FAMILIAL AND HEREDITARY COLORECTAL CANCER SCREENING IN NEWFOUNDLAND AND LABRADOR: SPECIALISTS' KNOWLEDGE, ATTITUDE AND PRACTICE PATTERNS

JILL MacEACHERN

Familial and Hereditary Colorectal Cancer Screening in Newfoundland and Labrador:

Specialists' Knowledge, Attitude and Practice Patterns

By

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Abstract

Objectives: To determine knowledge, practice patterns and attitudes of gastroenterologists and surgeons in NL regarding familial and hereditary colorectal cancer screening.

Methods: A self-administered mail-out survey was used to collect information on specialist understanding of best practice colorectal cancer screening guidelines.

Results: Eighty- four percent of eligible specialists responded. The majority of specialists begin screening at the appropriate age and preferred screening with colonoscopy. Interdisciplinary health team involvement varied. More than half of respondents are seeing patients with FAP and HNPCC gene mutations for colonoscopy within 3 months. Almost all respondents agreed there is a need for a province wide colorectal cancer registry.

Conclusions: Overwhelming preference for the colonoscopy is potentially contributing to extended wait times. Inconsistencies in practices are evident. Examining other models of colorectal cancer screening would help to provide clarity around interdisciplinary health team roles and guidance for moving towards a more organized screening approach.

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List of Abbreviations

AP.....Adenomatous polyps

ASGE.....American Society of Gastrointestinal Endoscopy

CAG.....Canadian Association of Gastroenterology

CRC.....Colorectal cancer

CCHS.....Canadian Community Health Survey

CCS.....Canadian Cancer Society

CIHR.....Canadian Institutes of Health Research

DCBE.....Double contrast barium enema

DRE.....Digital rectal exam

FAP.....Familial adenomatous polyposis

FOBT.....Fecal occult blood test

FS.....Flexible sigmoidoscopy

HNPCC.....Hereditary non-polyposis colorectal cancer

NHIS.....National Health Interview Survey

NHS.....National Health Service

NL.....Newfoundland and Labrador

PMGP.....Provincial Medical Genetics Program

PSA.....Prostate- specific antigen

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Chapter One - Introduction

1.1 Problem Statement

Colorectal cancer (CRC) is the fourth most commonly diagnosed cancer in Canada. It is also the second leading cause of death in the country (Health Canada, 2007). An estimated 22,000 Canadians are diagnosed with CRC each year and 9,100 die from it (Canadian Cancer Society {CCS}, 2009a). Currently Newfoundland and Labrador (NL) has the highest incidence rate of CRC among men (87/100,000) and second highest incidence rate among women (52/100,000) (CCS, 2009a). Based on the 2009 NL cancer statistics estimates, a total of 280 men and 200 women will be diagnosed with CRC and 130 men and 100 women will die from it this year (CCS, 2009a).

Fortunately, with regular screening, CRC is one of the most preventable forms of cancer. Screening reduces CRC incidence by identifying (and removing) premalignant polyps before cancerous tumors develop. Screening also reduces CRC related mortality through early detection and treatment. Since 2002, Health Canada has been recommending annual or biennial CRC screening for all adults over the age of 50. Meanwhile, advancement in genetics research has enabled certain individuals to seek screening earlier and more frequently. This has been particularly valuable for residents of NL where researchers believe genetics or at least familial factors are responsible for the excess CRC cancer burden in this province (Green, Green, Buehler, Robb, Daftary, Gallinger, et al., 2007).

Despite higher incidence and mortality rates of CRC in NL, screening rates in NL are among the lowest of all Canadian provinces. Based on data from the Canadian

Community Health Survey (CCHS) Cycle 2.1, the proportion of people who reported up-to-date CRC screening among the provinces assessed was lowest in NL at 12.6%. As few as 4% of women in NL reported having a fecal occult blood test (FOBT) within the last two years from when the survey was conducted (Zarychanski, Chen, Bernstein & Hebert, 2007). Evidence suggests that encounters with the health care system can have a strong influence on how patients perceive the burden of screening and can either facilitate or impede adherence to recommended screening protocols (Geary, Thomas, MacKay, Dorkins, Barwell & Hodgson, 2007). Based on findings from a NL study that involved interviews with hereditary non-polyposis colorectal cancer (HNPCC) mutation carriers, issues around extended wait times for a colonoscopy, lack of continuity of care, difficulties scheduling screening appointments and inconsistencies in screening recommendations and practices among health professionals were identified as barriers to routine screening (J. Stokes, Research Coordinator, personal communication, October 21, 2008)[1].

Gastroenterologists and general surgeons play a critical role in CRC screening in NL. These specialists are the only health professionals who perform colonoscopy, the endoscopy procedure most recommended for screening the high risk familial and hereditary CRC populations (Leddin, Hunt, Champion, Cockeram, Flook, Gould, et al., 2004; Levin, Lieberman, McFarland, Smith, Brooks, Andrews, et al., 2008). In many cases, specialists independently prioritize care for their patients and may or may not assume responsibility for scheduling follow-up screening (Dr. W. Pollett, Chair of

[1] Jackie Stokes has been involved with coordinating a 2007/08 research project in NL that involved qualitative interviews with HNPCC mutations carriers and their experiences pursuing CRC screening.

Surgery for the Faculty of Medicine at Memorial University, personal communication, October 6, 2008). Each specialist also determines which screening test to use, the age at which to begin screening and the frequency of repeat screening. This approach contributes to the confusion among health professionals and health administrators about the role the specialists play in the on-going surveillance and management of the familial and hereditary CRC populations.

1.2 Research Questions and Objectives

The purpose of this cross-sectional descriptive study is to determine whether gastroenterologists and general surgeons are knowledgeable about familial and hereditary CRC and associated risk factors and whether they follow best practice screening guidelines. Using a self-administered mail-out survey, the research objectives are:

1. To describe the specialists' characteristics including years since graduation, number of years practicing in NL, professional body certification, community size and number of colonoscopies performed annually.
2. To describe the specialists' knowledge of best practice guidelines and practice patterns for screening individuals with family history of CRC, a family history of adenomatous polyps (AP), HNPCC and familial adenomatous polyposis (FAP).
3. To describe the specialists' attitudes about current CRC screening services in NL including their attitudes about a provincially organized screening approach.

1.3 Rationale

CRC presents a significant burden on both the individual and society. For the individual, the burden is reflected in the potential years of life lost, the cost of treatment, the degree of disability, pain, and discomfort, and the impact on the family. For society, the burden may be described by mortality, morbidity and the costs of treatments (Health Canada, 2002). A study by O'Brien, Brown, and Kephart (2001) found hospital costs for a cohort of CRC patients (n = 593) in Nova Scotia over a three year period after diagnosis amounted to $9.8 million. Costs were significantly lower for patients with localized cancer, higher in the six months around the time of diagnosis and throughout the six months before death, and highest in patients who were older and had significant co-morbidities. Costs incurred in the three years after diagnosis were estimated to be less if the cancer was diagnosed early. This suggests that costs of CRC care may be reduced by screening for the disease and diagnosing it at an earlier stage.

Health Canada acknowledges that the benefits of CRC screening are most likely to be realized if offered through an organized screening program (McLeod, 2001). Included in this approach are evidenced-based screening and follow-up guidelines, recruitment and retention strategies to maximize participation, and quality assurance and information systems to support optimal program operation (CCS, 2009b). Currently in NL, there is no organized CRC screening program or CRC registry for either the general (average risk) or high risk familial and hereditary CRC populations. Individuals seeking screening are often left to navigate through the health care system alone and on an ad hoc basis (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, August 18, 2008). This is concerning, particularly for the familial and hereditary CRC populations,

because it is speculated that without adequate resources, individuals may have reservations about participating in genetic testing because of the challenges involved in managing screening protocols (J. Stokes, Research Coordinator, personal communication, October 21, 2008).

Screening of high risk familial and hereditary CRC populations begins earlier and occurs more frequently than does screening of the general (average risk) population. Often screening requires trained endoscopists to perform colonoscopy (Leddin et al., 2004). To date, very few studies have examined endoscopy specialists' knowledge and practice patterns around familial and hereditary CRC. Findings from this study identify if NL specialists' are knowledgeable about familial and hereditary CRC and related risk factors, their CRC screening practices and whether they are providing initial and follow-up CRC screening within a timely fashion. Information about interdisciplinary health professional involvement and overall level of satisfaction among the specialists about current CRC screening services in the province is also collected.

Combining findings from this study with the information about HNPCC patient experiences pursuing CRC screening in NL (J. Stokes, Research Coordinator, personal communication, October 21, 2008., 2008) will allow for a comprehensive understanding of CRC screening practices and services in the province. This knowledge will help to guide a provincial strategic plan to better manage CRC screening, particularly for high risk familial and hereditary CRC populations.

Chapter Two – Background and Literature Review

2.1 Colorectal Cancer

CRC is a malignant tumour of the digestive tract. The majority of CRC cases start in the cells that line the walls inside the colon or the rectum (CCS, 2009c). The colon and rectum make up the large intestine (large bowel) which is located in the last part of the digestive system (see Figure 1). After a relatively long period of localization in the wall of the colon or rectum, the tumour metastasizes to regional lymph nodes and distant organs (CCS, 2009c)

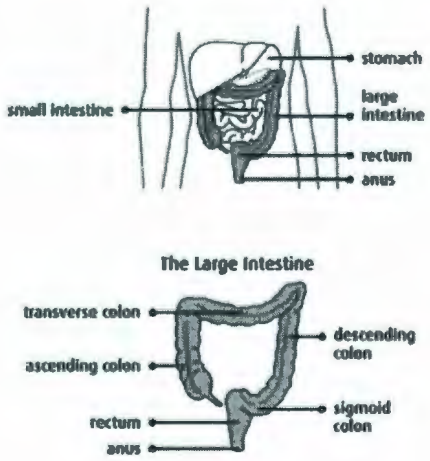

Figure 1. Human Digestive System. *Note:* From the Canadian Cancer Society (2009c). Used with permission of the organization.

Prognosis and survival rates for CRC are related to stage at diagnosis. The overall five year survival rate for CRC is approximately 50% but if caught early, the rate increases to almost 90% for localized CRC. Conversely, the five-year survival rate falls below 50% once the disease has spread (Health Canada, 2002).

2.1.1 Natural History

Colorectal tumours arise through complex interactions between genetic and non-genetic (environmental) influences (Alberta Cancer Board, 2008). The tumors present as neoplasms (abnormal growth of tissue), ranging from benign growth to invasive cancer and can be classified into three groups:

- non-neoplastic polyps,
- neoplastic polyps (AP, adenomas), and
- cancers (CCS, 2009c)

In general, CRC has a long pre-symptomatic stage. It can take up to ten years or more for a polyp to become malignant (Ahmed, Saleem & Kadla, 2005). It is estimated that approximately one-half to two-thirds of all polyps are adenomatous and it is generally accepted that the majority of cancers of the colon and rectum develop from them (Health Canada, 2002). Most AP occur sporadically (60-85%) with the remainder due to family histories of CRC or AP including genetic mutations (McLeod, 2001).

2.1.2 Risk Factors

Risk factors for CRC can be classified as modifiable or non-modifiable. A modifiable risk factor is defined as something that can be changed by intervention, thereby reducing the probability of occurrence of disease (Last, 2001). Personal behavior and lifestyle are considered modifiable. Non-modifiable risk factors include inborn or inherited characteristics which, on the basis of epidemiological evidence are known to be associated with health related condition(s) (Last, 2001). Some of these non-modifiable

risk factors include age, family history, hereditary syndromes and personal medical history. Examples of these risk factors are discussed below with particular emphasis on the non-modifiable factors.

2.1.2.1 Age

It is estimated that 70% of CRC cases are diagnosed in those older than age 65 and 40% of cases are diagnosed in those over 75 years of age (National Cancer Institute, 2001; Edwards, Howe, Ries, Thun, Rosenberg, Yancik, et al. 2002). While the incidence and mortality rates associated with CRC in Canada are falling with improved screening, it is projected that the absolute number of new cases and deaths will probably continue to rise due to the aging of the "baby-boom" generation (Health Canada, 2002).

2.1.2.2 Family history of CRC or AP

Individuals with a family history of CRC or AP are at a significantly increased risk of developing CRC. Actual level of risk depends largely on the closeness of the relationship, the age at which a family member was diagnosed with CRC or AP, and the number of affected relatives (Eisen & Weinberg, 2005). In a meta-analysis of 27 case-control and cohort studies by Johns and Houlston (2001) to determine familial risk of CRC, the relative risk of CRC was 1.99 with a first-degree relative with AP, 2.25 with a first-degree relative with CRC, 3.87 with a first degree relative with CRC before age 45 years and 4.25 with more than one first-degree relative with CRC.

2.1.2.3. Family history of HNPCC and FAP

Hereditary syndromes are estimated to account for approximately five to ten percent of all cases of CRC (Lynch & de le Chapelle, 2003). HNPCC and FAP are the two most common CRC hereditary syndromes. Both present in an autosomal dominant

manner and specific gene mutations associated with both disorders have been identified. FAP is associated with mutations in the APC (adenomatous polyposis coli) gene and presents with hundreds or even thousands of polyps throughout the large intestine. These benign polyps generally develop between ten and 20 years of age and if left untreated, affected individuals have an almost 100% risk for developing CRC (Merg, Lynch, Lynch & Howe, 2005). A variant of FAP, known as attenuated FAP or attenuated adenomatous polyposis coli, may involve between 20-100 AP proximally distributed in the colon. The onset of CRC is approximately ten years later for attenuated FAP than for classical FAP (Leddin et al., 2004).

HNPCC is associated with mutations in several mismatch repair genes including MSH2, MLH1, MSH6, and PMS2. Ninety percent of cases are caused by mutations in either MLH1 or MSH2 (Lynch & de le Chapelle, 2003). HNPCC shows incomplete penetrance meaning that not all mutation carriers will develop a cancer (Stuckless, Parfrey, Woods, Cox, Fitzgerald, Green, et al., 2007). The lifetime risk of developing CRC with HNPCC is up to 80% with a median age of diagnosis of 45 years (Barnetson, Tenesa, Farringonton, Nicholl, Cetnarskyj, Porteous, et al., 2006). Unlike FAP, HNPCC involves only a few polyps, however, these polyps may progress more rapidly from adenoma to cancer (Lynch & Lynch, 1998). Mutation carriers also have an increased risk for several extra colonic neoplasms including endometrial, small-bowel, gastric, renal pelvis, ureter, and ovarian cancers (Lynch & Smyrk, 1999).

To help promote consistency in recognizing those at high risk for HNPCC, a set of guidelines, known as the Amsterdam Criteria, was developed in 1991 by the International Collaborative Group on HNPCC. The guidelines are as follows:

1) At least three members of the family have CRC (FAP excluded), one of whom is a first-degree relative of the other two;

2) Two or more generations are affected; and

3) At least one relative was diagnosed before age 50 years (Vasen, Mecklin, Khan & Lynch, 1991).

These guidelines were later revised to be less restrictive because patients were discovered with identified HNPCC mutations but who did not meet these criteria. The new guidelines are known as Amsterdam II (Vasen, Watson, Mecklin & Lynch, 1999) and they also take into account the extra colonic cancers associated with HNPCC. Details of the guidelines can be found in Appendix A.

2.1.2.4 Other diseases/conditions

A personal medical history of a chronic inflammatory bowel disease such as ulcerative colitis and Crohn's disease is another risk factor for CRC (Bernstein, Blanchard, Kliewer & Wajda, 2001). People who have previously had CRC are also more likely to develop a new cancer in other areas of the colon and rectum, even if the CRC was completely removed. This is especially true if the first CRC developed before 60 years of age (Renehan, Egger, Saunders & O'Dwyer, 2002).

2.1.2.5 Modifiable risk factors

It has been estimated by the American Institute for Cancer Research and the World Cancer Research Fund that 30 to 40 percent of all cancers can be prevented by appropriate diets, physical activity, and maintenance of appropriate body weight (World Cancer Research Fund / American Institute for Cancer Research, 2009). In a recent US prospective study population of more than 900,000 adults, overweight and obesity were

estimated to account for 14 percent of all cancer deaths in men and 20 percent of those in women during a 16-year follow up (Calle, Rodriguez, Walker-Thurmond & Thun, 2003).

One of the most important messages around nutrition and cancer prevention is the importance of a diet rich in fruits and vegetables. A review of the relationship between vegetable and fruit consumption and cancer in 206 human epidemiologic studies and 22 animal studies found evidence to suggest an increased intake of vegetables and fruit helped to prevent cancers of the stomach, esophagus, lung, oral cavity and pharynx, endometrium, pancreas, and colon (Steinmetz & Potter, 1997). The fibre found in vegetables and fruit as well as in grain products has been specifically associated with prevention of CRC (Slattery, Curtin, Edwards & Schaffer, 2004). Similarly, it appears that allium vegetables (garlic, onion, leeks, and scallions) offer certain properties specific to CRC prevention (Fleischauer, Poole & Arab, 2000). In contrast, a high intake of red meat, particularly processed meat has been associated with a moderate but significant increased risk for CRC (Norat, Lukanova, Ferrari & Riboli, 2002).

2.1.3 High Rates of Hereditary CRC in NL

A five-year case control study in NL from January 1999 to December 2003 by Green et al. (2007) found genetic evidence to explain why NL has a higher proportion of high and intermediate risk CRC families than other Canadian provinces. Almost 4% of CRC cases were found to come from families meeting the Amsterdam I or II criteria associated with HNPCC and a further 0.9% of cases involved FAP. Meanwhile, 43% had a familial link to CRC (see Figure 2).

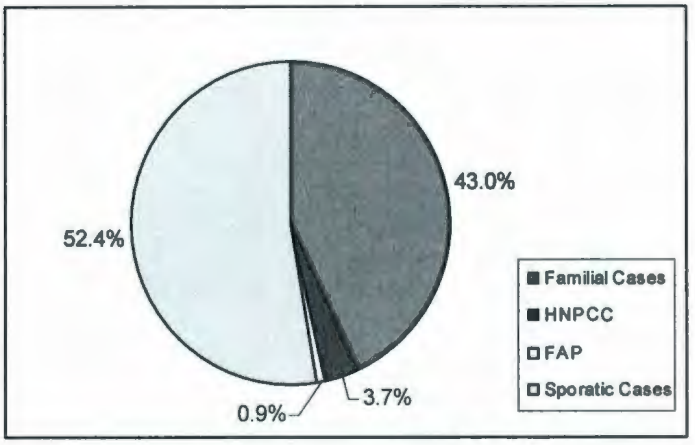

Figure 2: The fractions of familial and hereditary CRC cases in NL. *Note.* Adapted with permission from Green et al. (2007) study.

NL is among the most valuable populations for studying genetics because of how the province was settled. Until very recently little immigration or out migration has occurred and many large families have remained geographically isolated and religiously segregated around a core community for generations. This makes the identification of founder effects of disease including the discovery of multiple distinct gene isolates associated with CRC more easily identified (Stuckless et al., 2007).

2.2 CRC Screening

CRC is a good candidate for screening for several reasons: (i) high incidence, prevalence and cause of death worldwide; (ii) the long period between the development of polyps and of an invasive cancer (approximately 10 years); (iii) AP are well managed by endoscopic intervention; and (iv) survival depends on the stage of the tumour (early stage leads to better prognosis) (Labianca, Beretta, Mosconi, Milesi & Pessi, 2005). A systematic review was done by Pignone, Saha, Hoerger and Mandelblatt (2002) for the

US Preventive Services Task Force to measure the impact of CRC screening. The review included MEDLINE and the British National Health Service Economic Evaluation Database from January 1993 through September 2001. Results showed that mortality associated with CRC was significantly reduced with screening for adults 50 years of age or older as compared to no screening. The cost per life year saved was estimated at $10,000 to $25,000 which is comparable to other commonly endorsed preventive health care interventions such as mammography for women older than 50 years of age, or treatment of moderate hypertension (Pignone et al., 2002). The data did not suggest whether one screening strategy was superior to another.

2.2.1 Screening Tests

Four tests are commonly used to screen for CRC: FOBT, flexible sigmoidoscopy (FS), colonoscopy and double contrast barium enema (DCBE). In the last decade, the number of tests available for CRC screening has increased. This growth has been accompanied by changing patterns in the proportion of adults using different tests. In the US, rates of FS are declining, colonoscopy rates are increasing, use of FOBT remain somewhat constant, and the use of DCBE is now becoming very uncommon (Levin et al., 2008). Details of the different screening tests are discussed below and more specific performance characteristics of each are outlined in Appendix B.

2.2.1.1 Fecal occult blood test

The main appeal to the FOBT is that it can be done by the family physician or by the patient. It is the best studied screening test for CRC but it is also among the least sensitive of the tests (Leddin et al., 2004). Sensitivity refers to the probability that the test

will correctly detect the presence of disease or condition (Lazarus, 1999). While it is designed to detect blood in the stool that is not visible to the naked eye, the presence of blood does not necessarily mean cancer. For example, bleeding could be caused by a non-cancerous condition. Conversely, CRC tumours often bleed intermittently and/or blood may not be present throughout the entire stool and would therefore be missed in the sample (Alberta Cancer Board, 2008).

Three large randomized controlled trials on the FOBT have demonstrated that cancer is detected at an earlier and more curable stage among patients screened by FOBT than unscreened patients (Hardcastle, Chamberlain, Robinson, Moss, Amar, Balfour, et al., 1996; Kronborg, Fenger, Olsen, Jorgensen & Sondergaard, 1996; Mandel, Bond, Church, Snover, Bradley, Schuman, et al., 1993). Over an eight to 13 year period three studies were able to demonstrate a 14% to 18% reduction in CRC deaths with biennial screening (Hardcastle et al., 1996; Kronborg et al., 1996) and a 33% reduction in deaths with annual screening (Mandel et al., 1993).

2.2.1.2 Flexible sigmoidoscopy

FS can detect polyps located in the left distal end of the colon (the sigmoid colon). It is possible to take a biopsy and remove polyps if necessary and since anesthesia or sedation is generally not required, non-specialists (including nurses) if adequately trained, can provide this procedure in an office-based setting (Levin et al., 2008). In NL, FS may be performed by gastroenterologists, general general surgeons, internists, pediatricians, casualty officers and general practitioners (Dr. R. Young, Registrar with the College of Physician and Surgeon of NL, personal communication, July 27, 2009).

Two case control studies of the FS procedure found a 60% to 80% reduction in CRC mortality for the area of the colon within the reach of the scope (Selby, Friedman, Quesenberry & Weiss, 1992; Newcomb, Norfleet, Storer, Surawicz & Marcus, 1992). Other evidence suggests that the FS is only 60% to 70% as sensitive for advanced adenomas and cancers in the colon as the colonoscopy (Imperiale, Wagner, Lin, Larkin, Rogge, Ransohoff, et al. 2000; Lieberman & Weisse, 2001). However, sensitivity of FS is speculated to change with age and become even less when screening an older population as neoplasms in the proximal region of the colon become more common after 65 years of age (Levin, Palitz, Grossman, Conell, Finkler, Ackerson, et al., 1999).

Combining FOBT and FS has been proposed as a means of correcting some of the limitations of each method used alone. In a randomized control trial with 2885 patients, Lieberman and Weisse (2001) found that FS alone identified 70% of all subjects with advanced neoplasia, while combining it with FOBT increased those identified to 76%.

2.2.1.3 Colonoscopy

Colonoscopy is the most specific and sensitive of the tests. This means that not only is the probability high that it will correctly detect a particular disease or condition when it does indeed exist, but it is also highly likely to correctly indicate a negative test result when the condition is absent (true negative) (Lazarus, 1999). Such accuracy allows for a prolonged screen interval of approximately ten years after a normal test result (Leddin et al., 2004; Health Canada, 2002). Colonoscopy allows for direct visual examination of the entire colon and rectum and can detect 87-94% of polyps 6-10mm in size (Huang, Lal & Farraye, 2004). Similar to the FS, biopsies and polyp removal can be performed if necessary. Colonoscopy does carry a small but potentially very serious risk

of perforation and bleeding (approximately 1:1000 to 1:2000 cases) which can, in rare cases, result in fatalities (Leddin et al. 2004). It also requires full bowel preparation and sedation, making it the most inconvenient of the all the screening tests.

Two cohort studies suggest that screening with colonoscopy reduced CRC incidence by 90% among people with AP (Winawer, Zauber, Nah Ho, O'Brien, Gottlieb, Sternberg, et al., 1993; Citarda, Tomaselli, Capocaccia, Barcherini, Crespi & T.I.M.S. Group, 2001). Among HNPCC mutation carriers, colonoscopy surveillance has been shown to reduce the risk of CRC by more than half, and reduce morbidity and mortality by about 65% (Vasen, Taal, Nagengast, Griffioen, Menko, Kleibeuker, et al., 1995; Jarvinen, Aarnio, Mustonen, Aktan-Collan, Aaltonen, Peltomaki, et al., 2000). These results are despite the 0.2% risk of perforation (Gatto, Frucht, Sundararajan, Jacobson, Grann & Neugut, 2003).

2.2.1.4 Double contrast barium enema

DCBE is an x-ray that examines the whole colon and rectum. It is cheaper and has a lower complication rate than colonoscopy but requires full bowel preparation. There have been no randomized controlled trials evaluating its effectiveness in reducing incidence or mortality from CRC and no case-control studies evaluating its performance. One study by Rex, Rahmani, Haseman, Lemmel, Kaster and Buckley (1997) examined medical records of 2193 consecutive CRC cases that were identified in 20 central Indiana hospitals. The researchers found the relative sensitivity for detecting CRC was 82% for the DCBE as compared to colonoscopy which was 95%. This test is decreasing in popularity because a colonoscopy is necessary in follow-up if any polyps or cancers are found.

2.2.2 Quality Indicators

Appropriate preparation for all screening tests increases the ability to perform a complete examination while inappropriate preparation is a major contributor to costs (Rex, Petrini, Baron, Chak, Cohen, Deal, et al., 2006). While quality indicators for endoscopy procedures (i.e., colonoscopy, FS, gastroscopy, etc.) have been proposed, data are not routinely collected or reviewed. There is also currently no national standard for credentialing in gastrointestinal endoscopy (Hilsden, Tepper, Moayyedi & Rabeneck, 2007). As a result, different groups of physicians who provide endoscopy in Canada can undergo quite different training. Many sub-specialists (i.e., gastroenterologists and colorectal general surgeons) complete an accredited training program that includes extensive training and practical experience in endoscopy while other specialists (i.e., general internists and general general surgeons) receive less training (Hilsden et al., 2007). Approximately 100 colonoscopies or gastroscopies annually have been associated with a significant improvement in the rate of completion (Wexner, Garbus & Singh, 2001). Schulz, Vinden, and Rabeneck (2007) found that more than 25% of all physicians performing colonoscopies in Ontario between April 1, 2001 and March 31, 2002 performed less than 100 procedures.

In the US, a *Quality Assurance Task Group of the National Colorectal Cancer Roundtable* developed a reporting system for colonoscopy which is based on previously published continuous quality-improvement indicators (Lieberman, Nadel, Smith, Atkin, Duggirala, Fletcher, et al., 2007). The National Health Service (NHS) in the UK evaluates colonoscopists involved with their National Bowel Cancer Screening program through a regular practice audit that includes observation of two colonoscopies by triplet

video. Quality indicators include completion rates, adenoma detection rates, and correct identification of tumor location. In terms of safety measurement, indicators include perforation rates, post-polypectomy complications (such as bleeding and perforation), and rates of complications requiring hospital admission (Canadian Institute of Health Research {CIHR}, 2006).

2.2.3 CRC Screening Recommendations

CRC guidelines in Canada have been developed for general (average-risk) population which includes adults 50 years of age and older without other known risk factors for the disease aside from age (Health Canada, 2002; Leddin et al., 2004). Current Canadian guidelines include FOBT every other year, FS every five years, FS combined with FOBT every five years, DCBE every five years, or colonoscopy every ten years.

US guidelines are slightly different for the same groups of patients. Most recently, the American Cancer Society, the *US Multi-Society Task Force on Colorectal Cancer* and the American College of Radiology came together to develop a collaborative set of guidelines to test for AP and cancer. Current US recommendations include FS every five years, colonoscopy every 10 years, DCBE every five years or computed tomographic colonography every 5 years. To test for cancer specifically, they suggest annual FOBT, annual fecal immunochemical test, or stool DNA test (Levin et al., 2008).

At present, there is no Canadian consensus on screening of high risk familial or hereditary CRC populations. The Canadian Association of Gastroenterology and the Canadian Digestive Health Foundation have drawn from guidelines produced by the American Gastroenterology Association and the British Society of Gastroenterology

(Leddin et al., 2004). Meanwhile, certain provinces have released their own clinical practice CRC screening guidelines. Alberta's guidelines, for example, include a uniform and consistent list of evidence-based CRC screening recommendations for both the general (average risk) and high risk CRC populations (Alberta Cancer Board, 2008) (see Appendix C).

2.2.3.1 Organized screening programs

Compared to opportunistic or ad hoc screening, population-based CRC screening through an organized screening program is considered more effective and cost-efficient and improves adherence to screening recommendations (CCS, 2009d). Cancers with sufficient evidence for population-based screening include cervical, breast and CRC. Because screening subjects apparently healthy individuals to potential risk, it is only recommended when:

a) the screening test has been shown to reduce mortality;
b) the screening test is able to detect the disease in a pre-clinical phase;
c) the test is highly sensitive and specific;
d) the test is considered safe and does not subject an individual to an unacceptable; level of risk; and
e) if a cancer is identified through screening, effective treatment is available (Labianca et al., 2005).

When these criteria are met there are several other factors to be considered before full implementation of a screening program. This includes the acceptability of the test to the individual, costs of the test, and the extent to which there is sufficient capacity in the health care system to not only perform the screening test but also to provide the necessary

follow-up diagnostic confirmation and treatment for those with abnormal test results (Labianca et al., 2005).

In 2006, following a 6 year pilot project in England (Warwick and Coventry) and Scotland (Dundee), the NHS in the UK rolled out its National Bowel Cancer Screening Program. Emphasis was placed on wait times, the number of accredited colonoscopists to provide timely colonoscopy, maintenance of colonoscopists' workload at a minimum of 200 colonoscopies per year, and the ability to offer all patients a colonoscopy within two weeks of a nurse positive clinic appointment (CIHR, 2006). The Program currently centres around five hubs and each is connected to a series of services including screening facilities, local hospitals and cancer centre where the planning takes place for associated treatments such as pathology, surgery, further imaging, oncology and palliative care. Maximal screening capacity has been set at screening 2.5 million individuals between the ages of 60 and 69 per year. In addition, the single system entry database provides an excellent platform for conducting research.

In Canada, *The Canadian Partnership Against Cancer Screening Action Group* (2002) recently established a CRC screening network to provide a national forum to review, discuss and take action to enhance and improve CRC screening in Canada (http://www.partnershipagainstcancer.ca). Although Health Canada has been recommending population-based CRC screening programs since 2002 for all adults over 50 years of age, only in the last few years have provinces begun to explore this. In March of 2007, Alberta announced its plan to establish a provincial CRC screening program involving $500 million from the Alberta Cancer Prevention Legacy Fund. This program is to be rolled out over 5 years with an intensive education campaign and research focus.

Ontario launched its $193 million province-wide *ColonCancerCheck* program in April 2008 and Manitoba is proceeding with its CRC screening program that is borrowed heavily on methodology that has proven successful in the UK (Lett, 2007).

In NL, there is a Screening Working Group of the *Provincial Cancer Control Strategy* (CCS, 2006) which aims to provide strategic direction for improving CRC screening services for Newfoundlanders and Labradorians. The Working Group recommends many of the core components of an organized cancer screening program including: quality control/ quality assurance measures; organized follow-up; education and training for both the public and health professionals; program evaluation; information systems; and an accurate and up to date cancer registry (CCS, 2009d). The Screening Working Group specifically recommends that a "screening division" be created within the Provincial Cancer Care Program to ensure adherence to the core components (CCS, 2006).

2.3 Barriers to Screening

Despite evidence that suggests routine screening reduces incidence, morbidity and mortality associated with CRC, screening in Canada remains suboptimal (Rabeneck & Lawrence, 2004). Barriers exist at the patient, health provider and health care system level and all contribute to the underutilization of CRC screening (Beeker, Kraft, Southwell & Jorgensen, 2000; Klabunde, Vernon, Nadel, Breen, Seeff & Brown, 2005). Barriers include lack of awareness of CRC or screening among the public, inconsistencies in screening recommendations, lack of physician encouragement and patient-physician interaction, inadequate social support, negative attitudes toward the screening preparation

and procedure, and lack of access to health care (Beeker et al., 2000; Klabunde et al., 2005; Hilsden, McGregor, Murray, Khoja & Bryant, 2004b).

2.3.1 Adherence Rates

The 2003 CCHS 2.1 survey data indicated that only 30% of Canadians 50 years of age and older received FOBT and/or endoscopy in compliance with CRC screening guidelines, whereas 58% had never received either procedure (Sewitch, Fournier, Ciampi & Dyachenko, 2007). As depicted in Figure 3, the proportion of people who reported up-to-date CRC screening was highest in Ontario (20.0%) and lowest in NL (12.6%). As few as 4% of women in NL reported having a FOBT within the last two years from when the survey was conducted (Zarychanski et al., 2007). Most recently, McGregor, Hilsden, Li, Bryant, and Murray (2007) determined rates of CRC screening among adults aged 50 to 74 years in Alberta three years after Health Canada released screening guidelines in 2002 for the general (average risk) population. Findings suggested that women were more likely than men to have been screened with a home FOBT whereas men had slightly higher rates of screening endoscopy (FS or colonoscopy) in the previous five years. Overall, only 14.3% (n = 1476) of the participants were up-to-date on CRC screening.

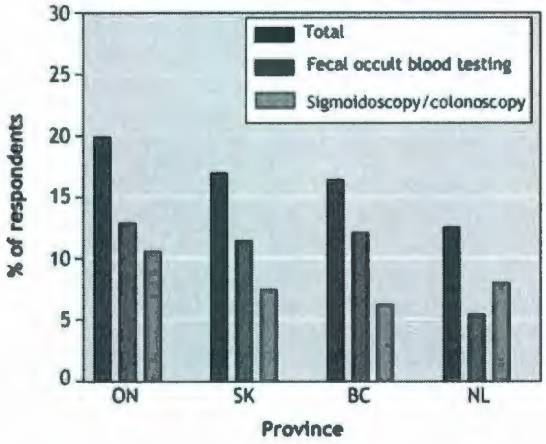

Figure 3: Proportion of survey respondents who reported up-to-date CRC screening by Canadian province. *Note:* From Zarychanski et al. (2007). Used with permission of the author.

Similar to Canada, the rate of CRC screening in the US is low (Shapiro, Seeff & Nadel, 2002; Meissner, Breen, Klabunde & Vernon, 2006; Seeff, Nadel, Klabunde, Thompson, Shapiro, Vernon, et al. 2004). The National Health Interview Survey (NHIS), a longitudinal national survey of households in the US, is the primary source of information on the health status of its non-institutionalized population. Findings from the NHIS 2000 study found only 45% of men and 41% of women aged 50 years or older had undergone FOBT and endoscopy (FS or colonoscopy) within recommended time intervals (Seeff et al., 2004). Shortly thereafter, NHIS data from 2003 found that rates had only increased minimally to 46% of men and 43% of women (Meissner et al., 2006). This slight increase among both men and women was attributed primarily to the increased use of colonoscopy as the screening test (32.2% and 29.8 %, respectively) as compared to the use of FOBT (16.1% and 15.3%, respectively) or FS (7.6% and 5.9% respectively).

The rate of CRC screening is the lowest among the cancers for which population-based screening is recommended (CCS, 2009d). Even prostate cancer screening rates using prostate-specific antigen (PSA) is higher than CRC screening rates, despite lack of evidence supporting population-based screening measures (Lemon, Zapka, Puleo, Luckmann & Chasan-Taber, 2001). As described by Lemon and colleagues (2001):

> The designation of breast cancer as a national public health priority, a major cancer control research initiative, promotion by public advocacy groups, studies confirming the effectiveness of screening, development of supportive state policies and legislation, wide promulgation of practice guidelines and widely promoting health plan and physician performance standards have all played important roles (p. 1265).

For prostate cancer screening, Lemon and colleagues (2001) feel that while the effectiveness of PSA screening on improving survival continues to be debated, the low cost and ease of performance are believed to be acceptable features of the test and thus influence uptake.

The public's reluctance to have CRC screening has been attributed to the relatively new release of guidelines as well as the complexity of the guidelines with numerous testing options. Potential confusion among the public as well as family physicians has been speculated to contribute to low screening rates (Madlensky, Esplen, Gallinger, McLaughlin & Goel, 2003). Moreover, public perception of CRC screening is frequently negative and concerns about test preparation requirements, pain and embarrassment are prevalent (Beeker et al., 2000; Klabunde et al., 2005).

2.3.1.1 Physician recommendation

Physician recommendation plays a large role in patient adherence to CRC screening as well as patient acceptance of a particular test regardless of their personal preference (Madlensky et al., 2003; Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, et al., 2002; Ramji, Cotterchio, Manno, Rabeneck & Gallinger, 2005; Klabunde et al., 2005; Seeff et al. 2004; Zapka, Puleo, Vickers-Lahti, & Luckmann, 2002). In a recent US national survey, primary care physicians reported relatively low volumes of ordering, performing or referring for CRC screening (Klabunde et al., 2005). This demonstrates that all eligible patients in their practices are not receiving screening. Among Alberta primary care physicians, 38% agreed that CRC screening was a lower priority than other health issues because of time restrictions during a routine physical examination (McGregor, Hilsden, Murray & Bryant, 2004). It is speculated that family physicians may not be encouraging CRC screening because of the lack of reimbursement specifically for CRC screening and for referring to specialists (McGregor et al, 2007).

2.3.1.2 Physician knowledge and practice patterns

A survey by Schroy, Barrison, Ling, Wilson and Geller (2002) found that gastroenterologists were more knowledgeable than family physicians about eliciting family history of CRC and implementing appropriate screening strategies. For example, gastroenterologists were more likely than family physicians to suggest the appropriate age of 25 to begin screening for HNPCC (73% vs. 43%) and the appropriate screening test, the colonoscopy (97% vs. 76%). A similar study by Barrison, Smith, Oviedo, Heeren and Schroy (2003) found that family physicians both in practice and in training were knowledgeable about existing screening recommendations for individuals with a family

history of CRC, but not AP. However, both groups lacked the necessary knowledge and risk assessment skills to appropriately screen individuals with or at risk for FAP and HNPCC.

Between October 2004 and March 2005, self administered questionnaires were distributed by Sewitch, Burtin, Dawes, Yaffe, Snell, Roper, et al. (2006) to 65 family physicians and gastroenterologists at three university affiliated hospitals in Montreal, Quebec. All respondents knew about the screening guidelines for the general (average risk) population and 95% said they were screening as suggested. Among those who screened, most preferred FOBT (88.3%) and colonoscopy (88.3%) rather than FS (10.0%) or DCBE (30.0%). Most family physicians knew the correct screening frequency for FOBT (87.6%) but less than 40% could identify correct screening frequency for the other modalities. Meanwhile, an Alberta study by McGregor and colleagues (2004), found that less than half (41.9%) of primary care physicians (n = 595) were familiar with the CRC screening guidelines. Seventy- four percent of the physicians recommended that asymptomatic patients undergo screening, however only 35.6% offered screening to at least 75% of general (average-risk) patients. Few (9.4%) rated FOBT as an "excellent or very good" screening test and most (64.1%) would choose colonoscopy, if they themselves were to undergo screening.

It is well documented in the literature that genetic testing is associated with increased adherence to screening guidelines for the high risk CRC population (Wagner, van Kessel, Kriege, Tops, Wijnen, Vasen et al., 2005; Halbert, Lynch, Lynch, Main, Kucharski, Rustgi, et al., 2004; Hadley, Jenkins, Dimond, de Carvalho, Kirsch, Palmer, et al., 2004). However, this requires that physicians are aware of diseases with defined

genetic linkages and are knowledgeable of the importance of involving genetic counselors to ensure that appropriate information is communicated to patients. A study by Giardiello, Brensinger, Petersen, Luce, Hylind, Bacon, et al. (1997) found that among physicians across 32 states in the US who requested genetic testing for patients with FAP, more than 80% did not offer genetic counseling before the test or obtain informed consent for testing. Additionally, in 31.6% of cases, the physicians misinterpreted the test results. A similar study in New York State by Batra, Valdimarsdottir, McGovern, Itzkowitz and Brown (2002) found that 99% of gastroenterologists obtained a family history from their patients when screening for CRC and 95% were aware of cancer genetic counseling. However, only 51% would routinely refer patients for genetic counseling before providing cancer predisposition testing. In addition, only 52% were aware of the availability of genetic testing for FAP and 34% for HNPCC.

2.3.1.3 Patient knowledge and attitudes

Attitudes and knowledge towards CRC screening among adults have been investigated quantitatively and qualitatively. A study by Shokar, Vernon and Weller (2005) conducted in-depth individual interviews (n = 30) with individuals 50 years of age or older, from diverse ethnic backgrounds. All participants, particularly minority participants, lacked knowledge of cancer, CRC and screening. Participants demonstrated difficulty understanding terms routinely used in practice, which the authors concluded underlie the challenges providers face in effectively discussing cancer and CRC screening recommendations with patients. Additionally, there was a lack of understanding about the concept of screening and that screening is performed when a person feels well. Another study by Janz, Wren, Schottenfeld, and Guire (2003) conducted telephone interviews (n =

355) with men and women, aged 50 to 79 years of age living in Michigan State. Less than 30% of participants were found to be adherent to the current screening guidelines. Reasons given were the belief that the screening test is not needed and that it is embarrassing.

In 2004, a series of focus groups was conducted in Ontario with several groups including the general (average risk) population, individuals with a personal or family history of CRC, and family physicians. The purpose was to help inform the *Ontario Expert Panel on CRC Screening* and to assist with preparation of their proposal for a provincial CRC screening program (Goel, Gray, Chart, Fitch, Saibil & Zdanowicz, 2004). Among the general (average risk) participants, there was limited experience with colonoscopy and it was not perceived to be a test that would be acceptable for screening. However, those who had already experienced colonoscopy were more willing to accept it and most agreed they would only be willing to go for the test if they had symptoms. The main concerns raised about colonoscopy included risks ("piercing") and pain that might be associated with it. Otherwise, the majority of general (average risk) participants chose FOBT as the preferred screening test. The higher risk participants felt that the onus to promote screening should be with the physician who should also explain the test in detail. They felt that education of physicians was important and the way screening is done should be standardized across all physicians.

People who practice other healthy behaviors have been found to be more likely to pursue CRC screening (Shapiro et al., 2002). For example, women who underwent a mammogram or pap smear test within recommended intervals appeared more likely to report having undergone CRC screening compared with those who did not (Seeff et al.,

2004). Individuals aware of their risk for CRC, particularly if notified through an affected family member (i.e., first degree relative affected with CRC) also appeared more likely to be screened (Lemon et al., 2001; Seeff et al., 2004; Manne et al., 2002). And finally, socio-demographics, including male sex (Sewitch et al., 2007; Brawarsky, Brooks & Mucci, 2003) and highest income level (Sewitch et al., 2007; Whynes, Frew, Manghan, Scholefield, & Hardcastle, 2003) have been associated with increased adherence to FOBT screening guidelines.

2.3.1.4 Health system barriers

Widespread implementation of CRC screening strategies in the past have been limited because of extended wait times for gastroenterology specialist care for patients with digestive diseases (Hilsden et al., 2007). This includes access to trained endoscopists who perform colonoscopies. In 2002, physician socio-demographic and activity data were obtained by Hilsden et al. (2007) from the Canadian Institute of Health Information's National Physician Database. Gastroenterologists and general surgeons performed over 97% of all colonoscopies. Gastroenterologists were the primary providers of colonoscopies in larger urban areas, whereas general surgeons were the primary providers in smaller urban and rural areas. Annually, an average of 317 colonoscopies was performed by each general surgeon, 516 by each gastroenterologist, and 203 by other physicians.

Recently, national guidelines were set by the Canadian Association of Gastroenterology regarding accepted wait times for specialist gastroenterology care in Canada (Paterson, Depew, Pare, Petrunia, Switzer, et al., 2006). A study by Leddin, Armstrong, Barkun, Chen, Daniels, Hollingworth and colleagues (2008) found that less

than one-half of the patients referred received a full evaluation within the suggested wait time. Canada is currently facing a national shortage of gastroenterologists, 33% of whom are expected to retire within the next 10 years. Based on the number of new gastroenterologists currently being trained, this would result in an estimated 10% reduction of gastroenterologists within 10 years time (Moayyedi, Tepper, Hilsden & Rabeneck, 2007). As described by Hildsen (2004a), these statistics are concerning when provinces such as Alberta are experiencing a colonoscopy rate that more than doubled (146% increase) from 1994 to 2002.

Canada currently has fewer gastroenterologists per 100,000 population than the US, France or Australia (Moayyedi et al., 2007). There is no definition of what the optimum number of gastroenterologists per 100,000 population should be. However, merely increasing endoscopy facility resources is not considered an adequate approach to meet the colonoscopy demand given that medical and surgical specialists are averaging 54.5 hours and 57.6 hours of work per week, respectively (Hilsden et al., 2007) Alternative care models involving primary care physician endoscopists, nurse practitioners, physician extenders such as nurse endoscopists and gastroenterology physician assistants have been suggested as a way to meet the rising demand while shortening wait times (Rabeneck & Adams, 2006).

Cotterill, Gasparelli and Kirby (2005) used the rural community of Wawa, Ontario to assess if a CRC screening program reliant on colonoscopy could be performed safely and effectively by non-specialist endoscopists in rural areas. Two family doctors were trained to do the colonoscopies, which were carried out in hospital. A small increase in staff and operation room time was required. Patients between the ages of 50 and 75 and

those at high risk of CRC based on family history were screened. Measures of safety and effectiveness were monitored. In two years of screening, one of 152 patients was found to have CRC and 23.7% had AP. There were no complications. Rates of CRC and adenoma detection were similar to rates found in other screening programs, suggesting that non-specialists can safely perform colonoscopies while better meeting the demands for CRC screening in rural communities.

Overuse of colonoscopy is also a potential problem to providing services within a timely fashion. The American Society for Gastroenterology Endoscopy {ASGE} (2006) and the *US Multi-Society Task Force on Colon Cancer* has published appropriate indicators for colonoscopy (Rex et al., 2006). A study by Minoli, Meucci, Bortoli, Garripoli, Gullotta, Leo, et al. (2000), attempted to evaluate the appropriate use of colonoscopy in the public health system in Italy and to assess whether the ASGE guidelines are useful in clinical practice. Approximately 21% of colonoscopy examinations requested were not indicated according the ASGE guidelines. A similar scenario appears to be occurring in Ontario, as FS rates have declined over past decades due to gastroenterologists and general surgeons preferring to do colonoscopies (Rabeneck & Adams, 2006).

2.3.2 Adherence to Repeat Screening

To achieve the goal of reducing cancer morbidity and mortality, it is imperative that patients receive timely and appropriate follow-up. It is also important that they have positive experiences when accessing the health system to prevent deterrence from the screening process (Geary et al., 2007). Adherence is especially difficult for colonoscopy

because of its rather invasive nature and the requirement for sedation (Goel, et al. 2004). While HNPCC gene mutation carriers in NL were able to identify the benefits of engaging in regular screening, the demands of scheduling appointments and waiting for results were identified as being overwhelming, confusing and time consuming. Follow-up monitoring by health care providers was considered critical to successful coping and overall adjustment to the disease. (J. Stokes, Research Coordinator, personal communication, October 21, 2008).

A Finnish study aimed at evaluating the compliance and satisfaction of HNPCC gene mutation carriers adjusting to a life of colonoscopy screening found a compliance rate that was extremely high (99.5% in the study group) (Pylvanainen, Kairaluoma, & Mecklin, 2006). Part of the reason was attributed to the comprehensive face-to-face counseling and continuous communication arranged with a professional from the Finnish HNPCC Registry. Another reason was attributed to the large number of neoplastic lesions that were discovered during follow-up. Similarly, a recent Swedish study involving 240 persons in long-term CRC surveillance, including 28 HNPCC mutation carriers, found that individuals who recalled detection of polyps in the past had an improved perception of the benefit behind screening, thus increasing patient motivation to take-up surveillance endoscopies (Liljegren, Lindgren, Brandberg, Rotstein, Nilsson, Hatschek, et al., (2004)).

Other positive influences on adherence to repeat screening have been demonstrated in a California-based study by Bastani, Yabroff, Myers, and Glenn (2004) who examined follow-up among women with abnormal pap tests. This study found that reminders delivered by mail or telephone as well as education to address fears related to an abnormal finding through telephone counseling, pamphlets or other material were

largely successful in improving timely follow-up. Another study also conducted in California by Engelstad, Stewart, Nguyen, Bedeian, Rubin, Pasick, et al. (2001) found that a specialized clinic involving a nurse case manager, tracking system, reminder calls, rescheduling of missed appointments, and clinic staffing with on-site colposcopy also achieved a significantly increased follow-up rate among women with abnormal pap tests. Same day follow-up has also been successful in increasing follow-up rate for an abnormal pap tests and colposcopy (Holschneider, Felix, Satmary, Johnson, Sandweiss, & Montz, 1999) as well as for abnormal colonoscopy and flexible sigmoidoscopy (Stern, Fendrick, McDonnell, Gunaratnam, Moseley, & Chey, 2000). In the latter study, when patients were asked their preference for future screening, 96% chose same day and same site follow-up colonoscopy.

Finally, the impact of patient navigators has been assessed by Nash, Azeez, Vlahov, and Schori (2006) in assisting patients obtaining both initial and follow-up colonoscopy screening. The purpose of the patient navigators was to increase efficiency and provide continuity for the patients at various points from time of referral to the completion of the colonoscopy procedure. The patient navigators assisted in completing paper work, scheduling appointments and providing appointment reminders. They were able to facilitate referrals either through the gastrointestinal or colorectal clinic. The likelihood of the patient keeping the appointment for colonoscopy after the patient navigator intervention increased by nearly three-fold. For those seeking the procedure for screening purposes, rates increased from 56.8 per month to 119 per month.

2.4 Summary

CRC is one of the most prevalent yet preventable forms of cancer. With CRC incidences in NL being approximately twice that of British Columbia and rates only expected to increase with the aging population, adherence to screening guidelines needs to be improved. This requires that family physicians and specialists are not only knowledgeable of CRC risk factors and screening guidelines but are also selective in the type of screening test so not to exhaust available resources, namely for colonoscopy. As described in this literature review, an organized and well coordinated approach to screening has been shown to improve rates of adherence to screening guidelines.

Chapter Three - Methodology

This descriptive, cross-sectional study profiles specific characteristics of colonoscopy service providers in NL. A 20 question self-administered survey (see Appendix D) is used to collect information about the knowledge and practice patterns of gastroenterologists and general surgeons regarding screening patients who have a personal or family history of CRC or AP and those with a genetic predisposition for HNPCC or FAP. It also describes their attitudes about current CRC screening services in the province. This information will help to address the ultimate objective of the study which is to inform and guide a comprehensive long-term strategic plan to manage CRC screening in NL, particularly for the higher risk populations.

3.1 Survey Development

Questions are modeled after a previously administered survey to physicians and specialists which covered similar content (Schroy et al., 2002). This is done to increase the validity and reliability of the findings while allowing for a comparison of findings. Questions are designed to reflect published CRC screening guidelines (Alberta Cancer Board, 2008; Leddin et al., 2004; Levin et al., 2008). Experts consulted during the development of the survey instrument include the Chair of Surgery for the Faculty of Medicine at Memorial University, a Medical Geneticist, a Medical Ethicist and a Professor in Health Policy/ Health Care Delivery. These individuals offered unique perspectives on the types of questions required to adequately address the research objectives.

The survey is divided into three sections: 1) specialist personal and practice characteristics, 2) hereditary CRC screening, and 3) attitudes about current CRC screening services. The majority of questions are closed-ended and involve clinical scenarios with the option to check more than one answer. Definitions of family history of CRC and AP are provided. Family history of CRC is defined as having a single first-degree relative with CRC diagnosed at younger than age 55. Family history of AP is defined as having a single first-degree relative with AP diagnosed at younger than age 60 (Schroy et al., 2002).

In the first section of the survey, the specialists are asked questions related to basic demographics including specialty, gender, age, year of graduation, years of practice in NL, professional body certification and community size (Questions # 1-6). They are asked if they perform colonoscopies in their practice, and if so, for how many years and how many annually (Question # 7-9). This information helps to identify the relative distribution of available gastroenterologists and general surgeons who provide colonoscopies across the province.

In the second section of the survey, the specialists are asked if they routinely ask asymptomatic patients (both under 40 years and over 40 years of age) about family history of CRC or AP. This is followed by specific sub-questions about screening practices for patients with: 1) family history of CRC; 2) family history of AP; 3) FAP, 4) HNPCC; and 5) asymptomatic patients 50 years of age and older with no family history of CRC or AP. Questions pertain to the age they recommend to begin screening, the type of screening modality, other health professionals involved and if genetic testing is routinely recommend for patients suspected of being carriers of HNPCC or FAP gene

mutations (Questions # 12-13). The specialists are asked if they discuss advantages/disadvantages associated with different screening approaches with their patients, and if yes, whether they give patients the opportunity to apply their own preference to the type of screening test used (Question #14). They are also asked who they feel should be responsible for monitoring patient compliance to screening, if and how they prioritize care, and expected wait times for their colonoscopy service (Questions # 15-17). The prioritization question (# 16) is open-ended as it was felt to be unique for each specialist, particularly those practicing in rural regions. This section concludes with a question about where the specialists have obtained information pertaining to CRC risk factors and screening recommendations and their preferred method of receiving such information (Question # 18).

In the final section of the survey a five-point Likert scale is used to measure attitudes about current CRC services in NL (Question # 19). This includes questions related to: the need for a province wide CRC registry; the need for a province wide CRC screening central booking centre; whether gastroenterologists, general surgeons and family physicians could use more education about familial and hereditary CRC screening; the usefulness of genetic testing to their practice; and whether health professionals other than gastroenterologists and general surgeons should be trained to perform colonoscopies.

Finally, the specialists are asked if they would be willing to be contacted for a follow-up interview and if they had any additional comments (Question # 20). This provides the opportunity for future contact if new themes of interest arise from analysis of the data.

3.1.1 Pretesting

The survey was pre-tested with one gastroenterologist and one surgeon at the Health Sciences Centre in St. John's. Feedback was used to improve clarity of questions while ensuring appropriate options for answering the different clinical scenarios. As a result of the pretesting, an additional option of "do not screen" was added for all clinical scenario questions (Question # 12-13). As well, the Likert scale question (Question # 19 c and d) regarding gastroenterologist and surgeon attitude about continuing education needs which were originally combined into the same question, were separated into two different questions following the pretesting.

3.2 Sample Frame

The sample frame includes all gastroenterologists and general surgeons registered with the College of Physicians and General surgeons of NL as of December 31st, 2008. Specialist mailing addresses are available on the College website. To be included in the study, specialists indicate on the first page of the survey that they practice in NL and perform colonoscopies. Excluded from the study are physicians completing their post graduate residency training or whose practice is primarily pediatric patients.

3.2.1 Representativeness of the sample

To assess the representativeness of the sample, chi square tests are used to compare respondents to non-respondents in terms of specialty, gender and community size of practice. These variables are available from College of Physicians and General surgeons of NL website allowing for the inference of traits of non-respondents.

3.3 Data Collection

Certain recommendations from the *Tailored Design Approach for Mail and Internet Survey* (Dillman, 2007) are used to maximize response rate. This includes the use of a respondent friendly questionnaire, repeat contact (second mailing to non-respondents 3 weeks after the initial mail-out with replacement questionnaires), return envelopes with postage, and personalization of correspondence. Attached to the first page of the survey is a cover letter which describes the purpose of the study and its potential impact in helping to improve CRC screening services in the province. The specialists are informed that the survey will take less than ten minutes to complete, as determined from the pretesting. Tracking of responses is done using postcards which are returned separately from the surveys (see Appendix E). This approach ensures anonymity of responses. The first round of surveys was mailed on January 28th, 2009.

Due to the relatively small number of specialists performing colonoscopies in NL, a few extra steps are taken to further increase response rate. For example, when the second round of surveys was mailed on February 21st, 2009, a phone call was also made to the specialists' respective secretaries. Additionally, the Chair of Surgery for the Faculty of Medicine at Memorial University along with a gastroenterologist from the Gastrointestinal Unit at Health Sciences Centre in St. John's reminded colleagues to complete the survey.

3.4 Data Management

Survey responses are entered into SPSS, a database for statistical analysis. Results are entered twice in order to minimize data entry errors (National Statistical Service,

2002). Completed surveys are given a unique identifier code so that if data entry errors are found, the original survey is easily checked and errors corrected (National Statistical Service, 2002). A separate electronic database is used to track the postcards returned, which includes respondent identity and mailing address. This is used to determine to whom to mail a second survey and follow up.

Prior to conducting any analysis, the data are cleaned to detect and remove any errors, inconsistencies and implausible entries by running frequencies for all questions and uni-variate descriptive statistics (mean, median, standard deviation, minimum and maximum) to identify any out-of-range values. Depending on responses, certain questions are recoded to either condense categories or to add categories based on responses to the "other" option. For example, certain respondents indicated they begin screening individuals with a family history of CRC at age 40 or ten years before the youngest affected family member. However, this option was not provided so the question is recoded for analysis. "Additional comments" are also recoded into new variables and analyzed for common themes.

Given the nature of the research objectives, the analysis is limited to descriptive statistics. Frequencies are used for categorical variables and means and standard deviations are used for continuous variables (e.g. responses using five-point Likert scale). Comparisons between groups are not done due to the small sample size and risk of potentially identifying individual specialists. Any missing values are excluded from the analysis. Missing values for individual questions range from 0 to 3 with most questions having no missing values. Details of the coding scheme for variables used in the analysis are outlined in Appendix F.

3.6 Ethical Considerations

The survey was reviewed by a Sub-Committee of the Human Investigative Committee with the Faculty of Medicine at Memorial University (see Appendix G). Final approval was granted on January 6th, 2009.

Results are reported in aggregate only due to the small sample size. Any question that could potentially identify a respondent is avoided (i.e., school of medical graduation or specific area of employment). In certain cases categories are re-grouped if there is any reason to believe respondents might be identified. As mentioned earlier, tracking of respondents' identity and ensuring anonymity is achieved through postcards which are returned separately from the surveys. Finally, all completed surveys are stored in a locked room with restricted access. Any electronic files of the data are password protected.

Chapter Four - Results

4.1 Survey Response

There were 58 gastroenterologists and general surgeons listed on the College of Physicians and Surgeon of NL website as of December 2008. Five could not be contacted because of an incorrect or missing address as reported on returned surveys or through contact with secretaries during follow-up. Nine do not perform colonoscopy and one respondent works with the pediatric population and is therefore excluded because the majority of questions are not applicable. The final sample frame is therefore reduced to 43. Of these, 36 returned a survey for an 83.7% response rate (see Figure 4).

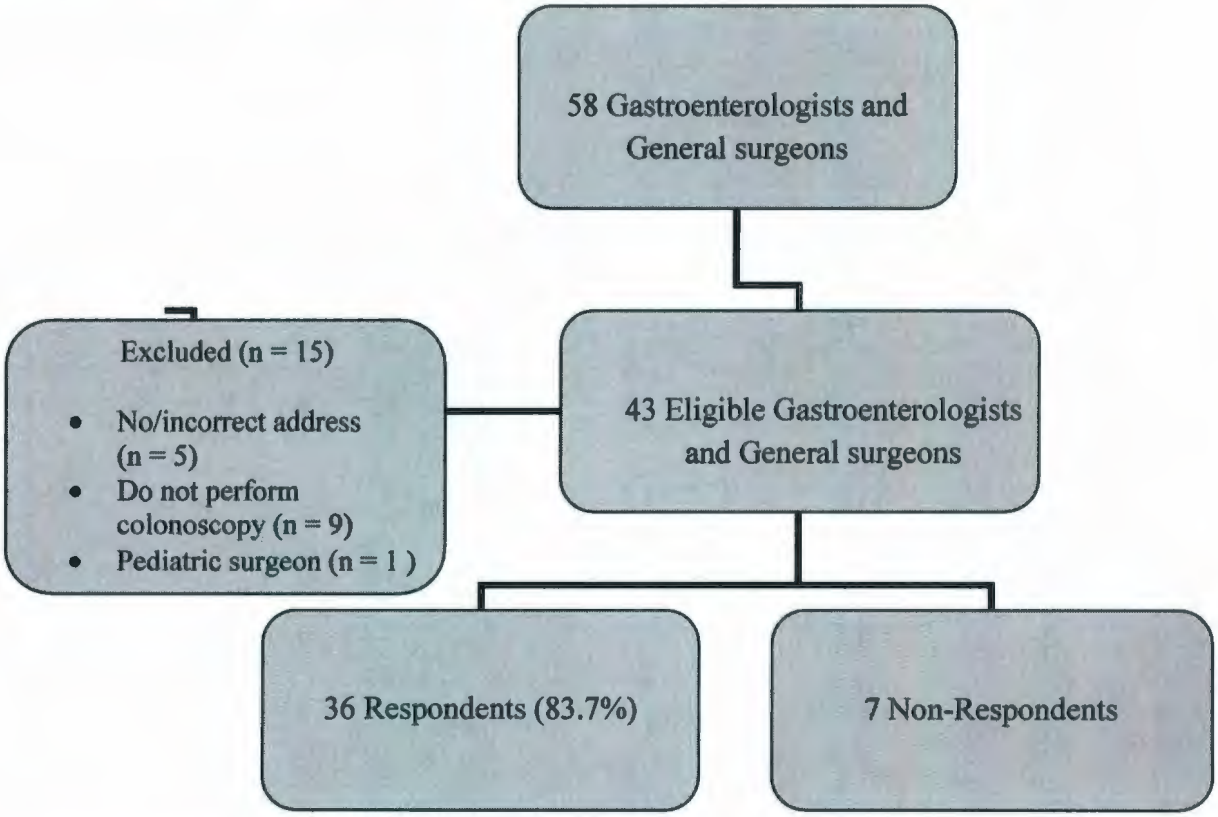

Figure 4: Determination of study sample and response rate

4.2 Representativeness of Sample

The gender, specialty and community size of the sample frame and respondents are compared by calculating chi-square tests by hand (see Table 1). These characteristics are selected because data are available (or inferred) from information provided on the College of Physicians and General surgeons of NL website for all specialists in the sample frame. Based on the chi square test statistical analysis, the sample is representative in terms of gender and specialty but not for community size. The sample slightly over represents specialists practicing in a community size of population <100,000 and under represents those practicing in a community size of population >100,000.

Table 1
Comparison of sample frame and respondents to assess representativeness of sample

	Sample Frame	Respondents	p value
Gender			
Male	36 (83.7)	29 (82.9)	>.05
Female	7 (16.3)	6 (17.1)	
Specialty			
Gastroenterology	9 (20.9)	9 (25.7)	>. 05
Surgery	34 (79.1)	26 (74.3)	
Community Size of Practice			
<10,000	7 (16.3)	7 (20.0)	< .05
10,000-100,000	15 (34.9)	15 (42.9)	
>100,000	21 (48.9)	13 (37.1)	

4.3 Respondent Characteristics

Table 2 describes respondent characteristics. Gastroenterologists make up one quarter of the sample. The majority of respondents are male. There is a fairly even spread of years since graduation among the respondents, however more than half of respondents have been practicing in NL for less than ten years. Sixty-two percent of respondents work in a rural/sub-urban community with a population <100,000 and the remainder in an

urban community with a population >100,000, presumably St. John's. The majority of respondents are certified with the Royal College of Physicians and General surgeons. Most perform around 250-500 colonoscopies per year and two of the respondents perform less than 100 per year.

Table 2
Characteristics of specialists who perform colonoscopies in NL

Specialty	**n (%)**
Gastroenterology	9 (25.0)
Surgery	27 (75.0)
Gender	
Female	6 (17.1)
Male	29 (82.9)
Years since medical school graduation *	
less than 10 years ago	12 (35.3)
10-20 years ago	7 (20.6)
20-30 years ago	8 (23.5)
more than 30 years ago	7 (20.6)
Number of years practicing in NL	
less than 10 years	20 (57.1)
10-30 years	12 (34.3)
more than 30 years	3 (8.6)
Professional body certification	
Royal College of Physicians and General surgeons of Canada	29 (82.9)
American Board of Surgery	3 (8.6)
Non-Certified Specialist	4 (11.4)
Other	3 (8.4)
Community size	
Rural (<10,000)	5 (14.3)
Small urban (10,000-100,000)	17 (48.6)
Urban (>100,000 population)	13 (37.1)
Number of years performing colonoscopies	
less than 10 years	12 (34.3)
10-30 years	21 (60.0)
more than 30 years	2 (5.7)
Number of colonoscopies performed annually	
less than 100	2 (5.9)
101-250	7 (20.6)
251-500	12 (35.3)
501-750	6 (17.6)
more than 750	7 (20.6)

* After releasing the survey, we noticed an overlap between the categories. None of the respondents indicated more than one category.

4.4 Respondent Knowledge and Practice Patterns

More than three quarters of respondents collect family histories about CRC and/or AP from patients greater than 40 years of age (see Table 3).

Table 3
Specialists who collect family history from patients with family history of CRC and/or AP

Percent of patients < 40 years of age	**n (%)**
0-25%	9 (25.7)
26-75%	4 (11.4)
76-100%	22 (62.9)
Percent of patients > 40 years of age	
0-25%	2 (5.7)
26-75%	5 (14.3)
76-100%	28 (80.0)

As shown in Table 4, 40 to 49 years of age or 10 years earlier than the youngest diagnosed family member is the most common age to begin screening patients with a family history of CRC (85%) and AP (69%). Fifteen to 24 years of age is the most common age to begin screening patients with FAP (86%) and 25-39 years of age for patients with HNPCC (61%). The preferred screening test for all groups is colonoscopy, followed by FS for patients with FAP (22%) and digital rectal exam (DRE) for patients with a family history of CRC (20%). For those who selected DRE, most also selected in combination FOBT. Although not provided as an option, two of the respondents indicate they use oesophago-gastro-duodectomy as a screening test for patients with FAP.

At least one third of respondents involve family physicians in the screening process for their patients. Another one-third of respondents do not include any other health professionals in the care of patients with a family history of CRC or AP. It should

be noted that it was not possible to determine from the survey which health professionals referred the patients to the specialists.

Genetic testing is routinely recommended by 97% of respondents for patients suspected for FAP and by 81% for patients with HNPCC. Of all the respondents, 72% involve genetic counselors with the Provincial Medical Genetics Program (PMGP) for patients with FAP, while 67% do so for patients with HNPCC. One quarter of respondents would also include a gynecologist and/or urologist for patients with HNPCC.

Colonoscopy every ten years is the most commonly reported screening test used with the general (average risk) population which includes adults 50 years with no other risk factors for CRC other than age. This is followed by FOBT. For those respondents who indicate they use DRE for the general (average risk) population, almost all report also using FOBT. Over three-quarters of respondents take the time to discuss the advantages and disadvantages of the different screening methods with patients and of these, most allow patient preference to influence the screening test used.

As shown in Table 5, only 15% of respondents report seeing general (average risk) individuals for screening with colonoscopy within three months while another one-third are not seeing them for over a year. Meanwhile, 24% of respondents will see patients with a family history of CRC; 30% will see patients with a family history of AP; and 56% will see patients with FAP or HNPCC within this same timeframe.

Table 4

Hereditary CRC screening practices (a) family history of CRC (b) family history of AP (c) FAP (d) HNPCC (e) general population

	Family history of CRC	Family history of AP	FAP	HNPCC	General Population
			n (%)		
Age					
15-24	0 (0.0)	1 (2.8)	31 (86.1)	12 (35.3)	n/a
25-39	4 (11.8)	2 (5.6)	5 (13.9)	20 (58.8)	n/a
40-49 (or 10 year before youngest affected family member)	29 (85.2)	25 (69.4)	0 (0.0)	2 (5.9)	
50+	1 (2.9)	8 (22.2)	0 (0.0)	0 (0.0)	n/a
Screening test *					
Digital rectal exam	7 (20.0)	5 (13.9)	5 (13.9)	5 (13.9)	5 (13.9)
Flexible sigmoidoscopy	1 (2.9)	1 (2.8)	8 (22.2)	1 (2.8)	2 (5.6)
Colonoscopy	33 (94.3)	34 (94.4)	29 (80.6)	34 (94.4)	25 (69.4)
FOBT	5 (14.3)	5 (13.9)	4 (11.1)	4 (11.1)	14 (38.9)
FOBT plus flexible sigmoidoscopy	0 (0.0)	1 (2.8)	0 (0.0)	1 (2.8)	2 (5.6)
Double contrast barium enema	2 (5.7)	2 (5.6)	2 (5.6)	2 (5.6)	3 (8.3)
Do not screen	1 (2.9)	1 (2.8)	1 (2.8)	1 (2.8)	
Other health professionals involved *					
Other gastroenterologists/ general surgeons	8 (22.9)	8 (22.2)	13 (36.1)	13 (36.1)	n/a
Family doctor	16 (45.7)	14 (38.9)	16 (44.4)	14 (38.9)	n/a
PMGP	9 (25.7)	5 (13.9)	26 (72.2)	24 (66.7)	n/a
Gynecology/ Urology	1 (2.8)	0 (0.0)	3 (8.3)	9 (25.0)	n/a
None	11 (31.4)	13 (36.1)	2 (5.6)	2 (5.6)	n/a
Genetic testing					n/a
Yes	1 (3.0)	3 (9.4)	32 (97.0)	25 (80.6)	n/a
No	32 (97.0)	29 (90.6)	1 (3.0)	6 (19.4)	n/a

* Responses add up to more than 100% because respondents were allowed to select more than one answer. PMGP = Provincial Medical Genetics Program; CRC = colorectal cancer; AP = adenomatous polyps; FAP = familial adenomatous polyposis; HNPCC = hereditary non-polyposis colorectal cancer; n/a = not applicable (certain questions were not asked about screening for the general population)

Table 5

*Reported wait times for a colonoscopy according to patient group**

	General population	**Family history of CRC**	**Family history of AP**	**FAP and HNPCC**
	n (%)			
< month	2 (6.1)	2 (5.9)	3 (9.1)	5 (14.7)
1-3 months	3 (9.1)	6 (17.6)	7 (21.2)	14 (41.2)
3-6 months	6 (18.2)	9 (26.5)	7 (21.2)	5 (14.7)
6-12 months	11 (33.3)	9 (26.5)	11 (33.3)	9 (26.5)
>12 months	11 (33.3)	8 (23.5)	5 (15.2)	1 (2.9)

CRC = colorectal cancer; AP = adenomatous polyps; FAP = familial adenomatous polyposis; HNPCC = hereditary non-polyposis colorectal cancer

* After releasing the survey, we noticed an overlap between the categories. None of the respondents indicated more than one category.

Over three quarters of respondents indicate they have a systematic approach to prioritizing their colonoscopy service (see Table 6). Slightly more than half of respondents use presenting symptoms as the basis for this prioritization. Of presenting symptoms, occult blood in the stool is the most frequently reported. Some of these presenting symptoms would presumably be included in the referral letter to the specialists (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, June 13, 2009).

As shown in Table 7, almost one quarter of respondents feel it is the responsibility of the patient to monitor compliance to screening. Another one quarter feel it is the responsibility of the patient and family physician combined. Meanwhile, 16% of respondents feel it is the responsibility of the gastroenterologist and/or surgeon but only with the patient and family physician also monitoring.

Table 6

Specialist criteria for prioritizing colonoscopy service

Do you have a systematic approach to prioritization?	**n (%)**
Yes	28 (80.0)
No	7 (20.0)
On what basis do you prioritize?	
Symptoms	19 (52.8)
Abnormal lab data (i.e. iron deficiency)	4 (11.1)
Occult blood	8 (22.2)
Change in stool pattern	4 (11.1)
Weight loss	2 (5.6)
Abnormal barium enema	2 (5.6)
Referral from Family Doctor/ Nurse Practitioner	3 (8.3)
Referral from PMGP/ Results from genetic testing	2 (5.6)
Family history (CRC, polyps, FAP, HNPCC)	11 (30.6)
Personal history of CRC or polyps	3 (8.3)
FAP/HNPCC patients well past their screening interval	2 (5.6)
Age	4 (11.1)

CRC = colorectal cancer; AP = adenomatous polyps; FAP = familial adenomatous polyposis; HNPCC = hereditary non-polyposis colorectal cancer; PMGP = Provincial Medical Genetics Program

Table 7

Specialist approach to monitoring hereditary CRC patients' compliance to screening

Who should be responsible?	**n (%)**
Patient	8 (22.2%)
G/S	1 (2.8)
PMGP	2 (5.6)
Family Doctor	4 (11.1)
Patient + G/S	2 (5.6)
Patient + PMGP	1 (2.8)
Patient + Family Doctor	8 (22.2)
Patient + G/S + Family Doctor	6 (16.7)
G/S + Family Doctor	2 (5.6)
Patient + G/S + PMGP + Family Doctor	2 (5.6)

PMGP = Provincial Medical Genetics Program; G/S = Gastroenterologist/Surgeon

Almost all respondents (94%) indicate they have heard or read information pertaining to risk factors and screening recommendations for hereditary CRC through medical journals. This is followed by information on the topic received through hospital

rounds (64%) and consultation with colleagues (50%). When asked in an open-ended question about the preferred method of receiving this type of information, mail (including letters and newsletters) and email/internet is most frequently selected (see Table 8).

Table 8
Received and preferred sources of information pertaining to risk factors and screening recommendations for hereditary CRC

Source	**n (%)***
Medical journals	33 (94.3)
Patient letter from PMGP	15 (41.7)
Patients	8 (22.2)
Hospital rounds	23 (63.9)
Colleagues	18 (50.0)
Text books	2 (5.6)
Conferences	4 (11.1)
Canadian Association of Gastroenterology	2 (5.6)
Internet	1 (2.8)
Endoscopy Unit	1 (2.8)
Preferred method of receiving this information	
Medical journals	6 (16.7)
Mail/Letters/Newsletters (i.e. from PMGP)	8 (22.2)
Email/Internet	8 (22.2)

* Responses add up to more than 100% because respondents were allowed to select more than one answer.
PMGP = Provincial Medical Genetics Program

4.4 Respondent Attitudes about Current CRC Screening Services in NL

Table 9 outlines respondent attitudes about current CRC screening services in the province. This question involves a repeated five- point Likert scale where one = strongly disagree and five = strongly agree. Given that data from the Likert scale is normally distributed, mean and standard deviations are used. Almost all respondents either agree or strongly agree there is a need for a province wide CRC registry in NL. Many respondents feel that family physicians need more continuing education regarding family history of

CRC and screening. Respondents did not agree that other health professionals besides gastroenterologists and general surgeons should be trained to perform colonoscopies.

Table 9
Specialist attitude about current CRC screening services in NL

Attitude	**mean (std deviation)**
There is a need for a province wide colorectal cancer registry	4.36 (0.72)
There is a need for a province wide colorectal cancer screening central booking centre	3.25 (1.23)
Gastroenterologists need more continuing education around family history and CRC screening	3.03 (0.87)
General surgeons need more continuing education around family history of CRC screening	3.34 (0.97)
Family physicians need more continuing education around family history of CRC screening	4.00 (0.80)
High risk patients (i.e. FAP, HNPCC) should be seeing the same gastroenterologist/ general surgeon for follow-up colonoscopies	3.75 (1.13)
Other health professionals besides gastroenterologists/ general surgeons should be trained to do colonoscopies	2.36 (1.13)
Wait times for your colonoscopy service is reasonable	2.81 (1.28)
Genetic testing is useful to prioritizing patient care	3.25 (1.00)
You are referring more patients for genetic testing than 5 years ago	3.12 (1.01)
There is sufficient support given to those patients who undergo genetic testing	3.51 (0.70)

CRC = colorectal cancer; AP = adenomatous polyps; FAP = familial adenomatous polyposis; HNPCC = hereditary non-polyposis colorectal cancer

At the end of the survey, respondents are given the opportunity to provide additional comments. Some of the comments included:

- *"I was going to get the screening guidelines from the CAG [Canadian Association of Gastroenterology] online but since I am not a member I would have had to pay for getting their guidelines".*
- *"Approving province wide system may not work as well or as effective as a regional program with dedicated staff who therefore knows the patients personally.*

- *"I'm not aware "genetic testing" is routinely being available in this province? HNPCC screening begins 5 yrs younger than affected family member".*
- *"I found little practical help from genetic referral and their recommendations were essentially identical in regards to stratification.*
- *"I have little or no contact with the PMGP. As a result I tend to leave it to the family doctor to refer. This is less than ideal and I would like to have more info on genetics service re: screening in breast as well as CRC".*
- *"Does a proposed central booking registry have to be located in Avalon??? I suspect it is pre ordained".*

Chapter Five - Discussion

This study examined the characteristics, knowledge, practice patterns and attitudes of gastroenterologists and general surgeons in NL regarding CRC screening. CRC screening is relevant to both of these groups as they provide the majority of specialized diagnostic testing and surgical therapy for CRC. They are the only providers of colonoscopy in NL, the preferred test for screening many of the high risk familial and hereditary CRC populations (Alberta Cancer Board, 2008; Leddin et al., 2004; Levin et al., 2008). These specialists play a pivotal role in ensuring that residents of NL receive recommended preventive health care. They also act as opinion leaders to their colleagues in family practice (Hilsden et al., 2004b).

The response rate of 84% is considered high, particularly among physician surveys (Kellerman & Herold, 2001). Even the National Physician Survey which is Canada's most comprehensive and authoritative survey of physicians, medical students, and residents only received a response rate of 35.9% in 2004 (Grava-Gubins & Scott, 2008). However, given the relatively small number of specialists eligible to participate, it was imperative that the majority would respond in order to adequately address the research objectives. Such a high response rate even on its own, speaks to the interest the specialists have on the topic.

5.1. Characteristics of the Sample

Respondents are representative of all specialists performing colonoscopies in NL with the exception of community size of practice. One-quarter of the respondents are

gastroenterologists and this includes all gastroenterologists currently practicing in the province (n = 9). Only one of these gastroenterologists indicated he or she practices in a rural setting (<10,000), meaning the majority of the higher risk CRC population (i.e. HNPCC and FAP mutation carriers) who often reside in small rural outport communities (Woods, Hyde, Curtis, Stuckless, Green, Pollett, et al., 2005) are seeing general surgeons for colonoscopy or are traveling to a larger centre to see a gastroenterologist. While it is likely these general surgeons obtain professional certification around colonoscopy and screening high risk CRC patients (i.e., only 11.4% indicated they were non-certified specialists), they may have received less specialized training compared to gastroenterologists (Hilsden et al., 2007).

5.2 Knowledge and Practice Patterns

Overall it appears the majority of specialists are aware of the recommended ages to begin CRC screening for the different groups of patients. As compared to the 35 gastroenterologists surveyed by Schroy and colleagues (2002), slightly fewer respondents from this study know to begin screening patients with a family history of CRC at 40 years of age or ten years earlier than the youngest diagnosed family member (91% vs. 85%). In contrast, significantly more respondents from this study (69%) are aware to begin screening patients with a family history of AP at 40 years of age or ten years younger than the earliest diagnosed family member as compared to 37% of participants in the Schroy et al. (2002) study. This may be attributed to the increased awareness among specialists of the CRC risk associated with these polyps.

A large number of specialists prefer colonoscopy for screening all groups of patients despite evidence to support the effectiveness of other tests. This increased preference for colonoscopy has been attributed to media coverage (Cram, Fendrick, Inadomi, Cowen, Carpenter & Vijan, 2003) documenting the advantages of colonoscopy, as well organizations adopting them into their guidelines as the gold standard (Alberta Cancer Board, 2008; Leddin et al., 2004; Levin et al., 2008). Despite guidelines that specify FS for screening patients with FAP, only 23% of respondents selected this test for screening this group of patients. However, this is likely due to the polyp locations in FAP families in NL. NL FAP families are not typical of most FAP gene mutation carriers because polyps may occur only in the right colon, making colonoscopy the preferred screening test (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, May 9, 2009).

In terms of time demands on the specialist, there does not appear to be much difference between FS and colonoscopy. The average FS takes 5-10 minutes while the average colonoscopy takes 5-20 minutes (although it can take up to 60 minutes) (Dr. W. Pollett, Chair of Surgery with the Faculty of Medicine at Memorial University, personal communication, July 7, 2009). Remuneration increases based on the distance the scope travels (Medical Care Plan, 2009), however, this increase is not overly significant and a specialists' choice of procedure is more dependent on medical indication (Dr. W. Pollett, Chair of Surgery with the Faculty of Medicine at Memorial University, personal communication, July 7, 2009). Therefore, it does not appear that preference for colonoscopy would be due to higher remuneration.

Given the increased preference for colonoscopy, improvement around quality indicators for this procedure is needed (Hilsden et al., 2007). As previously discussed, 100 colonoscopies or gastroscopies annually was found to be associated with a significant improvement in the rate of completion (Wexner, Garbus & Singh, 2001). There are two specialists who report performing less than this amount. Even though this is a small percentage, a negative experience with colonoscopy potentially deters a patient from future adherence to screening. For example, an HNPCC mutation carrier living in NL confided about a horrendous experience with colonoscopy. In this case, the colonoscopy was not performed by the usual specialist and the individual openly stated he/she would never go through it again. Another individual was extremely traumatized by the colonoscopy experience and speculated that not enough medication was given and would rather die before getting it done again (J. Stokes, Research Coordinator, personal communication, October 21, 2008).

5.2.1. Interdisciplinary Health Team Involvement

Despite extended wait times for colonoscopy for the general (average risk) population there are low levels of support among the specialists for allowing other health professionals to provide this service. However, this support might be different for the provision of other recommended CRC screening tests. Ontario, for example, is exploring the use of a nurse FS program which would be located at a colonoscopy hub in their new provincial CRC population-based screening program. According to Linda Rabeneck, Regional Vice President of Cancer Care Ontario and former Director of the Division of Gastroenterology at the University of Toronto:

> If 10% or even 15% of persons who have a FS have an abnormal examination and go on to require colonoscopy, this is fewer than the 100% that would have a colonoscopy if we were to use colonoscopy as the initial screening test in average-risk individuals (Rabeneck & Adams, 2006, p. 249).

It is not possible to determine from the findings whether colonoscopies done by specialists are for CRC screening or for other reasons (e.g., for other illnesses or for the management of CRC patients versus screening for CRC). Using colonoscopy to screen the general (average-risk) population is thought to place individuals unnecessarily at risk for severe consequences from colonoscopy (e.g., bowel perforation, hemorrhage and death), while inadvertently increasing health care costs (Sewitch et al., 2006). Further study is needed to understand how colonoscopy is being used in NL and to assess whether other modalities (e.g., FS) for CRC screening may be more appropriate for some general (average risk) patients. This type of information will help assess how best to accommodate the rising demand for colonoscopy.

As discussed earlier, genetic confirmation is shown to enhance adherence to screening recommendations and genetic counselors help to ensure the appropriate information is relayed to patients (Wagner et al., 2005; Halbert et al., 2004; Hadley et al., 2004). While almost all specialists include the PMGP for patients with FAP, fewer are doing so for HNPCC patients. Similarly, fewer specialists refer suspected HNPCC patients for genetic testing as compared to suspected FAP patients. One reason for this difference has been attributed to possible gene mutations associated with HNPCC that have not yet been identified (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, June 13, 2009). This would make it difficult for specialists to

differentiate patients with a strong family history of CRC from those who potentially carry a gene mutation associated with HNPCC. In any case, genetic testing in NL is only available through the PMGP so all specialists recommending genetic testing would need to go through this program (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, June 13, 2009). Findings highlight the need for increased continuing medical education among specialists about the genetic testing process in the province. Further study around referral patterns between specialists and the PMGP would highlight means of improving communication and coordination between the two.

There is little consensus or clarity around the roles of the patient and different health professionals in the on-going monitoring of high risk familial and hereditary CRC patients. Eighty percent of specialists indicate they take the time to collect family histories of CRC and AP from their patients as well as discuss the advantages and disadvantages associated with the different screening tests. However, time restraints likely make it impossible for the specialists to fully address patients' questions, concerns and emotional needs in regards to living with a familial or hereditary risk for CRC. For HNPCC mutation carriers, adjusting to a life of screening has been described as being emotionally draining (J. Stokes, Research Coordinator, personal communication, October 21, 2008). Continued collaboration among health professionals (e.g. family physicians, specialists, PMGP, etc.) would help to clarify the roles of the different specialists and also ensure patients receive the support they need. It is interesting that more than 60% of the specialists feel that family physicians should be involved in monitoring high risk CRC patients' compliance to screening yet almost all either agree or strongly agree that family

physicians need more continuing education about family history and CRC screening guidelines.

Survey findings indicate specialists prioritize high risk CRC patients and that more than half of them are seeing HNPCC and FAP mutation carriers within 3 months of referral. More strikingly, a large proportion of the general (average risk) population wait in excess of one year for colonoscopy. While the Canadian Association of Gastroenterology has set benchmarks that recommend a colonoscopy be completed within two weeks for patients referred because of high likelihood of cancer based on imaging or physical exam (Paterson et al., 2006), guidelines are not available to assess the appropriateness of wait times for other groups of patients. Further monitoring of this process would help to understand if the use of other health professionals or other screening tests might decrease screening wait times.

5.3 Attitudes

An overwhelming number of specialists strongly agree there is a need for a province wide CRC registry. This is also the position of the Screening Working Group of the *Provincial Cancer Control Strategy* (CCS, 2006) in NL. Similar to the National Bowel Cancer Screening Program in the UK, a registry would allow for a more comprehensive understanding of the geographic distribution of CRC incidence in the province including those families at highest risk for the disease. A registry could be customized to allow for the monitoring of patient compliance to screening protocols while ensuring different health professionals are aware of a patient's health status regardless of direct involvement during a particular visit to the hospital.

In the event NL moves towards a provincial CRC screening program, close examination of the existing Breast Cancer Screening Program currently operating in the province would be helpful. All women aged 50-69 are recruited into this program and they do not require a physician referral. The program tracks all women referred for follow-up, to the point of diagnosis. All the cases that are referred for further follow-up are reviewed once the follow-up is completed. This is done for quality assurance purposes. Women that are due for repeat screen are contacted and reminded to book an appointment for repeat screening. Since the program began in 1996 through to 2006, 29,500 women had been screened and 549 cancers detected (CCS, 2006).

5.4 Study Strengths

Use of self-administered mail-out surveys was the preferred type of data collection instrument for this study because this is relatively inexpensive, not labor intensive, has a rapid turnaround in data collection and are the most practical for reaching the widely geographically distributed gastroenterologists and general surgeons across the province (Dillman, 2007). Because all gastroenterologists and general surgeons in the province were invited to participate in the study there was minimal risk of selection bias which can result from systematic differences in characteristics between those who are selected for a study and those who are not (Polit & Beck, 2004).

Given the relatively low numbers of gastroenterologists and general surgeons performing colonoscopies in the province, a high response rate was paramount to the success of the study. This is also important to avoid sampling error which occurs when the precision of sample estimates is limited by the number of persons surveyed (Dillman,

2007). For this reason, the *Tailored Design Approach for Mail and Internet Survey* (Dillman, 2007) combined with input from "opinion leaders" was used to enhance the response rate. An "opinion leader" is defined by Kitson, Harvey, & McCormack (1998) as "an individual who is able to influence other individual's attitudes or overt behavior informally in a desired way with relative frequency" (p.152). This is shown to be particularly useful among clinicians (Lomas, 1997).

This study not only achieved a high response rate but there were very few missing values for the entire data set or for any individual question. It is the first study conducted in the province to examine the knowledge, attitude and practice patterns of endoscopy specialists involved with screening high risk familial and hereditary CRC populations. It is also among very few studies conducted in Canada on this topic. Exploring similar studies in the US, such as the Schroy et al. (2002) study allowed for certain survey questions to be adopted which added to the methodological rigor of the study. Meanwhile, consulting a Medical Geneticist involved with the PMGP, a Medical Ethicist and a Health Policy Professor from Memorial University in the development and interpretation of the study findings helped to ensure study conclusions and recommendations provide the necessary evidence and steps needed for planning for an improved CRC screening service in NL.

5.5 Study Limitations

The self-administered mail-out survey relied on respondents' ability to recall information and/or activities done in the past. Therefore inaccurate recall and bias are limitations to this method, particularly among respondents who perform colonoscopies

less frequently in their practice (Dillman, 2007). Social desirability is also a potential limitation as respondents may give answers that are congruent with prevailing social values (Polit & Beck, 2004). While questions in this survey are not intended to impose any risk of a socially unacceptable characteristic or behavior, and confidentiality and anonymity of responses is guaranteed, some respondents may have felt pressured to answer questions based on socially accepted standards and/or published clinical practice guidelines rather than personal practice. According to Dillman (2007), people are more likely to give honest answers to self-administered surveys than to interview questions; however, there is still a risk with this method (Klesges, Baranowski, Beech, Cullen, Murray, et al., 2004). Respondent knowledge of the relatively small sample included in the study may also contribute to specialists giving socially desirable responses.

Although the sample includes a slightly higher proportion of specialists working in rural regions of NL, there has been an increase in Medical Geneticist visits to rural areas to inform them about familial and hereditary CRC (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, July 13, 2009). Therefore, findings are not speculated to underestimate specialist knowledge on this topic despite challenges that rural physicians often face in receiving continuing medical education. However, it is possible that the level of satisfaction towards a centralized CRC screening booking centre is overestimated. Rural specialists are more exposed to the challenges and frustrations patients face when navigating through an unfamiliar health care system alone and seeking screening on an ad hoc basis (Dr. J. Green, Medical Geneticist at Memorial University, personal communication, July 13, 2009). A centralized booking centre would likely be viewed as an opportunity for more equal and efficient access to care.

Chapter Six – Conclusion

6.1 Summary of Findings

Gaining a better understanding of the knowledge, practice patterns and attitudes of gastroenterologists and general surgeons, the primary providers of colonoscopies in NL, is a key initial step in planning for an improved CRC screening service for the province. Through a cross-sectional, descriptive survey, this study demonstrates that the majority of gastroenterologists and general surgeons in NL are knowledgeable about screening guidelines and the appropriate age to begin screening. However, despite best practice guidelines, most specialists prefer to screen using colonoscopy rather than other recommended screening tests.

Survey findings suggest that gastroenterologists and general surgeons do not generally consider themselves to be responsible for monitoring screening compliance of the high risk familial and hereditary CRC patients. Yet, there was no clear consensus from the findings who they do consider responsible. There was also inconsistent involvement of other health professionals in the screening process. Experiences from existing CRC screening programs tell us that close monitoring of a patient's screening compliance and the involvement of other health professionals leads to better health promotion, health education, satisfaction among patients, more consistent messaging, improved timeliness and quality of care.

While most specialists indicate they prioritize high risk patients, they also report that the general (average risk) population may have long waits to access routine colonoscopy screening. Further research is needed to assess the appropriateness of these

wait times as well as the use of other screening tests in order to improve the management of colonoscopy services in the province. Findings also suggest there is strong support for a CRC registry, which would be a key component of an organized CRC screening program. Based on the findings we recommend:

1) Examining wait times and indications for colonoscopy in NL. This information will help to inform better management as we face a growing demand for colonoscopies.

2) Implementing collaborative model for CRC care and drawing on existing CRC screening programs for guidance.

3) Continuing medical education for gastroenterologists and general surgeons, particularly around the types of services offered through the PMGP.

4) Future research on the knowledge, practice patterns and attitudes of other health professionals involved with CRC screening. Gathering similar information from other health professionals may indicate unique strategies for improving CRC screening services in the province.

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Appendices

Appendix A - Clinical Criteria for HNPCC

Table 5. Clinical Criteria for HNPCC

Amsterdam Criteria[97] (for Clinical Identification of HNPCC)
At least 3 relatives with colorectal cancer plus all of the following:
One affected patient is a first-degree relative of the other two
Two or more successive generations affected
One or more affected relative received colorectal cancer diagnosis at age < 50 years
FAP excluded
Tumors verified by pathologic examination
Amsterdam II[98] (Criteria for Clinical Identification of HNPCC, modified to take into account the increased occurrence of cancer other than of the colon and rectum)
At least 3 relatives with an **HNPCC-associated cancer (colorectal cancer and cancer of the endometrium, small bowel, ureter, or renal pelvis)**[a] plus all of the following:
One affected patient is a first-degree relative of the other two
Two or more successive generations affected
One or more affected relative received colorectal cancer diagnosis at age <50 years
FAP excluded **in any case of colorectal cancer**[a]
Tumors verified by pathologic examination
Bethesda Guidelines[99] (For identification of patients with colorectal tumors who should undergo testing for microsatellite instability)
B1 - Individuals with cancer in families that meet the Amsterdam Criteria
B2 - Individuals with 2 HNPCC-related tumors, including synchronous and metachronous colorectal cancer or associated extracolonic cancer (endometrium, ovarian, gastric, hepatobiliary, or small-bowel cancer or transitional-cell carcinoma of the renal pelvis or ureter)
B3 - Individuals with colorectal cancer and a first-degree relative with colorectal cancer or HNPCC-related extracolonic cancer or a colorectal adenoma; one of the cancers diagnosed at age <45 years,[c] and the adenoma diagnosed <40 years
B4 - Individuals with colorectal cancer or endometrial cancer diagnosed at age <45 years[b]
B5 - Individuals with right-sided colorectal cancer with an undifferentiated pattern (solid, cribriform) on histopathology diagnosed at age <45 years[b] (solid or cribriform), defined as poorly differentiated for undifferentiated carcinoma composed of irregular, solid sheets of large eosinophilic cells and containing small gland-like spaces
B6 - Individuals with signet-ring-cell type colorectal cancer diagnosed at age <45 years[b] (composed of >50% signet-ring cells)
B7 - Individuals with adenomas diagnosed at age <40 years

[a]Differences between Amsterdam and Amsterdam II in **bold.**

[b]Modified Bethesda criteria replace the age of "<45" for colorectal cancer diagnosis in B3, B4, B5, and B6 to "<50"; see reference [73].

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Note. From Winawer, Fletcher, Rex, Bond, Burt, Ferrucci, et al., 2003. Used with permission of the author.

Appendix B - Performance Characteristics of CRC Screening Tests

Screening Method	Advantages	Disadvantages	Sensitivity	Specificity
FOBT	• Easy, safe, inexpensive, convenient and simple to complete • Strong evidence from randomized controlled trials of reduction in colorectal cancer mortality with screening	• Requires patient action for completion of test (stool collection) • Patients may find test unpleasant to do • No direct visualization of the colorectum • May miss many polyps	35 - 50% for cancer (one-time FOBT)	98 - 99%
Flexible Sigmoidoscopy	• Usually well tolerated without sedation • Moderate cost • Good evidence of reduction in mortality with screening	• Requires bowel preparation • Patients may find test uncomfortable or embarrassing • Small risk of perforation or bleeding • Screens only about half the colon.	50 - 70% of advanced adenomas and cancer	
Double Contrast Barium Enema	• Screens full colorectum • Sedation is not required • Relatively safe	• Requires bowel preparation • Exposure to radiation • Patients may find test uncomfortable or embarrassing • No controlled trials evaluate its effectiveness for CRC screening	48% for large adenomas (> 1cm) 55 - 85% for cancer	85% for cancer
Colonoscopy	• Direct visualization of the entire colorectum • Allows for removal of polyps at the same time • Reduction in CRC mortality in FOBT trials is attributable to follow-up diagnostic colonoscopy	• Requires bowel preparation • Patients need to be escorted home and are advised not to go back to work the same day • Small risk of bleeding and perforation • Patients may find test uncomfortable or embarrassing	90% for polyps > 1cm > 90% for cancer	99%.

Note. From the Alberta Cancer Board (2008). Used with permission of the organization.

Appendix C - CAG Algorithm to Screening (a) average risk population and (b) high risk population

(a)

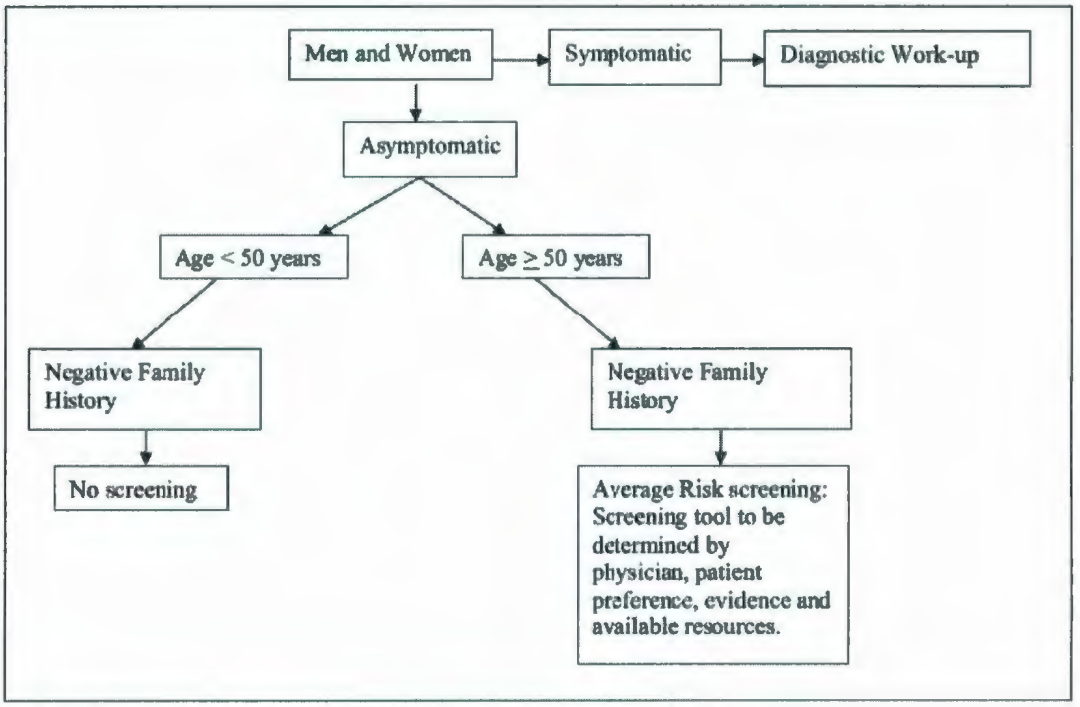
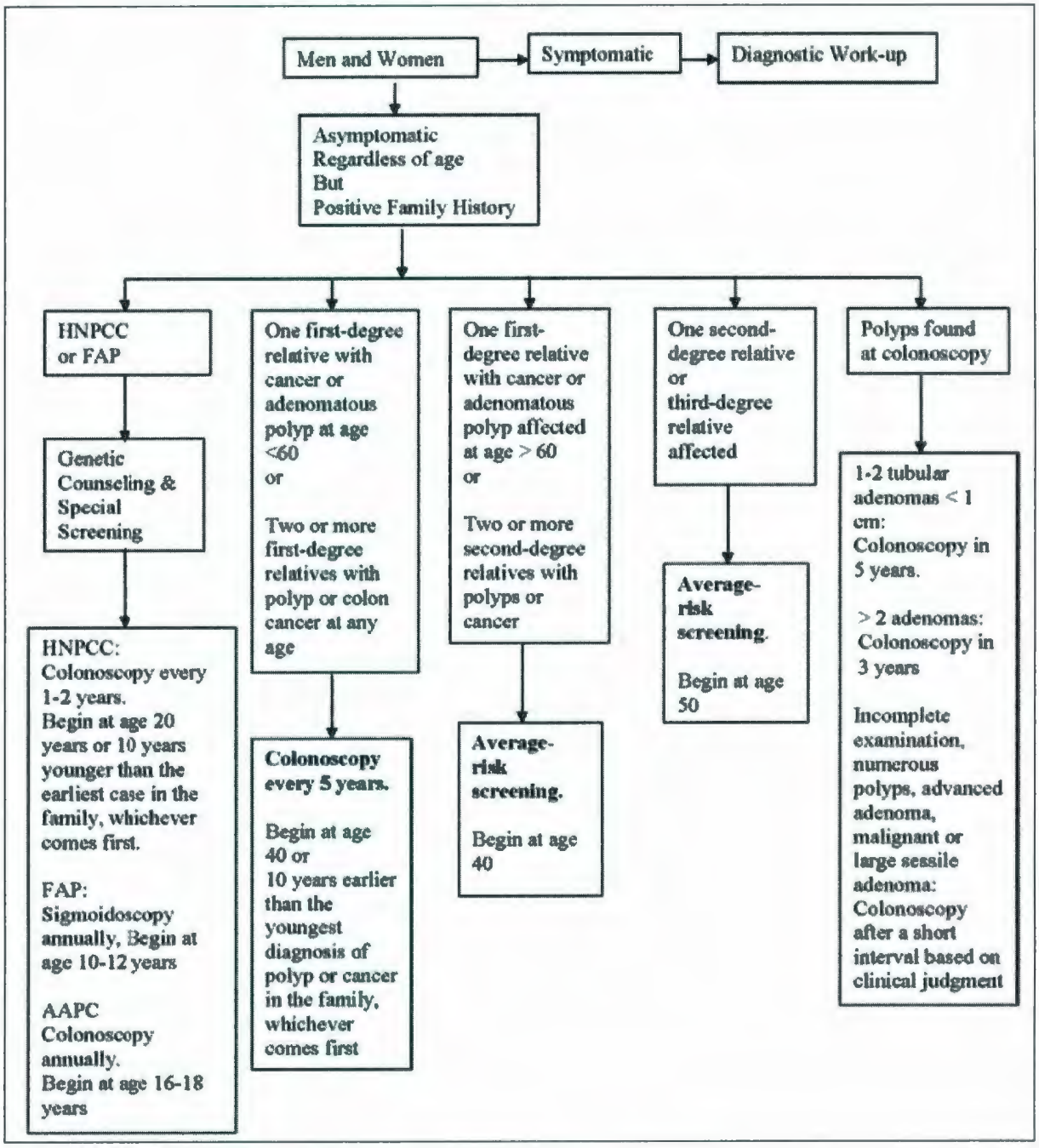


Figure 1) *Approach to average risk screening*

Note. From Leddin et al., 2004. Used with permission of the author.

(b)



Note. From Leddin et al., 2004. Used with permission of the author.

Appendix D - Cover Letter and Survey

COLORECTAL CANCER SCREENING SURVEY FOR

GASTROENTEROLOGISTS AND SURGEONS

February 2009

Dear Physician,

Newfoundland and Labrador has the highest rate of colorectal cancer of any Canadian province. We're interested in finding out about your knowledge, attitude and practice patterns regarding patients who have personal or family history of colorectal cancer or adenomatous polyps. The attached survey should take **less than 10 minutes to complete**. The results will be useful in planning for an improved colorectal cancer screening service in the province.

Please return the completed survey in the envelope provided along with the postcard which is to be mailed separately. Only the postcard will have your identification information to ensure anonymity of responses while providing us with a list of physicians who have completed and returned the survey.

I am a M.Sc. student in the Faculty of Medicine doing this research for my thesis and I work under the supervision of Dr. Jane Green, Medical Geneticist also in the Faculty of Medicine. If you have any questions or would like go through the survey together over the telephone my contact information is below. Thank you for your cooperation.

Sincerely,

Jill MacEachern
Graduate Student
Atlantic Regional Training Centre
Faculty of Medicine
Memorial University of Newfoundland and Labrador
St. John's, NL, A1B 3V6
Phone: 709-749-6130
Email: jill.maceachern@mun.ca

SECTION I- Physician Personal and Practice Characteristics

Please answer each of the following questions by placing a check (√) in the appropriate box

1. What is your specialty? ☐ Gastroenterology ☐ Surgery
   ☐ Other (*specify*): _____

2. What is your gender? ☐ Female ☐ Male

3. How many years ago did you graduate?
   ☐ < 10 years ago ☐ 10-20 years ago ☐ 20-30 years ago ☐ 30+ years ago

4. How long have you practiced in Newfoundland and Labrador? _____ year(s)

5. By what professional body are you certified?
   ☐ Royal College of Physicians and Surgeons of Canada
   ☐ American Board of Surgery
   ☐ American Board of Internal Medicine
   ☐ Non-Certified Specialist
   ☐ Other (*specify*): _____

6. How large is the community in which you practice?
   ☐ rural (<10,000)
   ☐ small urban (10,000-100,000)
   ☐ urban (>100,000)

7. Do you perform colonoscopies in your service?
   ☐ Yes
   ☐ No- ***If NO, please stop here and go to Question 20***

8. Approximately how many years have you been performing colonoscopies? _____ year(s)

9. Approximately how many colonoscopies do you perform every year? _____/ year

SECTION II- Hereditary Colorectal Cancer Screening

10. What percent of your asymptomatic patients age less than 40 do you ask about a family history of colorectal cancer or polyps?

- ☐ 0-25%
- ☐ 26-50%
- ☐ 51-75%
- ☐ 76-100%

11. What percent of your asymptomatic patients age 40 and above do you ask about a family history of colorectal cancer or polyps?

- ☐ 0-25%
- ☐ 26-50%
- ☐ 51-75%
- ☐ 76-100%

12. For the following groups, please identify the age you would recommend to begin screening, the screening modality, other health professionals you would involve and if you routinely recommend genetic testing.

Family History of Colorectal Cancer
(single first-degree relative with colorectal cancer diagnosed at younger than age 55)

Age you recommend to begin screening: ☐ 15-24 years ☐ 25-39 years ☐ 40-49 years ☐ 50+ years

Screening modality most frequently used:

- ☐ Digital rectal exam
- ☐ Flexible sigmoidoscopy
- ☐ Colonoscopy
- ☐ Do not screen
- ☐ Fecal occult blood test (FOBT)
- ☐ Combination of FOBT and sigmoidoscopy
- ☐ Double-contrast barium enema
- ☐ Other (*please specify*): _____

Other health professionals you involve:

- ☐ Other Gastroenterologists/ Surgeons
- ☐ Family Doctor
- ☐ None
- ☐ Provincial Medical Genetics Program /Genetic Counsellor
- ☐ Gynaecologist/ Urologist
- ☐ Other (*specify*):_____

Would you routinely recommend genetic testing? ☐ Yes ☐ No

Family History of Adenomatous Polyps

(single first-degree relative with adenomatous polyp diagnosed at younger than age 60)

Age you recommend to begin screening: ☐ 15-24 years ☐ 25-39 years ☐ 40-49 years ☐ 50+ years

Screening modality most frequently used:

☐ Digital rectal exam
☐ Fecal occult blood test (FOBT)
☐ Flexible sigmoidoscopy
☐ Combination of FOBT and sigmoidoscopy
☐ Colonoscopy
☐ Double-contrast barium enema
☐ Do not screen
☐ Other (*please specify*): _____

Other health professionals you involve:

☐ Other Gastroenterologists/ Surgeons
☐ Provincial Medical Genetics Program /Genetic Counsellor
☐ Family Doctor
☐ Gynaecologist/ Urologist
☐ None
☐ Other (*specify*):_____

Would you routinely recommend genetic testing? ☐ Yes ☐ No

Familial Adenomatous Polyposis (FAP)

Age you recommend to begin screening: ☐ 15-24 years ☐ 25-39 years ☐ 40-49 years ☐ 50+ years

Screening modality most frequently used:

☐ Digital rectal exam
☐ Fecal occult blood test (FOBT)
☐ Flexible sigmoidoscopy
☐ Combination of FOBT and sigmoidoscopy
☐ Colonoscopy
☐ Double-contrast barium enema
☐ Do not screen
☐ Other (*please specify*): _____

Other health professionals you involve:

☐ Other Gastroenterologists/ Surgeons
☐ Provincial Medical Genetics Program /Genetic Counsellor
☐ Family Doctor
☐ Gynaecologist/ Urologist
☐ None
☐ Other (*specify*):_____

Would you routinely recommend genetic testing? ☐ Yes ☐ No

Hereditary Non-Polyposis Colorectal Cancer (HNPCC)
previously known as Lynch Syndrome

Age you recommend to begin screening: ☐ 15-24 years ☐ 25-39 years ☐ 40-49 years ☐ 50+ years

Screening modality most frequently used:

☐ Digital rectal exam
☐ Fecal occult blood test (FOBT)
☐ Flexible sigmoidoscopy
☐ Combination of FOBT and sigmoidoscopy
☐ Colonoscopy
☐ Double-contrast barium enema
☐ Do not screen
☐ Other (*please specify*): _____

Other health professionals you involve:

☐ Other Gastroenterologists/ Surgeons
☐ Provincial Medical Genetics Program /Genetic Counsellor
☐ Family Doctor
☐ Gynaecologist/ Urologist
☐ None
☐ Other (*specify*):_____

Would you routinely recommend genetic testing? ☐ Yes ☐ No

13. What method of colorectal cancer screening do you recommend for your asymptomatic patients who are age 50 and older with no significant family of history of colorectal cancer or polyps?

☐ Digital rectal exam
☐ Fecal occult blood test (FOBT) annually
☐ Flexible sigmoidoscopy every 5 years
☐ Combination of FOBT and flexible sigmoidoscopy every 5 years
☐ Colonoscopy every 10 years
☐ Double-contrast barium enema every 5-10 years
☐ Do not screen
☐ Other (*please specify*): _____

14. Do you discuss advantages/disadvantages associated with different screening approaches with your patients? ☐ Yes
☐ No

If YES, do you give patients the opportunity to apply their own preference in selecting how they are screened? ☐ Yes ☐ No

15. In the table below, please indicate when the next colonoscopy appointment would be available for the different groups by placing a check (√) under the appropriate time frame.

	< month	1-3 months	3-6 months	6-12 months	> 12 months	Not Applicable
Family history of colorectal cancer	☐	☐	☐	☐	☐	☐
Family history of adenomatous polyps	☐	☐	☐	☐	☐	☐
FAP and HNPCC	☐	☐	☐	☐	☐	☐
General population (> 50 years old)	☐	☐	☐	☐	☐	☐

16. Do you have a systematic approach to prioritizing patients for your colonoscopy service?

☐ Yes ☐ No

If YES, on what basis do you prioritize?

_____
_____
_____
_____
_____

17. Who should be responsible for monitoring hereditary colorectal cancer patients' compliance to screening?

☐ The patient
☐ Yourself
☐ Provincial Medical Genetics Program/ Genetic Counsellor
☐ Family Doctor
☐ Other (*specify*):_____

18. Where have you read or heard information pertaining to risk factors and screening recommendations for hereditary colorectal cancer (*check all that apply*)

☐ Medical Journals
☐ Patient letter from the Provincial Medical Genetics Clinic
☐ Patients
☐ Hospital Rounds
☐ Colleagues
☐ Other (*specify*):_____

What is your preferred method of receiving this information? _____

SECTION III: Attitude about Current Colorectal Cancer Screening Services

19. On a scale of 1 to 5 how strongly do you agree with each statement? (*circle one for each statement*)

	Strongly Disagree	**Disagree**	**Neither Agree or Disagree**	**Agree**	**Strongly Agree**
a. There is a need for a province wide colorectal cancer registry	1	2	3	4	5
b. There is a need for a province wide colorectal cancer screening central booking centre which would include my colonoscopy service	1	2	3	4	5
c. *Gastroenterologists* could use more continuing education around family history and colorectal cancer screening	1	2	3	4	5
d. *Surgeons* could use more continuing education around family history and colorectal cancer screening	1	2	3	4	5
e. *Family physicians* could use more continuing education around family history and colorectal cancer screening	1	2	3	4	5
f. High risk patients (i.e. HNPCC and FAP) should see the same gastroenterologist or surgeon for follow-up colonoscopies	1	2	3	4	5
g. Other health professionals besides gastroenterologists and surgeons should be trained to perform colonoscopies	1	2	3	4	5
h. Wait times for my colonoscopy service is reasonable	1	2	3	4	5
i. Genetic testing is useful to me for prioritizing patient care	1	2	3	4	5
j. I am referring more patients for genetic testing than 5 years ago	1	2	3	4	5
k. There is sufficient support given to those patients who undergo genetic testing	1	2	3	4	5

20. Do you have any additional comments?

_____

_____

_____

_____

_____

You have now completed the survey. Please return it in the envelope provided.

Thank you

Appendix E - Postcard for Tracking Survey Responses

From:

Business reply postage here

Colorectal Cancer Screening Study
c/o Daryl Pullman, Room 2832
Division of Community Health & Humanities
Health Science Centre
300 Prince Philip Drive
St. John's NL
A1B 3V6

Please check one of the following:

☐ Would you be willing to be contacted for a follow-up interview?

☐ Please send me a summary report of the study

☐ Please do **not** send me a summary report of the study

Appendix F: Survey Variables and Coding Scheme

Variable Name	Q #	Category	Codes
Specialty	Q1	Gastroenterology	1
		Surgery	2
		Other	3
Sex	Q2	Female	1
		Male	2
Year of graduation from medical school	Q3	less than 10	1
		10-20	2
		20-30	3
		more than 30	4
Years practicing in NL	Q4	less than 10	1
		10-30	2
		more than 30	3
Professional certification	Q5	RCPSC	1=yes
		America Board of Surgery	2=no
		America Board of Internal Medicine	
		Non-Certified Specialist	
		American College of General surgeons	
		South African Medical and Dental Ass.	
Community size of practice	Q6	<100,000	1
		>100,000	2
Colonoscopy performed in practice	Q7	Yes	1
		No	2
Years performing colonoscopy	Q8	Less than 10	1
		10-30	2
		More than 30	3
Average annual number of colonoscopies performed	Q9	less than 100	1
		101-250	2
		251-500	3
		501-750	4
		more than 750	5
Percent of asymptomatic patients <40 yrs that are asked about family history of CRC	Q10	0-25%	1
		26-75%	2
		76-100%	3

Percent of asymptomatic patients >40 yrs that are asked about family history of CRC	Q11	0-25% 26-75% 76-100%	1 2 3
Family history CRC; Family history AP; FAP; HNPCC - age begin screening - screening modality - other health professionals involved - genetic testing routinely recommended	Q12 .	Age 15-24 years 25-39 years 40-49 years 50+ years Screening modality DRE FS Colonoscopy FOBT Combo FOBT and FS DCBE Other health professional involvement Other GIs/general surgeons Family doctor PMGP/ Genetic counselor Gynecologist/Urologist Routine recommendation for genetic testing yes no	 1 2 3 4 1=yes 2=no 1=yes 2=no 1 2
Screening of asymptomatic patients >50 yrs of age	Q13	DRE FOBT every 1-2 yr FS every 5 yr Combo FOBT and FS Colonoscopy every 10 yr DCBE Do no screen	1=yes 2=no
Advantages/ disadvantages of different screening tests discussed with patients. If yes, influence on type of test used.	Q14	Yes No Yes No	1 2 1 2

Wait times for colonoscopy: - Family history CRC - Family history AP - FAP - HNPCC	Q15	< month 1-3 month 3-6 month 6-12 month >12 month not applicable	1 2 3 4 5 6
Systematic approach to prioritizing care On what basis is care prioritized	Q16	Yes No Abnormal lab data occult blood Change in stool pattern Weight loss Abnormal barium enema Referral from family doctor/nurse practitioner Referral from PMGP/results genetic testing Family history Personal history of CRC/ polyps FAP/HNPCC patients past their screening interval Age	1 2 1=yes 2=no
Responsibility of monitoring patient compliance to screening	Q17	The patient Yourself PMGP/Genetic Counselor Family Doctor	1=yes 2=no
Method of receiving continuing medical education Preferred method of receiving information	Q18	Medical journals Patient letter from the PMGP Patients Hospital rounds Colleagues Textbooks	1=yes 2=no

		Conferences CAG Internet Endoscopy Unit No preference Journals Mail On-line	 1=yes 2=no
Attitude about existing CRC screening services: - CRC registry - CRC central booking centre - Gastroenterologists need more cont ed. - General surgeons need more cont ed. - Family physician need more ed. - FAP and HNPCC patients should see same specialist for follow-up - Other health professionals besides gastroenterologists/ general surgeons should be trained to perform colonoscopies - FAP/ HNPCC patients should see same specialist for follow- up - Wait times for colonoscopy are reasonable - Genetic testing is useful for prioritizing care - Referring more patients to genetic testing than 5 years ago - Sufficient support is given to patients undergoing genetic testing	Q19		1 2 3 4 5

Appendix G: Human Investigative Committee Approval Letter

Faculty of Medicine

January 5, 2009

Reference #08.173

Ms. Jill MacEachern
8 Barnes Road
St. John's, NL
A1C 3X2

Dear Ms. MacEachern:

This will acknowledge your correspondence dated January 5, 2009 wherein you clarify issues and provided a revised survey for your research study entitled "**Colorectal Cancer screening: Knowledge, attitudes and practices of colonoscopy service providers in Newfoundland and Labrador**".

This correspondence has been reviewed by the co-chair and **Full approval** of this research study has been granted for one year effective January 5, 2009.

Full approval has been granted for one year. You will be contacted to complete the annual form update approximately 8 weeks before the approval will lapse on **January 5, 2010**. It is your responsibility to ensure that the renewal form is forwarded to the HIC office not less than 30 days prior to the renewal date for review and approval to continue the study. The annual renewal form can be downloaded from the HIC website http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc.

For a hospital-based study, it is **your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate**.

This Research Ethics Board (the HIC) has reviewed and approved the application for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations.