospital care processes.

The community of Hay River within the Hay River HSSA exhibits the least complex information behaviour in colorectal cancer screening access, as it has an integrated primary care chart on Wolf EMR that is also used to manage endoscopy scheduling. As a result, complexity
of information storage and retrieval is less complex than in the more siloed systems of the small communities within the Hay River HSSA, the Fort Smith HSSA, and the Beaufort Delta HSSA. However, Hay River does not have a fully integrated information system, due to the separation of dictation systems used by Yellowknife-based endoscopists, requiring paper dictations generated after endoscopy to be scanned into the Wolf EMR for primary care providers to access the information. Because these colonoscopy dictations are generated for Hay River patient encounters and are not tied to a Stanton hospital encounter they are not stored on the Stanton Medi-Patient system, and there is potential for information to be lost if the paper dictation is misfiled or lost between Yellowknife and Hay River.

Accessibility of patient information is particularly important in an emergency setting, such as a colonoscopy complication.

“A lot of times someone comes to Emerg [...] it’s pretty relevant to know someone had a colonoscopy about a month ago, that doesn’t come up”

Due to the siloed nature of information systems, information that is available in one location may not be available in another location, as seen in Figure 18.
In an emergency setting where transfer of care between health care facilities occurs, information behaviour becomes dependent on transfer documentation and the ability of patients to accurately recall and communicate their medical history. In addition, depending on the timing of endoscopy and patient presentation to the Emergency Department, colonoscopy reports may not be available, as they may not be transcribed or available in the community at the time of presentation. Increasing complexity of information retrieval in an Emergency setting may result in information being lost or not accessed at a crucial juncture in patient care.

The siloed information systems currently in place across much of the Northwest Territories impact the complexity of information retrieval, particularly in the emergency setting, where timely access to information is crucial to inform care interventions and support positive patient outcomes. Integration of health information systems across the territory would decrease
the complexity of information behaviour interrelationships within colorectal cancer screening access. This decreased information behaviour complexity would support timely access to information among health care providers across all aspects of screening, including emergency care.

4.4.10 - Information Processes - Inconsistent colonoscopy follow-up communication

Communication of colonoscopy follow up information by endoscopists to patients and primary care providers is variable among providers, particularly for pathology results.

“Sometimes we get a pathology report. Sometimes we get a consult note that describes everything and the follow-up plan. Sometimes we get nothing.”

Without communication of a clear follow up plan by the endoscopist, primary care providers and patients may not understand the follow up screening plan. Primary care providers may be asked to provide follow up information to patients following colonoscopy and may feel ill-prepared or unable to appropriately communicate this information to patients due to lack of a clearly communicated follow up plan or lack of expertise.

“Just sending the GP the pathology isn’t really closing it because they just may file it and not really know what to do with that […] I think the solution is not to just provide the GP’s necessarily with the pathology report, but is to provide them with a direction with that.”

The issue of unclear follow up plans is linked to lack of formal recall reconciliation processes and is identified as more of an issue with locum-based endoscopy providers compared to permanent providers who have developed practices to try and fill the communication gap.

“Recently [Endoscopists] are better at making sure the primary care provider has that recall information, but in the years prior, it didn’t always happen. So they’re trying to plug that little hole.”
Efforts by General Surgery endoscopists to dictate a follow-up letter after pathology results are available, and by FP-ESS endoscopists to provide follow up information on annotated pathology reports have improved communication gaps, but they are still present.

Where the colonoscopy referral form is the only information process link from primary care to hospital-based care, colonoscopy follow-up communication forms a crucial information process link from hospital-based care back to primary care to support ongoing screening and surveillance in screening access. While primary care providers may get pieces of the follow up plan from the colonoscopy report and pathology report when they receive them, they do not have a clear sense of ongoing screening and surveillance planning without a final follow up plan.

“They will be appropriately vague about it saying “this person needs a colonoscopy in probably, you know, three to five years”, but then that follow up information never, never happens. No one, sort of summarizes it down the road.”

Both primary care providers and endoscopists identified that the follow up plan should be determined by recall reconciliation and should be the responsibility of the endoscopist. Developing consistent colonoscopy follow-up practices among endoscopists would support improved follow-up communications between hospital care and primary care processes.

Inconsistent colonoscopy follow-up impacts health system complexity through the potential for increased information seeking and communications by primary care providers to endoscopists and scheduling providers in an attempt to clarify the follow up plan. It may also negatively impact screening recall, as patients may be inappropriately recalled or lost to follow up. Clear colonoscopy follow-up plans are required facilitate information behaviour flows
throughout the screening continuum, particularly between hospital care and primary care processes, to support ongoing colorectal cancer screening access.

4.5 – Contextual factors influencing screening access

Several contextual factors within the rural and remote environment of the Northwest Territories impact colorectal cancer screening access. These can be categorized into barriers and enablers, as well as social, geographic and health system factors, summarized in Figure 19.

![Figure 19. Contextual enablers and barriers influencing colorectal cancer screening in the Northwest Territories](image)

4.5.1 – Screening access enablers

4.5.1.1 – Social enablers

Patient education and awareness was identified as an important social enabler of colorectal cancer screening. Providers identified it as being potentially easier in smaller communities where education initiatives and word of mouth helped increase awareness of
colorectal cancer screening. In addition, community members who had experienced colorectal cancer could have significant positive impacts on increasing awareness of screening options through communication with family members.

“I think the fact that we’re a smaller community, I think that just means that there’s more awareness because more people will know somebody who’s had cancer.”

4.5.1.2 – Health system enablers

As a health system enabler, territorial screening guidelines were cited by many primary care providers as a reminder to initiate colorectal cancer screening, as well as provide guidance for risk stratification and use of FIT testing and colonoscopy screening.

“We did create our own colon cancer screening guidelines for the Northwest Territories [...] in the last year and a half, I’ve seen less inappropriate referrals.”

“I have my little laminated colorectal screening guidelines, so I’ll pull it out because I can’t remember all the stuff and I’ll say you’re considered an average risk or you’re considered an increased risk [...] so we really should be looking at doing a colonoscopy for you.”

Longer appointments, particularly among community health nurses and nurse practitioners compared to family physicians, were identified as an enabler to screening, as they allowed more opportunity to address preventative care issues during the primary care encounter.

“Definitely, but you know what, nurse practitioners [...] are double appointments for 40 minutes, so that makes a big difference. When you’re seeing someone you don’t know for 20 minutes, it’s really hard to get everything in there.”

Primary care providers also identified female cancer screening practices for cervical cancer and breast cancer as enabling colorectal cancer screening, as both patients and providers may be more attuned to identify a need for and review other screening practices.

“I feel like women are more likely to do the poop test than the men. We see women more often for screening for things like pap and mammograms.”
In comparison, male patients may have fewer interactions with primary care and be less attuned to request screening as they are not regularly interacting with primary care screening. Multiple provider roles were also identified as a potential health system enabler to screening access, as health care providers with dual roles as endoscopists and primary care providers may be more attuned to offer colorectal cancer screening to patients.

Another important health system enabler within colonoscopy screening, is the practice of rebooking forgiveness, where patients are routinely sought out by scheduling providers for rebooking of missed colonoscopy appointments.

“...So we tend to try and look into why, and if it’s just they didn’t show up because basically they just neglected to do so, typically we’ll try to book them again one or two more times. [...] we’ve got a not absolute but by and large a three strikes you’re out system, because lots of times, often there’s good reasons.”

All endoscopy sites have an informal three strikes rule, whereby after three attempts at rebooking the case will be reviewed by an endoscopist and the patient may be contacted to reassess the indication for colonoscopy. However, patients who are considered at high risk who require ongoing screening or surveillance will often be rebooked more than three times in an attempt to support access.

“we also want to be careful it’s not a patient education or lack of education issue. [...] You don’t want to be missing people with significant pathology because of a prejudice or something else in the system, right?”

Endoscopists identified the importance of discussing reasons for missed appointments with the patient in order to mitigate access barriers.
4.5.2 – Screening access barriers

4.5.2.1 – Social barriers

Within contextual screening barriers, multiple social barriers were identified, including residential school experiences, substance abuse, social determinants of health, and sociocultural factors. Residential school trauma was identified as an important barrier to colorectal cancer screening by multiple participants, as patients with a history of sexual abuse may be triggered by discussions of colorectal cancer screening, particularly colonoscopy. This may influence screening initiation as well as colonoscopy no-shows.

“A lot of people have gone through the residential school and so that’s one of the reasons why they don’t want to go through the colonoscopy and they’ll actually outright tell me that.”

Substance abuse was also identified as a contributor to colonoscopy no-shows. Social determinants of health such as job security, housing security and food security were identified by primary care providers as influencing screening initiation, as patients with difficulties in these areas may be less inclined to prioritize colorectal cancer screening and other preventative health care practices.

“I would say tons of social issues or we know that the Territories have a lot of issues with helping with alcohol with a lot of other stuff and if people’s basic needs aren’t being met, the chances of them going to a doctor to ask about primary prevention and secondary prevention is pretty much slim to none.”

Sociocultural practices such as hunting season, while recognized as positive community activities, were also identified as posing additional contextual challenges with screening, particularly colonoscopy scheduling, when patients are on the land without phone access or do not wish to participate in screening at these times of year.

“If you’re booking a colonoscopy in hunting season [...] the guy is not going to come for the scope because there’s only a little bit of time when he could [hunt].”
4.5.2.2 – Geographic barriers

Widespread geography necessitating patient travel for care represents an important barrier to colorectal cancer screening access, particularly in colonoscopy scheduling and no-shows, as timing of flights in and out of small communities must be taking into consideration in scheduling colonoscopy.

“Air travel is always a bit of a challenge at certain times of the year because of the weather. So if there’s no flight because of the weather, patients just can’t go, so everything has to be reorganized and sometimes you don’t know that until the actual day [...] we do our best, but that is certainly a challenge.”

Patient travel and weather may also impact colonoscopy no-shows, particularly if multiple patients from the same community are unable to attend appointments due to travel issues.

4.5.2.3 – Health system barriers

Within the health system, locum-based practice was identified as a major barrier throughout the processes involved in colorectal cancer screening access. Within screening initiation, locum physicians may be less inclined to offer screening due to short term patient-provider relationships, as well as lack of familiarity with territorial screening guidelines.

“I think we provide good care, but some of that consistency is lost no matter how good your episodic practitioners are.”

Locum primary care providers may also be less familiar with EMR and paper charting systems to identify patients for screening recall. Locum endoscopy providers may also have a lack of familiarity with territorial screening guidelines and screening processes, resulting in inappropriate patient triage that does not take into consideration colonoscopy capacity limitations.
“The locums, even though they see our flow sheets, they still have their heads faced into what goes on in their clinics in the south and I have to reinforce the fact that you guys are dreaming.”

Similarly, locum endoscopy providers may not be familiar with the need for colonoscopy and pathology result reconciliation and may be less effective in communicating follow-up plans to primary care providers.

“For the locum specialists, I find that people are trying to tidy up their paperwork and they don’t want to necessarily leave a lot of paperwork for other colleagues. As such, they often fill out the recall sheets with their endoscopy findings, which may not correlate with the pathology findings. [...] With permanent specialists and having the ability to wait until the pathology comes back, you can get more accurate recalls based on a final pathology finding.”

Within the Northwest Territories health system, health care providers may also have multiple roles. This may present health system barriers to screening by impacting areas such as colonoscopy capacity and scheduling, as providers must also provide services in areas outside of colorectal cancer screening.

Patient acuity also presents a health system barrier to screening initiation, as primary care providers identified that acute patient care issues take priority over screening.

“It very much seems to be on an adhoc basis where if you have time during the appointment [...] we’re constantly putting out fires rather than just taking away the matches.”

While preventative care may have more long-term benefits for patients, it may be difficult for primary care providers to prioritize them when patients present with pressing acute care issues.
4.5.3 – Contextual complexity in screening access

While many of the enablers impacting screening access are modifiable, many of the barriers are not. Modification of enablers to improve screening access with mitigation of less modifiable screening access barriers such as residential school experiences, substance abuse and social determinants of health must be considered in developing and implementing solutions to screening access problems. While long term efforts to improve the challenges presented by social and health system barriers such as residential school experiences, substance abuse, and locum-based practices are necessary, improving colorectal cancer screening access in the immediate future requires adjustments to screening access that accounts for these challenges and manages the complexity associated with them.

4.6 – Screening access solutions

Participants identified a number of potential screening access solutions to health system problems in the areas of screening initiation, incomplete colonoscopy referrals, inconsistent recall reconciliation, and multiple patient charts. Within screening initiation, primary care providers identified development of an organized territorial screening program that includes direct outreach to patients and coordinated recall as a potentially high impact solution to limited screening initiation, particularly in a heavily locum-based primary care environment.

“It would be really nice if it was an organized program, especially for locum-based communities [...] the more of that stuff gets taken out of relying on Family Physicians remembering to do it, the more likely it is to actually happen when it’s supposed to”

In the areas of incomplete colonoscopy referrals and inconsistent recall reconciliation, the use of endoscopy referral forms and colonoscopy reporting forms to support recall reconciliation within the Beaufort Delta positively impacted the process problems in these areas identified in other
health authorities. Within the problem of multiple patient charts providers within Hay River noted the benefits of an integrated EMR in identifying and tracking screening information and facilitating patient recall.

“I do see it beneficial in that way so that everybody will be able to view kind of the same thing instead of everybody having different pieces of paper on their desk about different things”

“The Wolf system has given me the most satisfaction that people aren’t being missed as much as they were before […] people were always being missed and a piece of paper can fall out of a binder, so this is a lot better.”

Providers outside of Hay River also identified the potential benefits of integrated territorial information systems and were supportive of efforts for integration of information systems.

Several potential system impacts of proposed screening access solutions were also identified by providers. There was concern that implementation of an organized screening program without consideration of impacts on colonoscopy capacity would be detrimental to screening access and result in increased strain on colonoscopy capacity, where access problems are currently an issue in Yellowknife and Hay River.

“I think if we had everyone doing the immunochemical testing we end up with more positives and need to scope all those people. We’re far from having the capacity to do that many colonoscopies at this point, both in terms of space and labour”

“I think we have an obligation to the people of the Northwest Territories […] we need to make sure that we have the ability to meet those demands”

Potential workflow impacts of formalized recall reconciliation processes were also identified as a concern.

“[…]it becomes a really big enterprise. It’s all of a sudden from a small thing to a big thing, and so that seems unlikely that it’s going to happen on a consistent basis, let’s just put it that way.”
While participants were interested in engaging in problem solving and expressed a desire for colorectal cancer screening access solutions to be developed, they were also aware of potential system impacts of proposed solutions within the resource and contextual limitations of rural and remote practice in the Northwest Territories.

4.7 – System Dynamics (SD) design framework

Development of an SD model first requires an understanding of the system components and interrelationships within the system being modeled. In the case of this study, the system components and interrelationships were initially conceptualized and constructed through the development of the exploratory process models previously described. In its most simplified form, the patient stocks and flows in colorectal cancer screening can be modelled in the transition from screened to unscreened patients (Figure 20).

![Figure 20. Simplified patient stocks and flows within colorectal cancer screening.](image)

Based on results from the system conceptualization and process model construction, it is clear that the flows between unscreened and screened patient stocks is far more complex and...
involves multiple patient interactions and information processes to enable. In addition, there are multiple areas within the system where patients may be lost to follow up or attrition and not complete the entire screening continuum. A more complex SD design framework was required to adequately represent the complexity of colorectal cancer screening in the Northwest Territories.

In developing a more complex SD design framework that adequately captures the complexity of colorectal cancer screening access within the Northwest Territories, exploratory process model constructions were reviewed to identify the patient interactions within the system for translation into patient stocks, and information behaviour flows between them were identified for translation into patient flows (Figure 21a). These patient interactions and information behaviour flows were then translated into stocks as numbers of patients and flows as rates of patients completing each patient interaction required for continuation of screening, or rates of patients returning to the unscreened population by being lost to follow up or through attrition (Figure 21b).
Figure 21. Translation of exploratory process models to SD design framework
(a) Identification of patient stocks and flows within exploratory process models (b) System components and interrelationships shown in figure 21a represented in SD design framework
Stocks and flows across all exploratory process models were reviewed and common components and interrelationships from all FIT screening and colorectal cancer screening process models were incorporated into a final SD design framework representative of all colorectal cancer screening access models across the Northwest Territories (Figure 22). Flows that would be impacted by potential health system transformation initiatives of an organized screening program, clinic capacity modifications, and colonoscopy capacity modifications were also identified. This model could be used to compare quantitative outcomes in screening rates between different existing screening models, as well as the impacts of health system transformation initiatives. Further quantitative validation and evaluation of the design framework would be required prior to utilization in formal simulation modeling.
Figure 22. System dynamics design framework for modeling colorectal cancer screening access within the Northwest Territories
Development of the SD design framework focused on the patient interaction aspects of colorectal cancer screening access, requiring simplification of the complex information behaviours and information processes supporting patient interactions for representation of patient flows. In quantifying these relationships for formal simulation modelling, quantitative validation of the model would require review of patient charts and other information systems to obtain the information required. Rather than counting individual patients, the charts and information created through information processes and stored in information systems is used as a proxy for patients and patient interactions. In this way, the quantitative translation of simulation modelling depends on effective information processes. While this complexity is not explicitly represented in the SD design framework, understanding the health system relationships between patient interactions and information processes through health system conceptualization and process model construction can help identify quantitative data sources for simulation modelling. A combination of qualitative modeling through application of the exploratory process models, and associated quantitative modeling through the use of SD modeling is necessary to fully understand and appreciate the complexity of colorectal cancer screening access and areas where it may be improved.
5. Discussion

5.1 – Discussion overview

The discussion provides an overview of study findings in relation to the research objectives and discussion of findings in the context of established literature.

5.1.1 – Research objectives

This study aims to understand how current health care processes and system-level factors within the NWT health care system influence patient access to colorectal cancer screening. To achieve this, the following research objectives will be pursued:

1. Conceptualization of colorectal cancer screening access to identify and describe the health system components, interrelationships and contextual factors involved.

2. Construction of exploratory process models depicting the health care processes involved in colorectal cancer screening access in the NWT.

3. Translation of exploratory process models into a system dynamics design framework

5.2 – Conceptualization of colorectal cancer screening access

Colorectal cancer screening access in the Northwest Territories is complex with many health system components, interrelationships and contextual factors that impact screening. Screening access involves both patient interactions and information processes. Patient interactions occur between patients and health care providers, while information processes comprise both provider-provider interactions, often mediated through documents, as well as interactions between providers and information systems to retrieve and store patient care information. Screening access is also comprised of primary care processes involved in FIT
screening, as well as hospital care processes involved in colonoscopy screening. The continuum of screening access across primary care and hospital care processes is linked through information process components of referral forms, recall lists, and follow-up documentation.

Multiple configurations of colorectal cancer screening access are in place across the territory through variable combinations of primary care and hospital care access models. These configurations range in complexity, with patients from smaller communities generally experiencing less complex FIT screening access in primary care, with more complex colonoscopy screening access in hospital care. This relationship is inverted for patients in larger communities, where FIT access may be more complex and colonoscopy screening access is often less complex. Identifying opportunities to optimize the complexity of screening access is necessary to support equitable colorectal cancer screening access among patients across the Northwest Territories.

There are several unique contextual factors, both barriers and enablers, influencing screening in the rural and remote environment of the Northwest Territories. Barriers include locum-based practices, widely distributed geography requiring patient travel, and residential school experiences. Enablers include patient education and awareness initiatives, particularly in small communities, as well as health system enablers such as rebooking forgiveness and longer appointments. Some contextual factors impact specific areas of screening, such as the influence of rebooking forgiveness on colonoscopy scheduling, while some, such as locum-based practices, have a broader impact along the entire screening continuum. Social contextual factors influencing colorectal cancer screening such as residential school experiences, social
determinants of health, substance abuse and sociocultural practices were identified most frequently in relation to entrance into the health system at the point of screening initiation, and continuation through the system at the point of colonoscopy with regards to no-shows. Understanding patient engagement with the health system at these points of care is necessary to improve care access. The impact of screening knowledge, income and employment status, cultural beliefs, competing priorities, and language on patient attitudes and beliefs have been identified in the literature and studies specific to patient engagement in screening are currently underway in the territory (Kolahdooz, et. al., 2014; Sharma, 2015).

5.2.1 – Health system complexity

The complexity of colorectal cancer screening access within the Northwest Territories is to be expected, as health care is a complex adaptive system with many interconnections, mechanisms for intentional and random variation, and an ultimate fitness for purpose (Coeira, 2015). Fitness for purpose is how well the system is designed and able to achieve its desired outcomes (Coeira, 2015). In the case of colorectal cancer screening, these outcomes are decreased population incidence and mortality due to colorectal cancer through early detection and treatment. However, health care organizations often struggle with optimizing their fitness for purpose, as there is a lack of system-level understanding of health care processes and their interrelationships and how they contribute to achieving desired health outcomes (Coeira, 2015).

The complexity of the health care system is a major determinant of fitness for purpose. As a health system becomes increasingly complex the ability to optimize performance decreases, as system components are required to fulfill multiple roles instead of focusing on a single aspect
of care (Coeira, 2015). This is particularly true within the Northwest Territories, where health care providers are often required to manage a broader scope of practice and work in multiple care areas compared to their southern Canadian counterparts.

Process bundling provides an approach to managing complexity and working to optimize fitness for purpose within a complex environment by aligning health system processes towards a desired health outcome (Coeira, 2015). This can be seen within colorectal cancer screening access in the Northwest Territories in provider-based FIT screening and coupled models of colonoscopy screening where health care processes involved in screening are bundled and the resulting process complexity is decreased. Identifying opportunities for bundling of health care processes in other aspects of colorectal cancer screening, such as recall reconciliation and integration of computer information systems, may also improve access by decreasing system complexity to optimize fitness for purpose. As care processes are modified, elimination of redundant or ineffective processes in addition to the adoption of new processes must be considered in order to manage and contain the complexity of health system interrelationships to support health system optimization (Coeira, 2015).

Geographic complexity is also a reality of colorectal cancer screening in the Northwest Territories contributing to increased health system complexity (Coeira, 2015). Fitness for purpose cannot be optimized in a centralized or decentralized health care system. Instead, a balance between centralization and decentralization with intermediate coordination of services may support optimization (Coeira, 2015). Improving colorectal cancer screening access requires an understanding of access patterns across different models of colorectal cancer screening,
considering models of FIT and colonoscopy service delivery. Utilization of telehealth services to balance community outreach with centralization of specialist services has been shown to improve screening uptake in rural and remote communities and may represent an optimal level of system complexity for supporting screening access (Kinney, et. al., 2014). Further quantitative evaluation of these models may support health system transformation towards intermediate service coordination through full outreach, partial outreach, and distance models to optimize screening access.

5.3 – Construction of colorectal cancer screening access models

Colorectal cancer screening access within the Northwest Territories is complex, requiring links across primary care and hospital care processes. Throughout the continuum of screening access, information behaviour forms the foundational interrelationships between system components. Understanding upstream and downstream information behaviours within the health system, as well as the complexity of information behaviour within colorectal cancer screening access can help identify areas for health system improvements where information behaviours can be integrated and simplified. Integration of information systems through the use of health informatics tools such as EMR, as well as supporting information flow between primary and hospital care through standardized endoscopy referral forms and reporting forms to support recall reconciliation may support improved colorectal cancer screening access by facilitating necessary information behaviour flows and optimizing the complexity of information processes.

Many of the access problems identified within this study are interconnected through information behaviours throughout the health system and have upstream and downstream
impacts on colorectal cancer screening access. As a result of these health system interrelationships, transformation initiatives intended to resolve one screening access problem will likely impact both upstream and downstream aspects of colorectal cancer screening. For example, increasing screening initiation through adoption of a formal territorial FIT screening outreach program would require consideration of downstream colonoscopy capacity to meet the needs of increased numbers of FIT positive patients requiring follow-up colonoscopy screening. Understanding these health system interrelationships may help preserve positive information behaviour interrelationships, as well as understand potential trade-offs in health system impacts between proposed transformation initiatives.

Using a combined CIB and continuity of care framework to develop exploratory process models can provide an opportunity to conceptualize continuity of care concepts foundational to screening access and the multidisciplinary information behaviour processes that comprise them over time. This modeling framework provides an opportunity to understand not only patient flows through the health system through relational continuity, but the information behaviour interrelationships required to facilitate the management and informational continuity aspects of care access. The resulting exploratory process models also demonstrate the interrelationships between relational, management and informational continuity aspects of screening access required in multidisciplinary care processes over time. By providing a visual representation of complex health system processes, the exploratory process models generated through the application of a combined CIB and continuity of care modeling framework may also promote understanding of the complexity of colorectal cancer screening access among health system stakeholders including physicians and policy-makers.
5.3.1 – Information management

The field of health informatics recognizes information as a crucial foundation for clinical care (Shortliffe, 2010). As a result, effective information management is necessary to support timely, safe and appropriate patient care (CMA, 2010b; Porter, 2013). The use of integrated health informatics tools may provide a foundation that enables health systems to support and measure improved patient outcomes within a complex health care system (Porter, 2013).

This study identified the foundational role of information processes and information behaviour within colorectal cancer screening access, in addition to identifying multiple areas for health system improvements in these areas. Navigating the communication space between health care providers becomes increasingly complex within the Northwest Territories when it comes to colorectal cancer screening, as providers are often in different places at different times, necessitating asynchronous communication which is difficult to manage (Coeira, 2015). The high proportion of locum providers and associated high turnover rate adds an additional level of complexity. Within the health system context of short-term health care relationships between patients and locum providers, achieving informational continuity through effective information management becomes increasingly important in supporting colorectal cancer screening access.

Colorectal cancer screening requires multidisciplinary, preventative long-term processes that occur over space and time and are cyclical over a patient’s eligible life span. These processes are difficult to manage in the geographically widespread, locum-based environment of the Northwest Territories and require clear, complete information flow across the system, as well
as processes to support ongoing screening and surveillance among eligible patients. Informatics tools such as endoscopy referral forms, reporting forms to support recall reconciliation, and enterprise IT solutions to facilitate integration of patient information throughout the screening continuum may support improved screening access by facilitating flow of health information across the system that is clear, consistent and complete. The adoption of clinical analytics tools such as registries and computer decision supports embedded within EMR systems may also act as tools to facilitate screening initiation and recall in a locum-based environment (Sewitch, et.al., 2012).

5.3.2 – Health system trade-offs

Understanding health system interrelationships may help policy makers and health system managers appreciate the complex impacts of health care transformation initiatives (Kuziemsky, 2016). These impacts may be categorized as unintended consequences, or unanticipated and undesirable results, happy surprises, which are unanticipated but desirable results, or anticipated undesirable consequences which may be identified and managed prior to and during implementation (Harrison, Koppel & Bar-Lev, 2007). Because health system interrelationships do not occur in isolation, implementation of new initiatives or processes inevitably require trade-offs with another interrelated part of the system (Kuziemsky, 2015). Identifying these trade-offs in advance may assist with prioritization and implementation planning of health transformation initiatives (Kuziemsky, 2015; Harrison, Koppel & Bar-Lev, 2007).
Health care processes involved in colorectal cancer screening access within the Northwest Territories already demonstrate examples of system trade-offs. Between FIT screening and colonoscopy screening, smaller communities often experience less complex FIT access but more complex colonoscopy access, with the inverse generally being true for patients in larger communities. In addition, complexity across colonoscopy access models varies. However, increasingly complex access models such as partial service outreach models may provide increased opportunities for patients to access care close to home. When it comes to the goal of increasing colorectal cancer screening rates, trade-offs between process complexity and screening rates may need to be considered, in addition to other considerations such as cost between full outreach, partial outreach and distance models which may also impact decision-making.

Modelling provides an opportunity to understand health system interrelationships to identify potential system trade-offs prior to implementation of health system transformation initiatives, creating a control loop cycle of modelling, measuring and managing change impacts (Kuziemsky, 2016; Coeira, 2015). System trade-offs, particularly in health information technology (HIT) adoption, may include trade-offs in integration, workflow, individual-group, ergonomic, technology adoption, processes and policy (Kuziemsky, 2015). Potential downstream impacts of health system initiatives in colorectal cancer screening, particularly potential impacts of an organized territorial screening program on colonoscopy capacity, was identified as a concern by a number of participants. Identifying and mitigating these potential impacts within health system transformation planning is required to optimize screening access improvements across the colorectal cancer screening continuum.
5.3.3 – Health system modeling

While modeling can be an important tool in developing health system transformation initiatives, established modelling approaches are limited in their ability to fully characterize health system complexity (Coeira, 2015; Rad, Benyoucef & Kuziemsky, 2009). Established modeling approaches are often limited to representations of flow of data or flow of people, and are often focused on a specific group of health care actors, such as providers in a single hospital department, limiting the comprehensiveness and complexity that can be modeled using these approaches (Rad, Benyoucef & Kuziemsky, 2009; Jun, 2009). Modeling provides important opportunities to enhance understanding among stakeholders of local health system processes with the goal of quality improvement, but must also be sufficiently detailed to provide a representative picture of the processes in question (Jun, 2009; Rad, Benyoucef & Kuziemsky, 2009). The use of either multiple existing modeling approaches to describe health system processes, or the development of new health system models which integrate people, location, information flows, and their interrelationships are required to fully describe, model and understand health system complexity (Jun, 2009; Kuziemsky, 2016).

Within the context of this study, qualitative health system modelling using a combined CIB/continuity of care framework was able identify and describe the complex health system interrelationships in screening access across the continuum of care, including issues such as FIT screening initiation, colonoscopy scheduling, colonoscopy capacity, colonoscopy no-shows and follow up documentation in facilitating screening access. Translation of these process models into an SD design framework for quantitative modeling may support quantitative measurement
of the potential impacts of proposed health system transformation initiatives. Combining qualitative and quantitative modelling to identify, describe and prioritize system transformation initiatives and their potential trade-offs may support effective implementation of initiatives to improve colorectal cancer screening access across the Northwest Territories.

5.4 – Translation to system dynamics (SD) design framework

Applying a combined CIB and continuity of care qualitative modeling framework, patient interactions and information processes can be respectively translated into patient stocks and flows to develop an SD design framework for quantitative simulation modeling. However, through translation the level of information process complexity is simplified, and representation of the information process complexity within colorectal cancer screening access is lost. Access to both qualitative and quantitative models is necessary to fully appreciate the complexity of screening access and potential impacts of proposed solutions.

Despite its limitations in fully representing the health system complexity involved in screening access, the proposed SD design framework provides more insight into colorectal cancer screening access than a simplified model representing patient transition from screened to unscreened, and identifies areas where patients may be lost to follow-up or attrition throughout the screening process. As a design framework that is representative of screening processes across the territory, the proposed SD framework also provides an opportunity for comparison of screening access across the multiple screening models currently in place. Quantitative measurement of screening access using simulation modeling may provide information for health
system decision makers to optimize screening access through the adoption of standardized models that support improved, equitable screening access across the Northwest Territories.

5.4.1 – System Dynamics (SD) modeling opportunities

System dynamics modelling of colorectal cancer screening access within the Northwest Territories may assist health system decision-makers in the development and prioritization of colorectal cancer screening initiatives, as well as understanding potential health system trade-offs across the screening continuum.

Where this study identified multiple models of FIT and colonoscopy screening access with different combinations and permutations across communities, system dynamics modelling could be used to quantify access patterns across different screening models. It may also be used to predict potential impacts of territorial standardization in colorectal cancer screening access models as a consideration for health system transformation. The SD design framework proposed in this study reflects patient screening rates in the form of screening uptake and attrition within the eligible screening population in the Northwest Territories. It could be used to understand variability in access patterns across different screening access models, as well as adapted to reflect predicted impacts of interventions such as implementation of an organized screening program or adjustments to colonoscopy capacity.
6. Conclusions

6.1 – Study findings

Colorectal cancer screening in the Northwest Territories, like in many other jurisdictions, is a multidisciplinary continuum over a patient’s eligible life span. However, there are unique contextual and system-level factors that impact the complexity of screening access throughout the territory, many of which are not easily resolved. Contextual factors such as locum-dependent health human resources, health care providers with multiple roles, widespread geography and patient travel, sociocultural practices and the legacy of residential schools all influence colorectal cancer screening access throughout the continuum of care and are a reality of living and working in a Canadian rural and remote health care environment. The system-level impacts of these factors were particularly influential within the screening access problems of screening initiation and colonoscopy no-shows. Improving colorectal cancer screening access over the short term requires adoption of health system processes to manage and mitigate these factors, while working to improve social determinants of health and provide effective supports for patients managing substance abuse and residential school trauma over the long term.

Colorectal cancer screening access is a complex process that requires a combination of patient interactions with health care providers, patient and provider decisions, interactions between providers, interactions between providers and information systems, and the information behaviours that link them. While siloed information systems are a reality in many health care jurisdictions, this study demonstrates the foundational role of information in screening access and the need for increased integration and management of health information. Due to the contextual factors of widespread geography, health service availability, and health human
resource realities with a significant proportion of locum practitioners, the challenges and
downstream system impacts of fractured health information have the potential to be greatly
amplified. With this in mind, the use of health informatics tools to support clear, complete
documentation and communication between providers, and the development of integrated
information systems throughout the continuum of care across the Northwest Territories are
important considerations in health system planning to improve colorectal cancer screening
access. By understanding the health system complexity within screening access, targeted health
informatics tools to optimize system complexity by adding or streamlining necessary information
supports may be developed. Conceptualization of complex health system interrelationships may
also inform development of screening access solutions by identifying those that need to be
addressed in concert, versus those that may be addressed individually or sequentially.

The application of a combined CIB and continuity of care qualitative modeling
framework to describe and depict multidisciplinary health care processes over time provides an
understanding of the complex health system processes and system-level factors influencing
colorectal cancer screening access. In providing a system-level overview of the health care
processes involved in colorectal cancer screening access, multiple access problems could be
identified and their interrelationships within the health system described. In developing targeted
health transformation solutions to improve access to colorectal cancer screening, a systems
analysis overview supports the identification and management of downstream impacts of health
system modifications prior to implementation, such as colonoscopy capacity impacts of
implementing an organized territorial screening program.
Developing colorectal cancer screening access solutions may include adaptations of best practices across health and social service authorities, such as the use of specific endoscopy referral forms, as well as growth of developing territorial technologies such as territory-wide EMR systems. The development of new solutions may also be required, such as the development of an organized screening program, increased colonoscopy capacity, or the development of fully integrated enterprise IT solutions. The translation of health care processes from a combined CIB and continuity of care framework to a system dynamics design framework may provide additional guidance for the development of access solutions by supporting qualitative understanding of health system complexity combined with opportunities for quantitative evaluation of proposed health system transformation solutions. The use of complementary qualitative and quantitative modeling approaches is critical to fully characterize the health system complexity and context of quantitative data measurements to develop fully informed, meaningful health system solutions. This information may support policy makers, public health practitioners, and health system planners in prioritizing and implementing colorectal cancer screening access solutions over the short and long term.

6.2 – Study limitations

The limitations of this study include the contextual limitations specific to colorectal cancer screening access within the Northwest Territories. In addition, the system-level scope of the research required focusing on health care processes at the macro level of the health care system, and meso-level processes within health care teams, such as the multiple health care processes involved in colonoscopy, or micro-level processes are simplified and not fully captured within the bounds of the study models. Finally, the models developed demonstrate a
provider-centric view of the health care processes and system level factors impacting colorectal cancer screening access and do not reflect care access barriers that may be identified, perceived or described differently by patients.

Screening access is a complex problem and the patient interactions involved include both patients and providers to enable screening. Understanding patient perspectives on barriers and enablers to colorectal cancer screening access is a critical aspect of improving access that is not fully captured in this study. Work in the area of patient perspectives of colorectal cancer screening is currently underway within the territory and may complement this work to provide a more complete understanding of screening access (Sharma, 2015).

6.3 – Research implications

This study contributes to an increased understanding of the health system processes and system-level factors involved in colorectal cancer screening access within the Northwest Territories. It has also demonstrated the application of a combined CIB and continuity of care framework in modeling complex health care processes over time and as a foundation for further quantitative SD modeling. In conceptualizing colorectal cancer screening access as combination of patient interactions and information processes and understanding the complex interrelationships involved in current access problems, targeted health system transformation initiatives may be developed to improve colorectal cancer screening access across the territory. This may also inform implementation of transformation initiatives to identify and manage anticipated health system trade-offs and consequences within the health care system.
Study results have been shared with health system decision-makers to inform colorectal cancer screening initiatives, as well as guide ongoing territory-wide cancer strategy and health informatics work. In conceptualizing the system complexity and interrelated nature of screening access problems within the health system it is apparent that improving screening access within the Northwest Territories will require the implementation of multiple solutions, as there is no single solution to a single problem that would universally improve screening access. Ultimately, solutions must be developed for all problem areas identified to optimize screening access. However, within the problems identified, resolving the issue of multiple disconnected patient charts would have the greatest impact on supporting effective information flow between providers and sequential patient interactions throughout the health system. In optimizing system capacity, the issues of limited screening initiation, colonoscopy capacity and colonoscopy no-shows must be addressed in concert, as they are highly interconnected with similar influential contextual patient factors that require further research into patient engagement with the health system to fully address. Finally, additional information supports within an integrated health information system for improved FIT recall and colonoscopy recall reconciliation would help ensure patients who are gain initial access into screening will have ongoing access to screening throughout their eligible lifespan. Further SD modelling work may be undertaken to further inform policy makers and health system stakeholders in their efforts to improve colorectal cancer screening access by assisting with quantitative prioritization as well as cost modeling of possible system transformation solutions. Cost modeling is particularly important in areas such as expansion of colonoscopy capacity due to the human resource and capital resource implications. Findings from this study may also inform screening access in other areas of cancer screening such as cervical cancer, breast cancer, and lung cancer screening.
While the findings of this study are specific to the Northwest Territories, they may also be applied to other jurisdictions with similar rural and remote health care contexts, particularly in the circumpolar regions of Canada and around the world. They may also apply to colorectal cancer screening access in other rural and remote health systems with a large proportion of indigenous patients and a history of colonization.

Overall, this study can serve as a starting point for problem solving by providing a shared understanding of the complex health care processes involved in colorectal cancer screening access among health care practitioners and health system decision-makers in the Northwest Territories. This shared understanding may support collaborative efforts to develop health system transformation initiatives to improve patient outcomes, while considering and managing the contextual constraints and health system trade-offs within the rural and remote Northwest Territories health care system. Ultimately, this study may provide insight into areas for targeted program development and health system redesign to support equitable, timely colorectal cancer screening access for patients across the Northwest Territories.
References


https://www.cancercare.on.ca/pcs/screening/coloscreening


Fung-Kee-Fung, M., Boushey, R.P., Watters, J., Morash, R., Smylie, J., Morash, C., ...


Ottawa: Pauktuutit.

between residents of Inuit Nunangat and residents of the rest of Canada, 1989 to 2008.
*Health Reports, 24*(12), 3-9.


Appendix I.
Pre-structured case outline questions

**Health system agents**
(1) Primary care visit
   - How are patients identified for colorectal cancer screening?
(2) FIT lab testing
   - How are FIT screening tests distributed and completed?
   - How are FIT screening tests processed (i.e. locally vs. remotely, steps involved)?
(3) Colonoscopy
   - How are patients prepped for colonoscopy?
   - How are patients managed in the endoscopy suite?
(4) Pathology lab processing
   - How are pathology specimens from colonoscopy processed?
   - What process do pathology specimens from colonoscopy undergo for reading?

**Information problems**
(1) Primary care visit
   - How are patients risk-stratified once identified for colorectal cancer screening?
   - How are options for colorectal cancer screening discussed with patients?
(2) Surgeon assessment and plan (after colonoscopy and lab results)
   - What processes do surgeons follow for further patient planning once colonoscopy is complete and pathology results are available?
(3) Pathologist assessment
   - How are pathology specimens from colonoscopy read?
(4) Primary care assessment and plan (after colonoscopy and lab results)
   - What processes do primary care providers follow for further screening once FIT and/or colonoscopy is complete?

**Interactions - patients**
(1) Patient presentation to primary care
   - How are patients presenting to primary care for colorectal cancer screening?
   - How do patients present to primary care with a colorectal cancer diagnosis?
(2) Patient realized screening access
   - How do patients engage with screening options?
   - Which screening options do patients express a preference for?
(3) Patient travel
   - How is patient travel facilitated for colonoscopy?
   - What are the difficulties in patient travel for colonoscopy?
   - What supports are in place to facilitate patient travel for colonoscopy?
(4) Colonoscopy results
   - How are colonoscopy results communicated to patients?
(5) Colonoscopy follow-up plan
   - How is the colonoscopy follow-up plan communicated to patients?

(6) Primary Care follow-up plan (ongoing screening)
   - How is the primary care follow-up plan communicated to patients?

**Interactions - providers**

(1) Primary care provider and specialist provider interactions
   - How do primary care providers interact with specialists for colorectal cancer diagnosis and screening?

(1) FIT results
   - How are FIT lab results communicated to providers?

(2) Referral for colonoscopy
   - How are referrals for colonoscopy made?

(4) Colonoscopy results
   - How are colonoscopy results communicated to providers?
   - How are colonoscopy results stored in patient records (in the community and STH)?

(5) Pathology results
   - How are pathology results communicated to providers?

(6) Colonoscopy follow-up plan
   - How is the colonoscopy follow-up plan communicated to providers?

(7) Primary Care follow-up plan (ongoing screening)
   - How is the primary care follow-up plan documented in the patient chart?

**System behaviour**

(1) Continuity of provider-provider information (informational continuity)
   - How does information travel between providers through the continuum of colorectal cancer diagnosis and screening?

(2) Continuity of patient-provider information (informational continuity)
   - How does information travel between patients and providers through the continuum of colorectal cancer diagnosis and screening?

(3) Continuity of patient flow through system (management continuity)
   - How do patients move through the continuum of colorectal cancer diagnosis and screening?

(4) Continuity of screening? (relational continuity)
   - How is continued screening supported by primary care physicians?
   - How is continued screening supported by specialist providers?

**System context**

(1) Rural and remote care delivery
   - How does rural and remote health care practice impact colorectal cancer screening and diagnosis processes?

(2) Sociocultural factors
   - How do providers perceive cultural factors influence colorectal cancer screening and diagnosis processes?
   - How do providers perceive social factors influence colorectal cancer screening and diagnosis processes?
Appendix II.
Final codebook

Category: Health System Agents (HSA)
Definition: people (i.e. – users) and information systems, entities that must interact to address the information problem, number increases with increasing problem complexity (Reddy, 2013).

Describing the role of patients, health service providers, and information systems in colorectal cancer screening.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSA: Patient</td>
<td>Describing the role of the patient in colorectal cancer screening</td>
</tr>
<tr>
<td>HSA: Providers (PR)</td>
<td>Describing the roles of health service providers in colorectal cancer screening service delivery</td>
</tr>
<tr>
<td>HSA: PR - Primary Care Provider</td>
<td>Describing the role of the primary care provider in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR - Endoscopy Provider</td>
<td>Describing the role of the endoscopy provider in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR - Specialist Nurse</td>
<td>Describing the role of the specialist nursing staff in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR - Scheduling Provider</td>
<td>Describing the role of the scheduling provider staff in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR - Endoscopy Nurse</td>
<td>Describing the role of the endoscopy nursing staff in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR – GP Anesthesiologist</td>
<td>Describing the role of the GP Anesthesiologist in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR - Medical Travel</td>
<td>Describing the role of medical travel in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR – Boarding Home</td>
<td>Describing the role of boarding homes in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR – Laboratory</td>
<td>Describing the role of the laboratory in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: PR – Pathologist</td>
<td>Describing the role of pathologists in colorectal cancer screening services</td>
</tr>
<tr>
<td>HSA: Information Systems (IS)</td>
<td>Describing the role of information systems in colorectal cancer screening service delivery</td>
</tr>
<tr>
<td>HSA: IS – Computer Information Systems (CIS)</td>
<td>Describing the role of computer information systems in colorectal cancer screening service delivery – contents/information contained in CIS</td>
</tr>
</tbody>
</table>
**Category:** Information Problems (IP)

Definition: problems encountered within the system context and domain, ranging from simple to complex (Reddy, 2013).

Describing decision nodes within the colorectal cancer screening continuum and how they inform patient care decisions.

**Represented in exploratory process models as Decision Nodes**

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP: Screening Initiation</td>
<td>Describing how the decision to pursue colorectal cancer screening is initiated (i.e. – provider initiated, patient initiated, etc)</td>
</tr>
<tr>
<td>IP: Risk Stratification</td>
<td>Describing the decision-making process of risk stratifying patients as average risk or high risk in colorectal cancer screening</td>
</tr>
<tr>
<td>IP: FIT initiation</td>
<td>Describing how the decision to use FIT is determined (i.e. – applied as screening test or diagnostically)</td>
</tr>
<tr>
<td>IP: FIT result assessment</td>
<td>Describing how further patient care decisions are made based on FIT results.</td>
</tr>
<tr>
<td>IP: Colonoscopy referral sorting</td>
<td>Describing how referral sorting decisions between endoscopy providers are made – application of referral sorting list to send consults to GI vs GenSx</td>
</tr>
<tr>
<td>IP: Colonoscopy initiation</td>
<td>Describing how the decision to initiate colonoscopy in colorectal cancer screening is determined</td>
</tr>
<tr>
<td>IP: Colonoscopy booking prioritization</td>
<td>Describing how colonoscopy referral/booking prioritization decisions are made – deciding booking prioritization and filling out booking form</td>
</tr>
<tr>
<td>IP: Scheduling</td>
<td>Describing how colonoscopy scheduling decisions are made</td>
</tr>
<tr>
<td>IP: Colonoscopy result assessment</td>
<td>Describing how further patient care decisions are made based on colonoscopy results.</td>
</tr>
<tr>
<td>IP: Pathology result assessment</td>
<td>Describing how further patient care decisions are made based on pathology results.</td>
</tr>
</tbody>
</table>
Category: Interactions (IN)
Definition: Interactions between individuals and systems, ranging from direct to conversational. People are engaged as individuals or in some collaborative situation along a spectrum of activity affected by their interactions with other agents (Reddy, 2013).

Category: System Behaviour (SB)
Definition: System behaviour is defined as continuity of care, which is the degree to which a series of discrete healthcare events (interactions) are experienced as coherent, connected and consistent with the patient’s medical needs and personal context (Haggarty, 2009).

Describing the interactions between health system agents across the colorectal cancer screening continuum.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN/SB: Relational Continuity</td>
<td>An ongoing therapeutic relationship between a patient and one or more providers (Haggarty, 2009).</td>
</tr>
<tr>
<td>IN/SB: RC – Primary Care Presentation</td>
<td>Describing how patients and primary care providers interact at the time of screening initiation</td>
</tr>
<tr>
<td>IN/SB: RC – FIT Testing</td>
<td>Describing how patients and providers interact through FIT testing</td>
</tr>
<tr>
<td>IN/SB: RC – Consultation referral consultation</td>
<td>Describing how patients and providers interact regarding referral to endoscopist for consultation</td>
</tr>
<tr>
<td>IN/SB: RC – Pre-colonoscopy consultation</td>
<td>Describing how patients and providers interact at the time of pre-colonoscopy consultation</td>
</tr>
<tr>
<td>IN/SB: RC – Colonoscopy preparation</td>
<td>Describing how patients and providers interact during pre-colonoscopy bowel preparation.</td>
</tr>
<tr>
<td>IN/SB: RC - Colonoscopy</td>
<td>Describing how patients and providers interact at the time of colonoscopy. Includes location of colonoscopy interaction (i.e. – Yellowknife, Hay River, Inuvik)</td>
</tr>
<tr>
<td>IN/SB: RC – FIT result follow-up</td>
<td>Describing how patients and providers interact for follow up of FIT results</td>
</tr>
<tr>
<td>IN/SB: RC – Colonoscopy result follow-up</td>
<td>Describing how patients and providers interact for follow up of colonoscopy results</td>
</tr>
<tr>
<td>IN/SB: RC – Pathology result follow-up</td>
<td>Describing how patients and providers interact for follow up of pathology results</td>
</tr>
<tr>
<td>IN/SB: RC – Ongoing FIT screening</td>
<td>Describing how patients and providers interact to enable ongoing FIT-based screening</td>
</tr>
<tr>
<td>IN/SB: RC – Ongoing colonoscopy screening/surveillance</td>
<td>Describing how patients and providers interact to enable ongoing colonoscopy-based screening or colonoscopy surveillance</td>
</tr>
</tbody>
</table>
| IN/SB: Informational continuity | Use of information on past events and personal circumstances to make current care appropriate for each individual (Haggarty, 2009).  
Describing interactions between providers/information systems within colorectal cancer screening service delivery (i.e. – documentation, informational retrieval). |
| IN/SB: IC – Provider/CIS interactions | Describing interactions between providers and computer information systems – how providers use CIS to access information |
| IN/SB: IC – Provider/Paper-based charting system interactions | Describing interactions between providers and paper-based charting systems – how providers use paper charts to access information |
| IN/SB: Managerial Continuity | A consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing! needs (Haggarty, 2009).  
Describing interactions between providers across the colorectal cancer screening continuum. |
<p>| IN/SB: MC – FIT results | Describing interactions between providers through FIT results |
| IN/SB: MC – Colonoscopy Referral | Describing interactions between providers through the colonoscopy referral – referral form |
| IN/SB: MC – Notification of Consultation | Describing interactions between providers through the notification of consultation – notification form (on bottom of NWT specialist referral) |
| IN/SB: MC – Pre-Colonoscopy Consultation | Describing interactions between providers regarding the pre-colonoscopy consultation (i.e – consultation note/dictation) – includes provider-provider booking communications. |
| IN/SB: MC - Colonoscopy | Describing interactions between providers at the time of colonoscopy. Includes provider-provider booking communications. |
| IN/SB: MC – Colonoscopy Results | Describing interactions between providers regarding the colonoscopy results (i.e. – procedure note/dictation) |
| IN/SB: MC – Pathology Results | Describing interactions between providers regarding pathology results – receiving/reading lab results. |
| IN/SB: MC – Colonoscopy Follow-Up | Describing interactions between providers regarding colonoscopy follow up (i.e. – follow-up note) – communications to primary care providers. |
| IN/SB: MC – Verbal Communication | Describing verbal interactions between providers across the colorectal cancer screening continuum |
| IN/SB: MC – Ongoing FIT screening | Describing how providers interact to enable ongoing FIT-based screening |</p>
<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN/SB: MC – Ongoing colonoscopy screening/surveillance</td>
<td>Describing how providers interact to enable ongoing colonoscopy-based screening or colonoscopy surveillance – colonoscopy recall form/recall list, includes management of the recall list (waitlist) issues.</td>
</tr>
<tr>
<td>IN/SB: MC – colonoscopy cancellation notification</td>
<td>Describing how colonoscopy cancellation (i.e. – removing a patient from the recall list) is communicated between providers</td>
</tr>
</tbody>
</table>

Category: System Context
Definition: The environment and domain of information problem or need (Reddy, 2013).

Describing contextual factors influencing colorectal cancer screening within the Northwest Territories.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>SC: Weather</td>
<td>Describing weather influences on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Sociocultural</td>
<td>Describing sociocultural influences colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Resource Use</td>
<td>Describing resource-use influences on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Geography and patient travel</td>
<td>Describing influences of widespread geography and patient travel on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Language diversity</td>
<td>Describing language diversity influences on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Locum-based practice</td>
<td>Describing locum-based practice influences on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Organized screening program</td>
<td>Describing influences of a formal territorial colorectal cancer screening program or lack thereof on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Territorial screening guidelines</td>
<td>Describing influences of territorial screening guidelines on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Rebooking forgiveness</td>
<td>Describing how rebooking forgiveness (i.e. – multiple rescheduling of colonoscopy) influences colorectal cancer screening</td>
</tr>
<tr>
<td>SC: “Ick Factor”</td>
<td>Describing influences of stool collection for FIT testing on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Appointment length</td>
<td>Describing influences of appointment length on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Provider collegiality</td>
<td>Describing influences of provider collegiality on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: Patient education and awareness</td>
<td>Describing influences of patient education and awareness on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: transient patient population</td>
<td>Describing influences of a transient patient population on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: history of trauma/abuse</td>
<td>Describing influences of a history of trauma or abuse on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: female cancer screening tests</td>
<td>Describing influences of other female cancer screening tests (i.e. – paps/mammos) on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: substance abuse</td>
<td>Describing influences of substance abuse on colorectal cancer screening</td>
</tr>
<tr>
<td>SC: multiple provider roles</td>
<td>Describing influences of multiple provider roles on colorectal cancer screening</td>
</tr>
</tbody>
</table>
### Appendix III.
Colorectal cancer screening access models by community

<table>
<thead>
<tr>
<th>FIT screening services *included in process models</th>
<th>FP/NP clinic with lab interface</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yellowknife Health and Social Services Authority (Yellowknife)</td>
</tr>
<tr>
<td></td>
<td>Fort Smith Health and Social Services Authority (Fort Smith)*</td>
</tr>
<tr>
<td></td>
<td>Hay River Health and Social Services Authority (Hay River)*</td>
</tr>
<tr>
<td></td>
<td>Beaufort Delta Health and Social Services Authority (Inuvik)*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NP/CHN health centre with provider interface</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deh Cho Health and Social Services Authority (Fort Providence, Fort Simpson, Fort Liard)</td>
</tr>
<tr>
<td>Yellowknife Health and Social Services Authority (Yellowknife, Lutselk’e, Fort Resolution)</td>
</tr>
<tr>
<td>Tłı̨chǫ Community Services Agency (Behchokǫ, Whati)</td>
</tr>
<tr>
<td>Sahtu Health and Social Services Authority (Norman Wells, Fort Good Hope, Tulita, Délı̨nę)</td>
</tr>
<tr>
<td>Beaufort Delta Health and Social Services Authority (Inuvik, Tsiigehtchic, Fort McPherson, Aklavik, Tuktoyaktuk, Paulatuk, Sachs Harbour, Ulukhaktok)*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Colonoscopy screening services *included in process models</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coupled pre-colonoscopy consultation and colonoscopy appointments</td>
</tr>
<tr>
<td>Full service outreach</td>
</tr>
<tr>
<td>Hay River Health and Social Services Authority (Hay River)*</td>
</tr>
<tr>
<td>Full distance services</td>
</tr>
<tr>
<td>Yellowknife Health and Social Services Authority (Lutselk’e, Fort Resolution)</td>
</tr>
<tr>
<td>Deh Cho Health and Social Services Authority (Fort Providence, Fort Simpson, Fort Liard)</td>
</tr>
<tr>
<td>Tłı̨chǫ Community Services Agency (Behchokǫ, Whati)</td>
</tr>
<tr>
<td>Fort Smith Health and Social Services Authority (Fort Smith)*</td>
</tr>
<tr>
<td>Sahtu Health and Social Services Authority (Norman Wells, Fort Good Hope, Tulita, Délı̨nę)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Uncoupled pre-colonoscopy consultation and colonoscopy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locally-based services</td>
</tr>
<tr>
<td>Yellowknife Health and Social Services Authority (Yellowknife)</td>
</tr>
<tr>
<td>Beaufort Delta Health and Social Services Authority (Inuvik)</td>
</tr>
</tbody>
</table>
| Full distance (Telehealth) services | Deh Cho Health and Social Services Authority (Fort Simpson **General Surgery only)*
| Sahtu Health and Social Services Authority (Norman Wells, Fort Good Hope, Tulita, Délı̨nę)
| Fort Smith Health and Social Services Authority (Fort Smith **General Surgery only)*
| Fort Smith Health and Social Services Authority (Fort Smith)
| Fort Smith Health and Social Services Authority (Fort Smith)*
| Beaufort Delta Health and Social Services Authority (** Endoscopist primary care-assigned communities only)*
| Beaufort Delta Health and Social Services Authority (Tsiigehtchic, Fort McPherson, Aklavik, Tuktoyaktuk, Paulatuk, Sachs Harbour, Uluhaktok)*
| Beaufort Delta Health and Social Services Authority (** Endoscopist primary care-assigned communities only)*
| Tłı̨chǫ Community Services Agency (Behchokǫ, Whati)
| | Fort Smith Health and Social Services Authority (Fort Smith)

| Full distance (Travel) services |
| Deh Cho Health and Social Services Authority (Fort Simpson **General Surgery only)*
| Fort Smith Health and Social Services Authority (Fort Smith **General Surgery only)*
| Fort Smith Health and Social Services Authority (Fort Smith)*
| Beaufort Delta Health and Social Services Authority (** Endoscopist primary care-assigned communities only)*

| Partial service outreach |
| Fort Smith Health and Social Services Authority (Fort Smith)*
| Beaufort Delta Health and Social Services Authority (** Endoscopist primary care-assigned communities only)*

| |
Appendix IV.
FIT screening access models

Electronic version available from the author on request.

*Hay River HSSA (Hay River) – Lab Interface*
Hay River HSSA (Communities) – Provider Interface
MR - Patients who are symptomatic (i.e., rectal bleeding, abdominal pain, change in bowel habits, weight loss, etc) are NOT considered eligible for screening; these patients require acute management not reflected here.

*FIT indication regularly occurs outside of colorectal cancer screening environment when used as a diagnostic test.
Fort Smith HSSA (Fort Smith) – Provider Interface

NB: Patients who are symptomatic (i.e., rectal bleeding, ulcerative pain, change in bowel habits, weight loss, etc.) are NOT considered eligible for screening; these patients require acute management not reflected here.

*FIT initiation regularly occurs outside of colorectal cancer screening environment when used as a diagnostic test.
Beaufort Delta HSSA (Inuvik) – Lab Interface

Legend
Health System Agents
- Person
- Computer-Based Information System
- Paper-Based Information System

Relational Continuity
- Patient-Provider Interaction

Management Continuity
- Provider-Provider Documentation
- Provider-Provider Interaction

Decision Nodes:
- Primary Care Provider Decisions
- Endoscopy Provider Decisions
- Patient-Provider Joint Decisions
- Endoscopy Provider Joint Decisions
- Scheduling Provider Decisions

Information Exchange

Connects to:
Colorectal Cancer Screening Map

NB: Patients who are symptomatic (i.e., rectal bleeding, abdominal pain, change in bowel habits, weight loss, etc.) are NOT considered eligible for screening; these patients require acute management not reflected here.
Beaufort Delta HSSA (Inuvik) – Provider Interface
Appendix V.
Colonoscopy screening access models

*Electronic version available from the author on request.*
Hay River HSSA (Hay River) – Full service outreach
Hay River HSSA (Communities) – Coupled full distance service (Travel)
Fort Smith HSSA (Fort Smith) – Partial service outreach
Fort Smith HSSA (Fort Smith) – Coupled full distance service (Travel)
Fort Smith HSSA (Fort Smith) – Uncoupled full distance service (Travel)
Beaufort Delta HSSA (Inuvik) – Locally-based service
Beaufort Delta HSSA (Communities) – Uncoupled full distance service (Telehealth)
Appendix VI.
Post-colonoscopy emergency models

Electronic version available from the author on request.

Hay River HSSA (Hay River) – Post-colonoscopy emergency
Fort Smith HSSA (Fort Smith) – Post-colonoscopy emergency

NB: Patients who are symptomatic (i.e., rectal bleeding, abdominal pain, change in bowel habits, weight loss, etc.) are NOT considered eligible for screening; these patients require acute management not reflected here.

*IF* initiation regularly occurs outside of colorectal cancer screening environment when used as a diagnostic test.
Beaufort Delta HSSA (Inuvik) – Post-colonoscopy emergency

NB: Patients who are symptomatic (i.e., rectal bleeding, abdominal pain, change in bowel habits, weight loss, etc.) are NOT considered eligible for screening; these patients require acute management not reflected here.