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Post-Colorectal Cancer Screening: Knowledge and Understanding

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Post-Colorectal Cancer Screening: Knowledge and Understanding" submitted by Robin L. Walker in partial fulfilment of the requirements of the degree of Master of Science.

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Abstract

Objective: To determine what type of information patients perceive to receive throughout the process of colorectal cancer (CRC) screening using colonoscopy in Calgary, Alberta and their knowledge of important aspects of colonoscopy screening.

Methods: Self-administered questionnaires were mailed one-week and three-months post-colonoscopy to consenting participants who underwent screening colonoscopy. Participants were asked questions regarding what type of information they received from health professionals throughout CRC screening and what additional information they would have liked to receive.

Results: 630 participants completed the 1st questionnaire (78% response rate) and 460 completed the 2nd questionnaire. When referred for screening, 48% of participants reported receiving no information from their family physician. Prior to colonoscopy, 42% of participants did not recall receiving information on the risks of colonoscopy. Of the 93% of participants who received screening test results, 72% reported negative results and 28% positive. The majority of participants (79%) were told when to have their next colonoscopy. Among those participants, 48% with negative test results and no family history of CRC, repeat colonoscopy in 3 to 5 years was recommended. Common additional information participants requested included written copy of test results, preventive measures, and different CRC screening tests.

Conclusion: This study identified important knowledge gaps among patients undergoing screening colonoscopy. Educational strategies to ensure patients undergoing screening colonoscopy are informed of the risks of the procedure and proper follow-up screening intervals are needed.

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List of Abbreviations

CRC	Colorectal cancer
PYLL	Potential years of life lost
95% CI	Ninety-five percent confidence interval
FAP	Familial adenomatous polyposis
HNPCC	Hereditary non-polyposis colon cancer
IBD	Inflammatory bowel disease
FOBT	Fecal occult blood test
CAG	Canadian Association of Gastroenterology
US	United States of America
NHIS	National Health Interview Study
GI	Gastrointestinal
ID	Identification

Chapter One: Introduction

Colorectal cancer (CRC) is a malignant tumour, which, after a relatively long period of localization in the bowel wall, invades the wall and metastasizes to regional lymph nodes and distant organs. It is the fourth most commonly diagnosed cancer and the second most common cause of cancer mortality among Canadians (1).

CRC affects both men and women, and it accounts for 12% of new invasive cancers each year (1;2). In 2006 it is estimated that 20,000 new cases of CRC will be diagnosed in Canada, with a mortality of approximately 43% (8500 deaths) (1). This year in Alberta alone it is estimated that there will be 1620 new cases of CRC and 600 deaths (1). During a person's lifetime Canadian men have a 1 in 14 chance of developing the disease and women have a 1 in 16 chance (1). One in 28 and 1 in 31 of Canadian men and women, respectively, will die of CRC (1).

Death from CRC can be prevented by the detection of early-stage disease that has not metastasized. Screening is the presumptive identification of unrecognized disease or defects by means of tests, examinations, or other procedures that can be applied rapidly (3). The aim of cancer screening is the identification of an asymptomatic and earlier stage disease, when it is potentially treatable and curable, resulting in an improvement of outcomes, modifying the natural history of the disease. Effective, safe, and relatively inexpensive methods for screening for the disease have been available for decades, however they have been underutilized (4).

CRC screening has been advocated increasingly during the past two decades by physicians and public health agencies. There is now evidence from randomized controlled trials that screening can reduce mortality by 18% to 33% using the fecal occult

blood test (FOBT) (5-10). The evidence in reducing CRC incidence and mortality has been reviewed by many organizations in Canada such as the Canadian Cancer Society and the Canadian Task Force on the Preventive Health Care (11). All agencies recommend that people aged 50 years and older who are at average risk for CRC be screened, although the frequency and recommended screening test varies somewhat.

Before the potential widespread use of CRC screening in Canada there are many issues that need to be addressed. It is essential that patients are educated about the risks of CRC, availability of screening, and other CRC-related health information with the hopes that increasing knowledge will in turn increase screening compliance, and over time decrease CRC incidence and mortality. This research project will focus on post-screening knowledge and understanding of those currently undergoing CRC screening in Calgary, Alberta. This study is needed to identify potential information gaps of those undergoing screening such as lack of CRC education, appropriate test results and follow-up. These gaps may be prevented and information from study findings will be used to develop education strategies on this important health issue. It may also help in the planning for and the implementation of population-based CRC screening programs.

Chapter Two: Literature Review

2.1 Colorectal Cancer

Among Canadians, incidence rates of CRC peaked in 1985 for both men and women. Since then overall rates have declined by approximately 8% among men and by 19% among women (12). Mortality from CRC has also declined among both men and women since 1985, especially among women (12). When provincial rates are compared, incidence of CRC appears to show a slight east-to-west gradient (12), indicating that incidence rates are slightly higher among both men and women in eastern provinces than in western Canada. This east-west gradient is not as apparent in rates of mortality (12).

Although incidence and mortality rates for CRC in Canada are falling, it is projected that the absolute number of new cases and deaths will probably continue to rise to the year 2010 due to the aging of the "baby boom" generation. Projected estimates of prevalence indicate that by 2010 the number of men and women in Canada who have CRC or have recovered from the disease will be approximately 1.7 and 1.5 times the number with CRC in 1998 (56,752 projected cases for males and 50,070 projected cases for females) (12).

The risk of CRC increases with advancing age, and more than 90% of cases occur in persons aged 50 years or older (1;13). It is estimated that the incidence of CRC in the next 10 years is 1 in 500 for those aged 40-49, but increases to about 1 in 125 in the 50-59 year old age group (14). The cancer occurs most frequently in the proximal colon, followed by the rectum and the distal colon (12).

Prognosis and survival rates of CRC are related to stage at diagnosis (12). Stage I tumours invade no farther than the muscularis propria of the bowel wall. Stage II tumours

are more invasive and may have directly invaded other organs or structures. Stage I and II tumours have no lymph node involvement or distant metastases. Stage III tumours have lymph node involvement but no distant metastases. Stage IV tumours have distant metastases.

The single most important prognostic indicator is the stage at which CRC is diagnosed. The overall 5-year survival rate is approximately 50% but rises to almost 90% for localized CRC (12). Conversely, the 5-year survival rate falls below 50% once the disease has spread (12). Unfortunately staging data are not routinely collected or reported in Canada. Only a few cancer centres routinely record stage, and no provincial population-based registries routinely compile and report on incidence and outcome by stage.

In 2001 Statistics Canada calculated age-standardized incidence and mortality rates for Canadian men and woman using incidence data from the Canadian Cancer Registry and mortality data from the Canadian Vital Statistics Database (15). Not taking staging into account, they reported that the overall estimated 5-year survival for CRC decreases as age increases. Among those diagnosed with CRC at 40-49 years of age, it is predicted that 57% of men and 64% of women will survive 5 years (12;15). However, among those diagnosed at 80-89 years of age, survival drops significantly to 24% for men and 30% for women. This is not unexpected, as crude survival reflects mortality from cancer as well as all causes. However, relative survival, which is the preferred method for analyzing the survival of cancer patients in population-based studies, also decreases with increasing age. For example, Canadian men 60-69 years of age with a diagnosis of CRC have a 56% chance of surviving for 5 years compared to men living in the same

province who is 60-69 years old and not diagnosed with CRC (12;15). The relative survival of women in this same age group is 62%. The relative survival drops to 50% for men and 51% for women by age 80-99 (12). In Canada the 5-year relative survival rate for all CRC cases in 1995-1997 was 60% (1).

The burden of CRC may be considered in terms of the impact on both the individual and society. For the individual, the burden is reflected in the potential years of life lost (PYLL), the cost of treatment, the degree of disability, pain, discomfort, financial hardship, and premature death, not to mention the social and economic burden the disease has on the family. In 2002 CRC was ranked as the second leading cancer in terms of PYLL for both Canadian men and women (58 200 and 53 800 PYLL respectively) (1). The burden on society may be described as including mortality, morbidity, lost productivity and the costs of prevention and treatment. As the population ages, a substantial increase in the social and economic burden of CRC is expected.

2.1.1 Natural History

Colorectal tumors present with a broad spectrum of neoplasms, ranging from benign growths to invasive cancer (16;17). Pathologists have classified the tumors into 3 groups: non-neoplastic polyps, neoplastic polyps (adenomatous polyps, adenomas), and cancers. Polyps are mucosal masses found in the colon and rectum that differ histologically and according to clinical significance (16).

Non-neoplastic polyps include hyperplastic, juvenile, hamartomatous, inflammatory, and lymphoid polyps (17). They have not generally been thought of as precursors of cancer, however research suggests increased CRC risk in some families

with multiple members affected with inherited forms of polyps (juvenile polyposis and hyperplastic polyposis) (17).

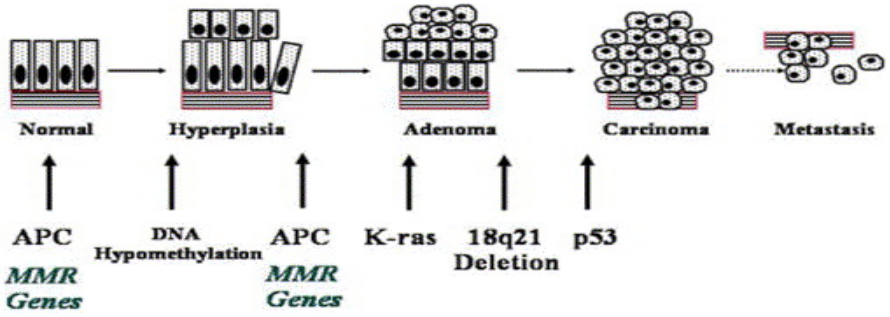
There is good evidence that the majority of CRC's arise from adenomatous polyps (16;18;19). An adenomatous polyp is glandular benign tumor which may undergo malignant transformation. They have been classified into 3 histological types, with increasing malignant potential: tubular, tubulovillous, and villous (16;19). The probability that invasive cancer is contained within a colorectal adenomatous polyp increases with the size of the adenoma, the degree of dysplasia, and the degree of villous content (19;20). Adenomatous polyps are found in about 25% of people by the age of 50; the prevalence continues to increase with increasing age as seen in Figure 1.

Figure 1: Prevalence of adenomatous colonic polyps increases with age (21).

The progression from adenomatous polyp to CRC has a natural history of approximately ten years (19;22) (refer to Figure 2). The progression of CRC is multi-factorial and is accompanied by changes in a number of suppressor genes that result in abnormalities of cell regulation. Environmental factors and inherited susceptibility are also important in the progression as genetic alterations are hypothesized to lead to the

development of adenomatous polyps, and then further genetic changes are thought to be responsible for the progression of the polyps to cancer (18;19;23;24).

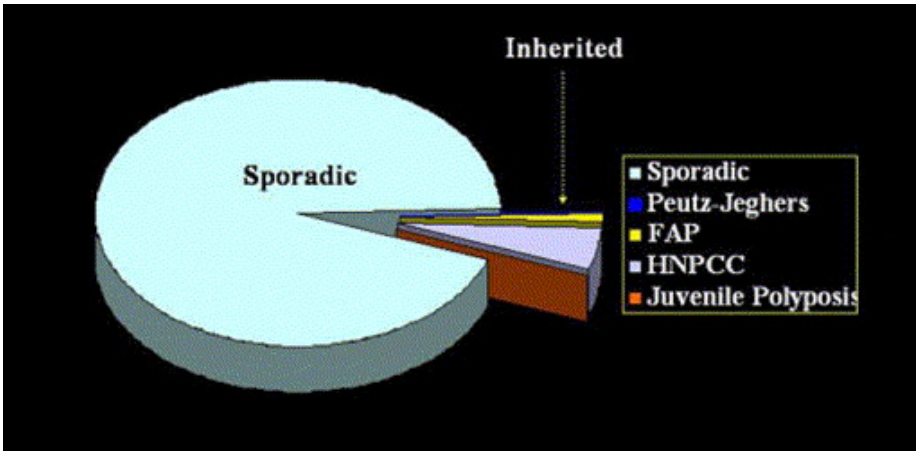
Figure 2: Accumulation of genetic changes in the progression from normal colonic mucosa to adenomatous polyp to cancer (23).



2.1.2 Etiology

The etiology of CRC is unknown, however it is thought that most cancers (up to 95%) arise from benign adenomatous polyps following the polyp-cancer sequence as described above (4;22). Most cancers occur sporadically (60-85%) with no apparent evidence of having inherited the disorder (22;25). Thus non-hereditary forms of CRC are described as a multi-factorial disease and involve diet, lifestyle and environmental factors. Up to 15% of CRC may have a genetic basis (refer to Figure 3) (22;23), therefore, people with inherited syndromes such as familial adenomatous polyposis (FAP) and hereditary non-polyposis colon cancer (HNPCC) are at high risk for development of CRC. As the sequence of genetic events leading from normal to cancerous tissues is not completely understood, it is likely that other undiscovered major genes and background genetic factors contribute to the development of CRC, in conjunction with environmental risk factors (12;16).

Figure 3: Proportion of hereditary cancer burden and the respective cancer-prone syndromes (23).



2.1.3 Risk Factors

In Last's *Dictionary of Epidemiology* (26), a risk factor is defined as "an aspect of personal behavior or lifestyle, an environmental exposure, or an inborn or inherited characteristic which on the basis of epidemiological evidence is known to be associated with health related condition(s) considered important to prevent". A modifiable risk factor is defined as a determinant that can be modified by intervention, thereby reducing the probability of occurrence of disease (26). A large body of evidence indicates that there are several non-modifiable and modifiable risk factors for CRC which will be discussed below.

2.1.3.1 Non-modifiable

Non-modifiable, well-established risk factors for CRC include age, hereditary conditions (FAP, HNPCC), and family history of CRC. The risk of CRC begins to increase after the age of 40 and rises sharply at the ages of 50 and 55 for men and women

(16). The risk doubles with each succeeding decade, and continues to rise exponentially (27;28). Numerous studies have consistently found that people with one or more first-degree relatives with CRC (but without one of the genetic syndromes) are at a 2-fold to 3-fold increased risk of developing CRC compared to individuals at average risk (27). In those with a single first-degree relative, the risk significantly increases in the 4th decade and continues to rise with age (27). Risk appears to be further increased if more than one first-degree relative has CRC and if the relatives' cancers occurred before age 60 (27).

People with inflammatory bowel disease (IBD) such as Crohn's disease and ulcerative colitis are at a substantially increased risk for CRC although IBD only contributes a small proportion (less than 1%) of new cases (28). Individuals with a personal history of CRC have an increased risk for developing CRC. This risk increases if the initial diagnosis of CRC was before the age of 60 (27). Those with history of previous polyps also have an increased risk (27;28).

2.1.3.2 Modifiable

Physical activity has the strongest evidence showing an inverse relationship between level of physical activity and CRC incidence (the average relative risk reduction is reportedly 40-50%) (27). Other modifiable factors that have been shown to play a role in CRC risk include body mass index, alcohol, cigarette smoking, hormone replacement therapy, and other dietary factors including fat intake and fibre. Although there are numerous studies examining the relationship between diet and CRC much still remains conflicting and unclear.

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) adenomatous polyps are well-managed by endoscopic intervention; and (iv) survival depends on the stage of the tumour (early stage leads to better prognosis) (29). The goals of CRC screening are to reduce CRC mortality through early detection and curative intervention and to reduce CRC incidence by detecting and removing adenomatous polyps (30).

There are several screening modalities available for the detection of CRC. Recommended screening strategies include colonoscopy, fecal occult blood test (FOBT), flexible or rigid sigmoidoscopy, and double-contrast barium enema. These tests all differ in terms of sensitivity, specificity, cost, safety and the screening test interval required. All of the screening tests are available in Canada; however they differ in terms of their ease of completion and availability.

2.2.1 Screening Tests

There is strong evidence that screening can reduce mortality from, and the incidence of, CRC (4). Results from four large randomized controlled trials (5-10) and one meta-analysis (4) have consistently demonstrated that FOBT screening reduces CRC, with relative risk reductions ranging from 15% to 33% in a targeted population of 50 years of age or older (10). Reduced mortality is likely due to both the early detection of existing cancers and the prevention of subsequent cancer development by removal of adenomatous polyps at colonoscopy in people with positive FOBTs (31). Despite the fact

that randomized controlled trial-based evidence only exists for FOB testing, observational studies and cost-effectiveness models have also shown a reduction in CRC mortality using flexible sigmoidoscopy and colonoscopy (a reduction over 70% for colonoscopy) (32). The data have suggested that removal of adenomatous polyps with colonoscopy reduces the incidence of CRC by up to 90% (33).

Several cost-effectiveness studies have supported the use of all CRC screening modalities (34-38). A 2002 systematic review of seven United States (US) cost-effectiveness studies (39) concluded that compared with no screening all commonly recommended screening modalities (for adults over age 50) will reduce CRC mortality at a cost of $10,000 to $25000 per life-year saved. The data did not suggest whether one screening strategy was superior to another.

2.2.1.1 Colonoscopy

Colonoscopy is the screening test that will be examined in this study. Colonoscopy is an invasive procedure generally performed by specialists using a 160cm endoscope. The endoscopic procedure can detect 87-94% of polyps 6-10mm in size (40) and is the most specific and sensitive of all the available CRC screening tests thus giving the most accurate results (41;42).

The main advantages of colonoscopy over other screening modalities include the ability to visualize the entire colon and simultaneously perform biopsy and polypectomy (29). With evidence mounting that polypectomy reduces incidence from CRC, this is of substantial importance. Colonoscopy is the recommended test to investigate positive findings on any of the other screening modalities and is considered the diagnostic gold standard (29;40). The sensitivity and specificity of colonoscopy allow prolongation of

the screening interval required (approximately 10 years after a normal test result). However, important disadvantages of colonoscopy include risk of complications, relatively high costs, use of conscious sedation (which increases post-procedure recovery time and may result in more lost time from work), and the need for more highly trained health personnel (40).

2.2.2 Canadian Screening Recommendations

Canadian public health recommendations and clinical practice guidelines regarding CRC screening have been produced by many organizations and societies. All agencies, including the Canadian Task Force on Preventive Health Care and the Canadian Association of Gastroenterology (CAG) recommend that people aged 50 years and older who are at "average" risk for CRC be screened (11;41). Individuals at average risk for CRC are healthy people with no known risk factors other than age (29;43). However, there are differences in terms of the recommended screening tests and frequency of testing. For example, the Canadian Task Force on Preventive Health Care recommends annual/biennial screening with FOBT or flexible sigmoidoscopy every five years (44). Other guidelines such as that of the CAG recommend that all asymptomatic men and women over 50 years of age and with no family history of CRC should choose one of the following: FOBT every two years, flexible sigmoidoscopy combined with FOBT every five years, double contrast barium enema every five years or colonoscopy every ten years (refer to Appendix 1) (41). It is recommended that the choice for testing should be determined by patient preference, current evidence, and local resources.

Inconsistent recommendations and guidelines pose a problem for both health care providers and public health professionals (45-47). The recommendations in Canada need to be closely assessed and more research needs to be conducted to create an effective, evidence-based national screening policy. This will aid health care providers in medical practice as well as allow public health professionals to provide a consistent message to the public in hopes of encouraging and increasing compliance with CRC screening.

In 2001, the National Committee on Colorectal Cancer, convened by Health Canada, recommended the development of organized population-based screening programs using FOBT that provide information about potential risks and benefits of screening for Canadians who are at average risk for CRC in an effort to reduce the burden of the disease (12). Because screening involves subjecting apparently healthy individuals to potential risk, population-based screening programs are only recommended when: a) the screening test has been shown to reduce mortality; b) the screening test is able to detect 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) effective treatment is available if carcinoma is found (1). Once these criteria have been met, other factors may be considered before evidence-based population level screening is implemented such as acceptability of the test, the cost of the intervention, and the extent to which there is sufficient capacity and resources in the health care system to perform the screening and appropriate diagnostic test, as well as treatment for those with abnormal test results. Although population-based screening programs for CRC have been recommended in Canada they have yet to be implemented.

2.2.3 Translating Screening Recommendations into the Community

Screening programs must be implemented at a population level with high uptake of screening in order to achieve the full benefit of mortality and incidence rate reduction (48). This becomes complicated for CRC screening due to the variety of available screening tests and the fact that only FOBT has been evaluated in randomized controlled trials. Other issues include lack of screening resources, adherence to screening and adherence to the recommended follow-up. Despite evidence for the efficacy of CRC screening and current Canadian recommendations, there are many barriers that need to be considered before the implementation and adoption of population-based screening programs.

2.3 Barriers to Screening

A barrier to screening is something that obstructs or impedes a person from undergoing CRC testing (49). Research has discovered patient, health provider and health care system barriers that contribute to the underutilization of CRC screening (49;50). Barriers include lack of awareness of CRC or screening; lack of physician recommendation; test preparation requirements; concerns about pain; embarrassment; inadequate social support; and lack of access to health care (49;50). Barriers and issues surrounding adherence to screening and regular repeat screening are discussed below.

2.3.1 Adherence to Screening

2.3.1.1 Screening Rates

Despite CRC screening recommendations from expert groups and organizations, CRC screening rates remain low and are much worse than other, more established, cancer screening tests (51-54). A study conducted in Ontario (55) used administrative data to identify a cohort of all residents aged 50 to 59 in 1995 (n = 982 443). The study followed the cohort for 6 years and discovered that less than 20.5% of screen-eligible 50 to 59 year old men and women were screened for CRC (55). Another study by Ramji et al (2005) evaluated the lifetime prevalence of CRC screening among a population-based sample of Ontario residents never having had CRC (56). The study recruited 1994 participants from 1998-2000 and found that 23% of participants greater than 50 years of age self-reported ever having had CRC screening (17% FOBT, 5% sigmoidoscopy, 4% colonoscopy) (56). In 2003 the Canadian Community Health Survey (cycle 2.1) asked questions about CRC screening use (57), covering the entire population of British Columbia and Newfoundland. The self-reported data reported rates from a low of 4% in women in Newfoundland to 13-14% of men in British Columbia (58). Another recent study conducted a random digit dial telephone survey of 1808 Albertans aged 50 to 74 years in 2004 (59). Overall, the study found that only 14.3% of 1476 average risk adults were up-to-date on CRC screening (any combination of FOBT within the past 2 years and/or endoscopy within the past five years). The studies above provide evidence of low CRC screening rates in Canada to date.

Direct comparisons of screening rates between countries are difficult to obtain due to recommendation differences in the criteria for types of tests to include and

differing time frames. However, in general, rates of CRC screening in Canada are reported to be lower than in the US (60-62). Nevertheless, US national data still shows low utilization of CRC screening in the general population. Findings from the National Health Interview Survey (NHIS) indicate that in 2000, only 45% of men and 41% of women aged 50 years or older had undergone any of the recommended CRC screening tests (50). Another NHIS survey in 2003 showed that CRC screening rates had increased only minimally with 46% of men and 43% of women reporting having had any recommended tests (63).

2.3.1.2 Physician Recommendation

Physician recommendation plays a large role in patient acceptance and adherence to screening. It has been shown to be a strong predictor of the acceptance of other cancer screening tests such as mammography, the Papanicolaou test and the prostate-specific-antigen test (64-66). It has also been shown to be the strongest predictor of patient acceptance of CRC screening regardless of patient preference for a particular screening modality (67-72). In a recent US national survey, primary care physicians reported relatively low volumes of ordering, performing, or referring for CRC screening, demonstrating that the majority are not reaching all eligible patients in their practices (50). Other studies have shown that attending a medical check-up visit (which presumably offers the opportunity to discuss screening), and having a usual source of medical care are both strongly associated with CRC screening (67;71;73-76).

2.3.1.3 Personal Attitudes

Attitudes towards CRC screening among average risk adults have been investigated quantitatively and qualitatively. A study by Janz et al (2003) (30) assessed

the attitudes and practices regarding CRC screening among men and women, 50-79 years of age, and found that less than 30% (n = 355) of participants were adherent to the current CRC screening guidelines. The study explained that two constant barriers to CRC screening were the belief that the screening test is not needed and that it is embarrassing (30). In two qualitative studies, focus groups were conducted among North American adults to identify barriers to the adoption of CRC screening (49;77). The results indicated that a lack of knowledge about CRC and the screening tests available, lack of understanding of the concept of screening, and negative attitudes towards the screening test itself are key barriers. A common theme resulting from the focus groups was that there was low visibility (for example little information in the media) compared to other more public diseases such as prostate cancer. Lack of visibility led participants to conclude that CRC was either "unimportant, untreatable, or a private disease". Another study by Shokar et al (2005) involved conducting in-depth individual interviews in a diverse patient population (n = 30), aged 50 or above (53), and emphasized that a barrier to the adoption of screening was that participants did not understand "the concept of screening". The study explained that participants were hopeful about the benefit of early cancer diagnosis but remained reluctant to get tested when symptom-free.

A recent study by Klabunde et al (2005) (50) compared barriers to CRC screening reported by a nationally representative sample of US primary care physicians (n = 1235) and average risk adults (n = 6497). Both physicians and average-risk adults identified lack of patient awareness and physician recommendation as key barriers to adherence to screening. Physicians commonly suggested that patient embarrassment and anxiety about testing were common barriers but few adults identified these as major barriers.

Interestingly, only 10% of adults not current with screening (those who had not undergone FOBT in the past year and/or endoscopy in the past ten years) and who had a physician visit in the past year reported receiving a screening recommendation.

2.3.2 Adherence to Regular Repeat Screening

Once a patient has undergone screening another necessity is adherence to regular repeat screening. Obtaining adherence to repeat screening is difficult for CRC due to the differing Canadian guidelines, as well as the fact that each screening test differs in terms of repeat screening intervals (43). Adherence is especially difficult for colonoscopy as the test is invasive and requires sedation (77;78). Many patients may not want to experience the test again particularly if their previous colonoscopy test was normal. As the repeat screening interval for normal test results is 10 years this adds to the complexity of compliance as patients may forget to go for another colonoscopy.

In order to increase patient adherence to repeat screening, patients need to receive information regarding the disease, test results, and future screening recommendations. Unfortunately many patients who are screened receive inadequate communication from health care providers about test results, and fail to receive education regarding the disease, further screening requirements and recommendations for diagnostic follow-up of an abnormal screen (79). However, it is imperative that patients receive this information in order to achieve the goal of reducing cancer morbidity and mortality (79). Failure to obtain this information can not only have an effect on morbidity and mortality (by reducing the benefits) but can also have cost implications for the individual and the health care system.

A 2003 review on follow-up care after abnormal cancer screening results indicated that the promise of screening to reduce cancer incidence and mortality may be compromised as most studies reported that fewer than 75% of patients received appropriate follow-up care (80). With regards to CRC the majority of research regarding follow-up has been conducted on FOBT. A study by Nadeem et al (2003) determined common reasons for non-performance of appropriate follow-up or complete diagnostic evaluation after an abnormal FOBT result (81). The study found that 46% of patients failed to receive the appropriate follow-up. The main reason for non-performance was physician decision-making which does not always conform to expert recommendations for follow-up (81). Other studies have reported that only 37-63% (82) of patients who present an abnormal FOBT result will undergo the appropriate follow-up. Similarly, a report from a community-based study of FOBT screening in the US also indicated that the majority of individuals who have an abnormal screening FOBT result do not undergo the appropriate follow-up and diagnostic evaluations (83). Although research in this area has focused on FOBT it is likely that some of the issues surrounding appropriate follow-up are similar for both FOBT and colonoscopy, for example follow-up of polyps. However these are important issues that have yet to be explored specifically in relation to colonoscopy.

2.4 CRC Screening Education

Patient education about CRC screening is critical because of the newness and complexity of available tests, conflicting clinical practice guidelines, and recommendations that patients undergoing screening be advised of the potential risks and

benefits (19;41). It is important that information on CRC be readily available, accessible and in a format and language that is well understood (12). Public education is available from a number of organizations, including the Colorectal Cancer Association of Canada, which is a non-profit organization dedicated to the provision and education of CRC.

2.4.1 Type of Education

It is essential that the risk of developing CRC, information about screening tests available, and other CRC-related health information is conveyed to patients with the hopes that increasing knowledge will in turn increase screening compliance (84;85). This information may come from many possible sources such as the media, family physicians, organizations, family, friends etc.

Once a patient is interested in pursuing screening there is an ethical and legal obligation on the part of the physician to obtain informed consent from a patient before any test or procedure is carried out. Thus, it is the patient's right to be informed about the possible advantages, adverse effects and potential complications that may arise from a screening test. Complications from colonoscopy include bleeding, perforations and even death (86). The risks vary according to the reporting source and whether biopsies or polypectomies are performed (12). Elderly patients or those with heart or lung disease are at increased risk of complications due to sedation (86). In order for truely informed consent, patients need to play an active role in the decision-making process and all the information about the steps of the screening process, along with their associated risks and complications must be presented at the outset (87). Without such accurate and comprehensible information, the patient may never be in a position to make an informed choice.

In 2001, Mayberry et al (2005) conducted a study on information and the consent process for endoscopy procedures (88). The study concluded that consent needs to be supported by easy-to-read information and the patients' understanding needs to be formally tested. Important concepts must be included in this information as well as uncommon risks of the procedure. Education and the source of information about colonoscopy are key factors that have an important influence on whether patients will consent to undergo screening (89).

After the patient has received the appropriate information and consented to the procedure it is vital that the patient is also educated throughout the process of screening. This includes being informed regarding bowel preparation, the results of the procedure (and its implications), diagnosis and relevant follow-up information including surveillance and treatment.

2.4.2 Benefits of Education

There are several benefits to CRC screening education. By increasing knowledge of CRC, risk and screening recommendations, not only is it possible to increase screening adherence, it is also possible to increase lifelong, long-term screening adherence, rather than one-time compliance (52;85;90-92). This is especially important because CRC screening can be unpleasant and if patients are not clear of their risk and other important information about CRC, they may be reluctant to continue to be screened. CRC education additionally addresses the legal and ethical issues of informed consent (12;87;93), improves patient satisfaction with the procedure (49), encourages preventive measures to reduce the risk of CRC and decreases distress (85;94;95).

2.5 Calgary Gastrointestinal Clinic

Over 10, 000 colonoscopies are performed in Calgary, Alberta each year. Of those, approximately 30% are for screening purposes. Usually patients are referred to the Gastrointestinal (GI) Clinic for colonoscopy by their family physician (refer to Appendix 2). The wait time for a screening colonoscopy (time between being referred and undergoing the test) is approximately 12 to 18 months.

After patients are referred for colonoscopy there is no standard approach for how patients receive the appropriate information on test results, follow-up etc. However, described below is the procedure and timeline of what typically happens to patients who attend the Calgary GI Clinics. Prior to colonoscopy (approximately 2 to 12 weeks) most patients will either have an appointment with a nurse/physician at the GI Clinic or receive information in the mail. After patients undergo colonoscopy, most patients will receive their test results on the day of the procedure. These results may be communicated verbally, in written format or both. Some patients, however, may receive their test results from their family physician, or some may not receive their test results at all. Patients may or may not receive information regarding appropriate follow-up from either the GI Clinic or from their family physician. The recommended repeat screening interval is 10 years for a normal (negative) test result and 3-5 years for an abnormal (positive) test result (19). However if a patient has a family history of CRC the recommended repeat screening interval is 3-5 years regardless of colonoscopy test results.

This study is focusing on colonoscopy due to the lack of literature available, specifically for colonoscopy, regarding the type of information patients receive throughout the process of CRC screening. For example there is lack of data regarding

how patients receive their test results, and if patients receive the appropriate follow-up. As well, it has been shown in Alberta that there has been a marked increase in colonoscopy rates (96) and that the procedure is being recommended by physicians (54) in contrast to the Canadian screening guidelines supporting FOBT and flexible sigmoidoscopy.

2.6 Rationale and Significance

There is a lack of Canadian data regarding what information patients receive throughout the process of CRC screening, specifically for colonoscopy. Thus there is a need to uncover the important issues surrounding screening colonoscopy. It is important to determine post-CRC screening knowledge and understanding in order to provide valuable information on patient's understanding of the disease, their risk, test results and subsequent follow-up in hopes of further reducing CRC incidence and mortality. It is essential to obtain this information to facilitate the subsequent development of educational strategies on this important health issue. In May 2007, the University of Calgary is opening a Colon Cancer Screening Centre. This innovative, high volume outpatient endoscopy Centre will be contracted by the Calgary Health Region to initially provide 10,000 screening-related colonoscopies per year with a goal of 20,000 per year within five years. Thus, as the focus of this Centre is not only on CRC screening, but also on education and research, the information from this study may contribute to delivering the appropriate information and counselling to patients within the Centre. The information from this study may also aid in the development and evaluation of population-based screening programs for CRC in Canada. Overall, this project may

indicate the need for CRC screening programs to consider and incorporate other aspects into screening programs such as educational initiatives.

2.7 Design Considerations

This research project is a descriptive study utilizing self-administered questionnaires as described in more detail in the next chapter. Within this study there are aspects that have known limitations which will be acknowledged at this point.

This study desires to collect data over the time period of being referred for CRC screening up until three months post-CRC screening. To obtain this information data will be collected at two points in time (1 week post-colonoscopy and 3 months post-colonoscopy). Collecting data prior to colonoscopy was examined, however it was deemed impractical for both family physicians and the GI Clinics.

The retrospective study design of this study has limitations related to the participants' ability to recall information asked of them in the questionnaires. Although self-administered questionnaires are often selected because they are relatively inexpensive, not labour intensive and have a rapid turnaround in data collection, there is little doubt that inaccurate recall is a disadvantage of this method. As well, given that the measurement instruments used in this study are self-administered participants are required to read, write and understand English.

2.8 Objectives

To determine what type of information patients perceive to receive throughout the process of CRC screening using colonoscopy in Calgary, Alberta and their knowledge of important aspects of colonoscopy screening.

2.9 Research Questions

1. What type of information, if any, do patients report was given to them by medical professionals throughout the process of CRC screening?
2. What proportion of patients are aware of his/her screening test results and the recommended follow-up?
3. What proportion of patients are satisfied with the information given throughout the process of CRC screening and what proportion believe the information was useful?

2.9.1 Secondary Research Question

1. What additional type of information would patients have liked to receive from medical professionals throughout the process of CRC screening?

Chapter Three: Methods

This research study received ethical approval prior to initiation from the Conjoint Health Research Ethics Board, Faculty of Medicine, University of Calgary on December 15, 2005 (Appendix 3).

3.1 Study Design

This project is a prospective descriptive study surveying people at average or moderate risk for CRC who have undergone screening colonoscopy in Calgary, Alberta. As defined previously individuals at **average risk** for CRC are healthy people with no known risk factors other than age (being >= 50 years) (29;43). Individuals at **moderate risk** are those with a first or second-degree relative(s) with CRC (43).

3.2 Sample

The target population was asymptomatic people at average or moderate risk for CRC who underwent screening colonoscopy. The study sample was asymptomatic people at average or moderate risk for CRC who underwent colonoscopy from mid-January to mid-May, 2006 at the Foothills Hospital or the Peter Lougheed Hospital in Calgary, Alberta. Participants in the study must have fulfilled the following inclusion and exclusion criteria:

3.2.1 Inclusion Criteria

1. Males and females who are at average or moderate risk for CRC (43).
2. Able to speak and read English.

3.2.2 Exclusion Criteria

1. All those undergoing colonoscopy for reasons other than screening.
2. High risk for CRC defined as a member of a FAP or HNPCC CRC kindred, personal history of CRC or polyps, or suffer from IBD (43).
3. CRC found at colonoscopy.

3.2.3 Sampling and Recruitment

Each person who underwent screening from January 24th until May 18th at the two hospital sites were invited to participate in the study. The procedure of recruiting participants is outlined below:

- All patients undergoing colonoscopy (for any reason) were given a consent form by the GI receptionist prior to their colonoscopy (Appendix 4). The form briefly described the purpose of the study and stated that they may be chosen to participate in the study. Patients were asked to consent to the release of their name, address and reason for their colonoscopy to the investigators in order to send them a questionnaire in the mail. The receptionist stamped each form with the patient's hospital identity card which included the patient's name, hospital identification number and mailing address.
- Patients who gave consent returned their form to the GI receptionist in the GI Clinic prior to their procedure.
- To identify potential participants undergoing colonoscopy for screening purposes, physicians/nurses filled out a form after performing colonoscopy (Appendix 5) which was included in the patient's chart. At the Foothills Hospital, procedure

nurses filled out the form and at the Peter Lougheed Hospital physicians filled out the form. The form asked physicians if the purpose of colonoscopy was for screening (average risk or family history) as well as any reasons why the investigators shouldn't send the patient a questionnaire (such as discovering CRC or not speaking English).

- All forms were picked up on a weekly basis by Dr. Robert Hilsden at the Peter Lougheed Hospital and by Robin Walker at the Foothills Hospital.
- A weekly printout including the name of the hospital where the procedure took place, first and last name, date of colonoscopy and the indication of the colonoscopy from Endopro, an electronic endoscopy database, was used to confirm the inclusion and exclusion criteria for each potential participant.
- Indications recorded in Endopro to identify those who had undergone colonoscopy for screening purposes is provided in Table 1. To identify participants with a family history of CRC the following indications recorded in Endopro were used: >1 1^{st} degree relative, >1 2^{nd} degree relative, one 1^{st} degree relative, and one 2^{nd} degree relative.
- Mailed questionnaires were sent out to consenting participants who met the inclusion and exclusion criteria approximately 1 week post-colonoscopy.

Table 1: Endoscopy database indications identifying those who underwent colonoscopy for screening purposes

	Colonoscopy Screening Indication
Average risk	• Average risk • Family history of polyps • Polyp 1st degree relative
Moderate risk	• One 1st degree relative with CRC • One 2nd degree relative with CRC • >1 1st degree relative with CRC • >1 2nd degree relative with CRC

3.3 Sample Size:

Over a four month period approximately 400 screening colonoscopies are done at each medical site for a combined sample size of approximately 800. Anticipating a 50-60% response rate results in a conservative sample size estimate of approximately 400 participants for the study. It is estimated that 15-25% of people aged 40–75 at average or moderate risk of CRC would be expected to have an adenomatous polyp detected at a colonoscopy screening (21). Therefore, as an example, using the conservative sample size it is anticipated that approximately 80 people will be in the positive screening test group and 320 in the negative screening test group. As this study is not testing a hypothesis the sample size presented will give reasonably precise estimates allowing the study to compare potential differences between groups. For example, anticipating the worst case scenario (50% prevalence), the proportion of patients aware of their screening test results for the positive and negative screening test group are 40 (95%CI: 0.38, 0.61) and 160 (95%CI: 0.44, 0.56).

3.4 Instruments

The two questionnaires in this study were created through discussion with 7 experts in the field (family physicians, surgeons, gastroenterologists, population health investigators) as well as using the literature to address the issues of post-CRC screening knowledge and understanding. The questionnaires were pilot-tested in a sample of patients who had undergone colonoscopy (see 3.5.1 below). Both questionnaires included cover letters addressed from the investigator (Appendix 6). In the first questionnaire participants provided information on basic demographics including age, sex, marital status, smoking status and highest educational attainment. Additional questions covered CRC screening test results, how the test results were conveyed, understanding and implications of test results and recommended follow-up.

Questionnaire 1 (1 week post-colonoscopy): (refer to Appendix 7)

Part 1 of the questionnaire determined if the patient had ever been screened for CRC (using any available screening test) prior to their recent colonoscopy. This information was helpful in determining who had informational needs (for example, those previously screened vs. those not previously screened etc.).

The next section of the questionnaire, Part 2, provided information on the process of family physician referral for colonoscopy (Q#2-6). This included how long ago the screening referral was given (Q#2). Questions #3 and #4 asked for the participant's reasons for undergoing screening. This included source of screening recommendation and whether other CRC screening test options were discussed. Question #5 provided information received from their family physician prior to screening. Question #6, an open-ended question, determined if the patient would like to have received additional

information from their family physician. The purpose of this question was to determine informational needs prior to screening.

Part 3 of the questionnaire addressed what information the patient received from the GI Clinic 2 to 12 weeks prior to his/her colonoscopy. This included whether the patient had an appointment with the GI Clinic (Q#7), whether they received information in the mail from the Clinic (Q#8) and if so the type of information received (Q#9). Question #10, an open-ended question, determined if the patient would like to have received any other information from the GI Clinic. The purpose of this question was again to establish informational needs prior to screening.

Part 4 of the questionnaire pertained to information the patient received on the day of his/her colonoscopy (Q#11-15), in order to determine whether the patient received their test results, and if so how the information was conveyed to them. A positive screening test was defined as discovering at least one polyp and a negative test was when no polyps were found. Question #15, an open-ended question, determined patient informational needs post-colonoscopy.

Part 5 of the questionnaire revealed satisfaction level of the participant and usefulness of information received throughout the process of screening.

The next section concerned information related to future screening. Question #18 established how many participants were aware of the recommended follow-up (when to have their next colonoscopy) and the source of that information. This information is important as compliance to follow-up procedures is essential in order to reduce the incidence and mortality of CRC. Question #19 determined the likelihood of participants undergoing another screening colonoscopy.

Questionnaire 2 (3 months post-colonoscopy): (refer to Appendix 8)

The purpose of the follow-up questionnaire was to determine if the patient had received any more information regarding CRC, test results, appropriate follow-up etc. It determined if the patient had gone to see their family physician or back to the GI Clinic to discuss test results or relevant information. It also included some of the same questions from the first questionnaire such as colonoscopy test results, when to have their next colonoscopy, how likely the participant was to have another colonoscopy, and satisfaction with information received throughout the process of screening. Finally participants were asked additional information they would liked to have received throughout each stage of screening, using categories created from responses to the open-ended questions from the first questionnaire.

3.5 Data Collection

The data collection timeline is illustrated in Appendix 2. All participants in this study completed a structured self-administered questionnaire. Questionnaires are the preferred type of data collection instrument for this study as they are relatively inexpensive, not labour intensive and have a rapid turnaround in data collection. The limitations of self-administered questionnaires are discussed below in Chapter 5, section 5.2. The questionnaires were administered through postal mail with the first questionnaire mailed approximately one week post-colonoscopy. This is an appropriate length of time to capture accurate and reliable post-CRC screening visit information. A reminder questionnaire was mailed 3 weeks after the first mail-out if the initial

questionnaire was not returned (refer to Appendix 9). The study stopped accepting questionnaires 3 months post-CRC screening.

Participants were asked in the first questionnaire if they could be contacted again for another short questionnaire. For those who agreed a second questionnaire was sent out approximately 3-months post-CRC screening. Again a reminder questionnaire was mailed 3 weeks after the first mail-out if the initial questionnaire was not returned (Appendix 9). Three months is a reasonable amount of time for participants to go to their family physician and/or obtain further information on CRC screening. The purpose of the follow-up was to determine if participants had received further information and/or knowledge surrounding CRC screening since the first questionnaire. This allowed the study to obtain a more complete picture of what information and knowledge patients received throughout the screening process.

3.5.1 Pilot testing

The purpose of the pilot study was to test the methodology used for the questionnaire. The pilot study goal was to recruit approximately 10-15 people (using the criteria stated in section 3.2) and ask them to complete the first questionnaire. Thirteen people completed the questionnaire. While there are no guidelines for sample size calculations in a pilot study, 13 people was deemed a reasonable number by the investigators to test the methodology of this study. The pilot test questionnaire included a question at the end asking if the study coordinator could contact them by phone in order to receive important feedback regarding the clarity of the questionnaire. For the 13 people who agreed, telephone interviews included questions regarding questionnaire

length, difficult wording, difficult questions, and the flow of the questionnaire (refer to Appendix 10). Additional input was welcomed. Revisions based on the pilot were then made to the questionnaire.

3.5.2 Maximizing the response rate

To maximize the response rate in this study both questionnaires included cover letters addressed by the investigator describing the purpose of the study, how the participant's involvement would contribute to the body of knowledge, and to thank the participant in advance (97) (Appendix 6). The letters emphasized that all information obtained by the study is kept strictly confidential. Clear instructions were included on how to complete the questionnaires (Appendix 7, Appendix 8). The questionnaires were designed to avoid any possible questionnaire bias. For example, it was carefully and sensitively worded, had an attractive layout and presentation, and took a short period of time to complete (less than 10 minutes). Return envelopes with postage (business reply envelopes) were included in the mailed questionnaires. If the questionnaires were not returned within approximately 3 weeks, a reminder questionnaire (Appendix 9) was mailed in order to maximize the response rate (97).

3.6 Data Management

A database including study ID number, address, date the questionnaire was mailed, if a reminder questionnaire was mailed, and whether the completed questionnaire was received, tracked consenting participants. Electronic databases were used for questionnaire data entry. Data from completed questionnaires were entered into the

Access database twice in order to minimize data entry errors. A 10% random sample of entries were compared to the original questionnaire to determine the accuracy of the data entry. All databases were created using Microsoft Access 2003.

3.7 Data Analysis

All statistical analyses were performed using Intercooled Stata Version 8 (Stata, College Station TX).

3.7.1 Data Screening

Uni-variate descriptive statistics (mean, median, standard deviation, minimum and maximum) were examined to check the range of the variables and ensure that the data values fell within the appropriate range, as well as to identify out-of-range values (outliers). The amount and distribution of missing data was assessed. Initially, missing data was compared with the original questionnaires to determine if the data was actually missing and the coding of the data was evaluated to ensure it was correct.

3.7.1.1 Open Ended Questions

Answers to open ended questions (e.g., “other” categories) were explored multiple times (and on different days) to find common themes. Participant’s responses were coded according to the themes found (multiple themes were allowed within a single response). Next, the responses for each theme were isolated to ensure the theme accurately captured the participant responses and appropriate corrections were made. Once themes were finalized new variables and coding were generated in Stata.

3.7.2 Descriptive Statistics

To address the purpose of this study the data analysis was primarily descriptive. Frequency counts were examined and presented for each question. Three main predictors (prior CRC screening experience, family history of CRC and age) of post-CRC screening knowledge were explored in relation to the descriptive variables.

3.7.3 Inferential Statistics

Post-screening knowledge differences among groups (for example positive and negative colonoscopy test results) were tested and reported using the Pearson's Chi-squared test. To detect a difference the statistical significance level was set at 0.05 (by convention). Additional differences were identified by subgroups such as those who requested to be screened and those who have been previously screened.

Chapter Four: Results

4.1 Recruitment

Participants were recruited from January 24, 2006 to May 18, 2006. The response rate statistics for the study are presented in Figure 4. There were a total of 2711 colonoscopies during the study period, 892 (32.9%) were for screening purposes. A total of 1819 participants were excluded as they underwent colonoscopy for reasons other than CRC screening, were at high risk for CRC, or CRC was found at colonoscopy. Among those who were eligible for the study, only 83 (9.3%) did not consent. Therefore, 809 participants comprised the study group and were mailed questionnaires. Four hundred and eighty-seven participants responded to the first mail-out within 3 weeks and 26 questionnaires were returned by Canada Post due to incorrect addresses. Three-hundred and twenty-two reminder questionnaires were mailed and of those 170 were returned completed. Despite the reminder, 179 (22.1%) participants who were eligible for the study did not return their questionnaire. In total, 630 completed questionnaires were returned for an overall response rate of 77.9%.

All of the questionnaires that were returned were well-completed. Less than 6% of questions had missing values (range: n = 1 to n = 38). The most common missing value was self-reported colonoscopy test results (n = 38). Given that the missing data was a small percentage participants with missing data were removed from each specific analysis.

Figure 4: Study response rates

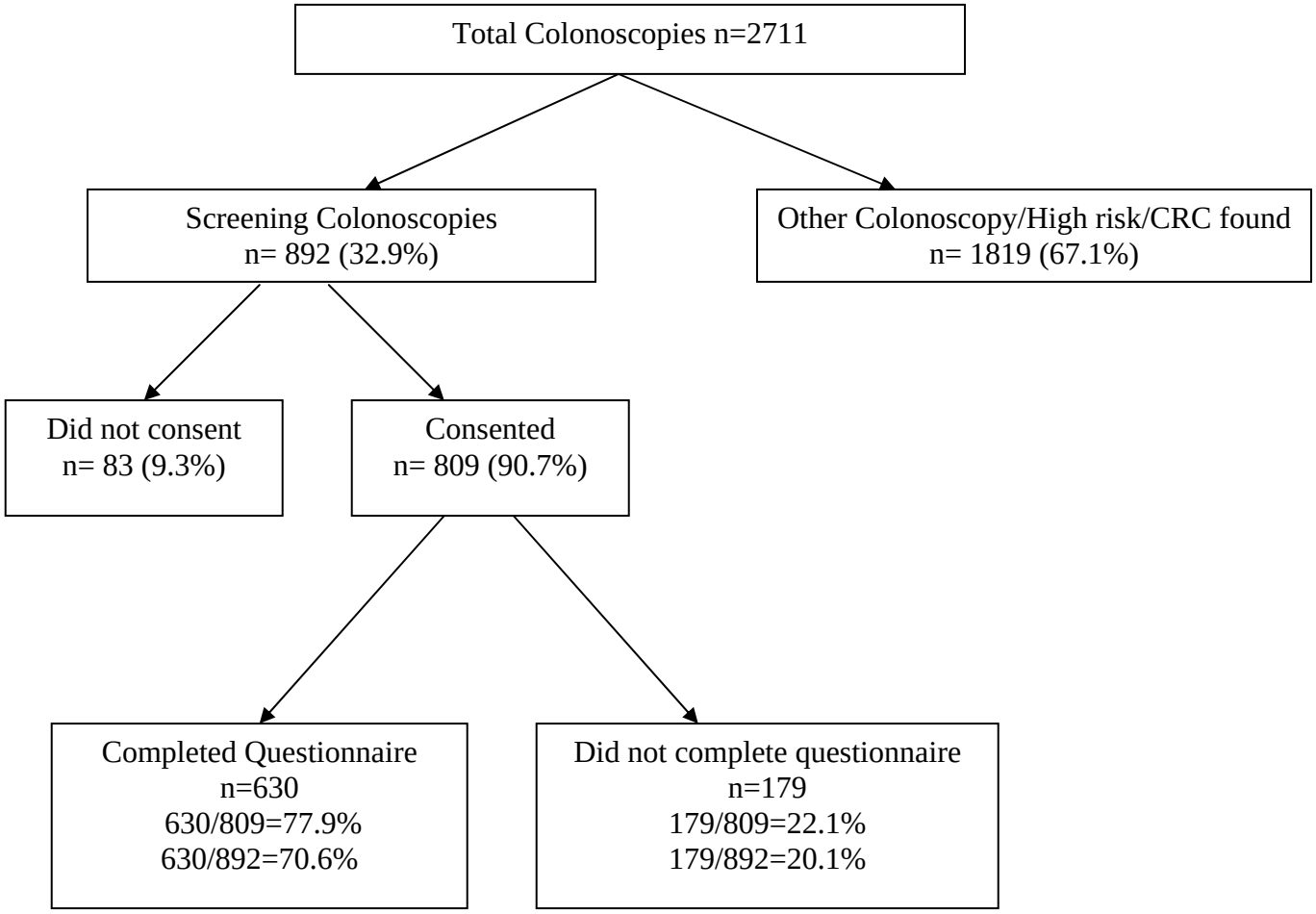


Table 2: Participant Characteristics (n = 630)

Characteristic	Frequency (%)
Sex	
Male	289 (45.9)
Female	341 (54.1)
Age Group	
<40	22 (3.5)
40-44	45 (7.2)
45-49	75 (12.0)
50-54	134 (21.3)
55-59	132 (21.0)
60-64	90 (14.4)
65-69	61 (9.7)
>70	68 (10.9)
Smoking	
Does not smoke	555 (88.1)
Current smoker	75 (11.9)
Education	
Elementary	13 (2.0)
High School	94 (14.9)
Community College	148 (23.5)
University Degree	142 (22.5)
Post Graduate Training	113 (17.9)
Other	116 (19.2)
Relationship Status	
Married	479 (76.0)
Common-law	45 (7.1)
Separated/Divorced	54 (8.6)
Widowed	23 (3.7)
Single (never married)	29 (4.6)
Family History of CRC	
Yes	305 (48.4)
No	325 (51.6)
Previously screened for CRC	
Yes	254 (40.7)
No	370 (59.3)

The characteristics of the participants are shown in Table 2. Most participants were over age 50 (77.4%), 48.4% of participants had a family history of CRC, and 59.3% were first-time screeners.

When asked who recommended participants to be screened for CRC, 41.1% of participants reported that they requested screening themselves and 58.3% of participants reported that their family physician recommended screening. Only 21.6% (n = 136) of participants reported that they were given other CRC screening test options (other than colonoscopy) from their family physician when referred for screening. Among those with a family history of CRC, 17.1% (n = 52) were given test options and among those with no family history of CRC, 25.9% (n = 84) were given test options.

For participants who were provided with options, the primary reason why they choose colonoscopy is provided in Table 3. Most participants reported the main reason for choosing colonoscopy was the accuracy of the test (48.5%), followed by the ability to remove polyps (22.1%) and that their physician recommended it (21.3%).

Table 3: Main reason for choosing colonoscopy (n = 136)

Main Reason	Frequency (%)
Accuracy of the test	66 (48.5)
Removal of polyps	30 (22.1)
Physician recommended it	29 (21.3)
Other	6 (4.4)
Test is not required every year	2 (1.5)
Sedated	2 (1.5)
Performed by physician in a clinic	1 (0.7)

After colonoscopy referral, there was a range in wait times for the procedure which is shown in Table 4. The wait times did not vary by family history.

Table 4: Wait time for colonoscopy (since family physician referral) (n = 630)

Months	Frequency (%)
<6	182 (28.9)
6-12	215 (34.1)
12-18	102 (16.2)
>18	124 (19.7)
Don’t remember	7 (1.1)

The type of contact participants had from the GI Clinic prior to colonoscopy is depicted in Table 5. The most common type of contact was mail only (34.3%) followed by a Clinic appointment only (25.6%).

Table 5: Type of contact participants had from the GI Clinic prior to colonoscopy (n = 616)

Contact	Frequency (%)
Clinic appt only	158 (25.6)
Mail only	211 (34.3)
Both Clinic appt and mail	112 (18.2)
No Clinic appt and no mail	135 (21.9)

Whether prior CRC screening experience affected the type of contact participants reported having with the GI Clinic prior to the procedure is show in Table 6.

Table 6: Type of contact from GI Clinic prior to colonoscopy by CRC screening experience (n = 610)

Contact with Clinic	Previously Screened (n = 250)	First-time Screeners (n = 360)
Appt only	31 (12.2)	127 (34.3)
Mail only	112 (44.1)	96 (25.9)
Both appt and mail	50 (19.7)	59 (16.0)
No appt, no mail	57 (22.4)	78 (21.1)

4.2 Information Participants Received Throughout the Process of Screening

Participants reported the type of information they received from their family physician when they were referred for screening, as well as what information they received from the GI Clinic (including nurses and physicians) where they had their colonoscopy procedure.

4.2.1 Family Physician

The type of information patients reported receiving from their family physician is shown in Table 7. A large proportion of participants received no information (n = 303, 48.4%). Among those who received no information, 32.2% had been previously screened for CRC (using any test) whereas 67.8% had never been screened. Thirty-seven percent of participants received information regarding colonoscopy and 20.9% received information about CRC itself. Most participants (87.9%) did not receive information about different CRC screening tests (such as FOBT or flexible sigmoidoscopy) and 6.8% of participants did not remember the type of information they received.

Table 7: Type of information participants received from their *family physician* when they were referred for screening (n = 627)

Type of information*	Frequency (%)	95% CI
No information	303 (48.4)	44.3, 52.3
Colonoscopy	232 (37.1)	33.2, 40.9
Colorectal cancer	131 (20.9)	17.8, 24.3
Different screening tests	76 (12.1)	9.7, 14.9
Participants did not remember	43 (6.8)	5.0, 9.1
Other information	6 (1.0)	0.3, 2.0

*multiple responses permitted

4.2.2 GI Clinic Prior to Colonoscopy

Prior to colonoscopy, the type of information participants reported receiving from the GI Clinic is shown in Table 8. The most common type of information received was what to expect during the procedure (69.2%). Less than half (41.9%) received information on the risks of colonoscopy. Twenty-nine percent received information on CRC and 16.9% on different screening tests. Originally in the "other category" 110 participants volunteered they had received instructions regarding bowel preparation for colonoscopy. However, all participants in this study must have received bowel preparation instructions to undergo the procedure, thus, bowel preparation responses were removed from the "other category" and the analysis.

Table 8: Type of information participants received from the *GI Clinic* prior to their colonoscopy (n = 628)

Type of information*	Frequency (%)	95% CI
What to expect during colonoscopy	434 (69.2)	65.3, 72.7
Risks of colonoscopy	263 (41.9)	37.9, 45.8
Colorectal cancer	183 (29.2)	25.6, 32.9
Different screening tests	100 (16.9)	13.1, 19.0
No Information	79 (12.6)	10.1, 15.4
Participants did not remember	12 (1.9)	0.9, 3.3
Other information	11 (1.8)	0.8, 3.1

*multiple responses permitted

Table 9 shows the type of information participants reported receiving from the GI Clinic by the type of contact they had with the Clinic prior to colonoscopy.

Table 9: Type of information participants reported receiving from the GI Clinic by the type of contact from the Clinic prior to colonoscopy (n = 616)

Type of information*	Appt Only (n=158)	Mail Only (n=211)	Both Appt and Mail (n=112)	No Appt, No Mail (n=135)
What to expect during colonoscopy	141 (89.2)	137 (64.9)	97 (87.4)	49 (36.8)
Risks of colonoscopy	111 (70.3)	60 (28.4)	26 (23.4)	19 (14.3)
Colorectal cancer	75 (47.5)	29 (13.7)	57 (51.3)	16 (12.0)
Different screening tests	57 (36.1)	8 (3.8)	26 (23.4)	5 (3.8)
No Information	5 (3.2)	10 (4.7)	3 (3.7)	61 (45.9)
Participants did not remember	2 (1.3)	6 (2.8)	-	2 (1.5)
Other information	1 (0.6)	3 (1.4)	7 (1.4)	4 (3.0)

*multiple responses permitted

The appointment group and both appointment and mail group were very similar in the type of information participants reported receiving except in regards to the risks of colonoscopy. Having an appointment appears to be the best way to receive information on the risks of colonoscopy. The reason that only 23.4% of participants in the both appointment and mail group received information on the risks of the procedure needs to be further explored. Compared to the other groups, the appointment and both appointment and mail groups were more likely to receive information on what to expect during the procedure, CRC, and different CRC screening tests. Those who had no appointment and received no mail from the Clinic were more likely to receive no information compared to the other groups.

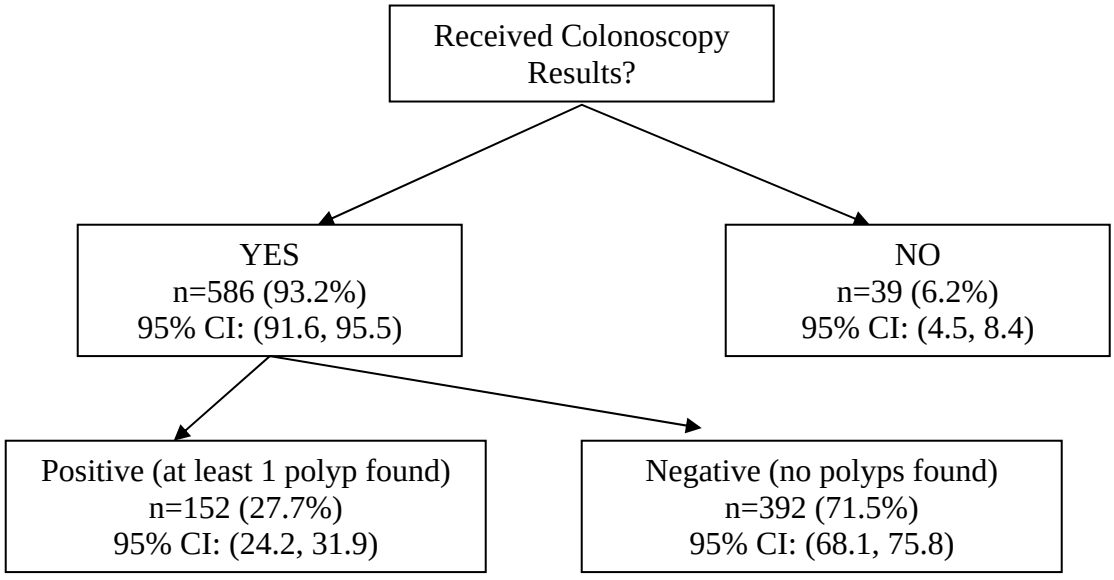
4.3 Screening Test Results and Recommended Follow-up

4.3.1 Test Results

On the day of colonoscopy, 90.3% (n = 566) of participants met with the physician who performed the procedure after it was complete. Ninety-three percent (n = 586) of participants received their test results of which 27.7% were reported positive (Figure 5).

Of those who received their results, 86.5% (n = 545) were informed by the physician who performed the colonoscopy. Ninety-four percent (n = 550) of participants were given their results on the day of the procedure and 6.0% (n = 36) were told after the day of the procedure. Eighty-nine percent of those with positive test results and 97.9% of those with negative test results were given their test results on the day of the procedure. Merely 84 participants (13.4%) received a written copy of their results.

Figure 5: Self-reported colonoscopy test results (n = 625)



4.3.2 Recommended Colonoscopy Follow-up

Seventy-nine percent (n = 495, 95% CI: (75.1, 81.7)) of participants reported being told when to have their next colonoscopy. Table 10 shows where they reported receiving this information.

Table 10: Of those participants who have been told when to have their next colonoscopy where did they receive this information? (n = 495)

	Frequency (%)
Physician who performed colonoscopy	419 (84.7)
Family physician	76 (15.3)
Other	11 (2.2)
Nurse	10 (2.0)
Friends/Family	10 (2.0)
Books/articles/news/radio	2 (0.4)
Internet	1 (0.2)

Of those who had positive and negative test results, 81.6% and 79.6% knew when to have their next colonoscopy respectively. Regardless of screening test results, most participants (n = 328, 66.3%) reported that their next colonoscopy should be within 3 to 5 years. Nineteen percent (n = 96) reported that it should be in at least 10 years.

Family history of CRC is important to examine in regards to follow-up as it has an impact on the recommended screening interval for colonoscopy. Among those with negative test results, Figure 6 shows CRC family history and when participants should have their next colonoscopy. Among those with negative test results, 74.4% (n = 122) and 47.6% (n = 70) with a family history and no family history, respectively, were recommended to have their next screening colonoscopy within 3 to 5 years. Forty percent (n = 58) of participants with no family history were told to have their colonoscopy in at least 10 years. The repeat screening interval recommended most

commonly for those with positive test results was 3-5 years (Figure 7) regardless if they had a family history (n = 47, 83.9%) or no family history (n = 45, 66.2%).

Figure 6: CRC family history status by when the participant was told to have their next colonoscopy among those who reported *negative test results* (n = 312)

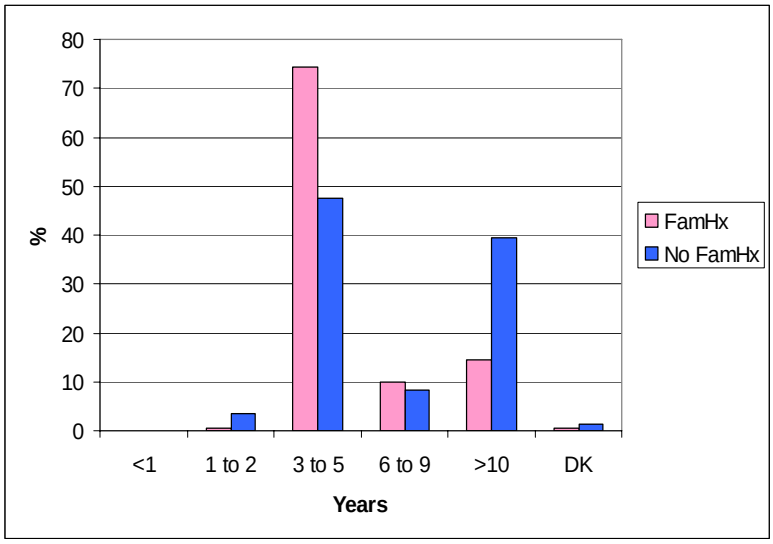
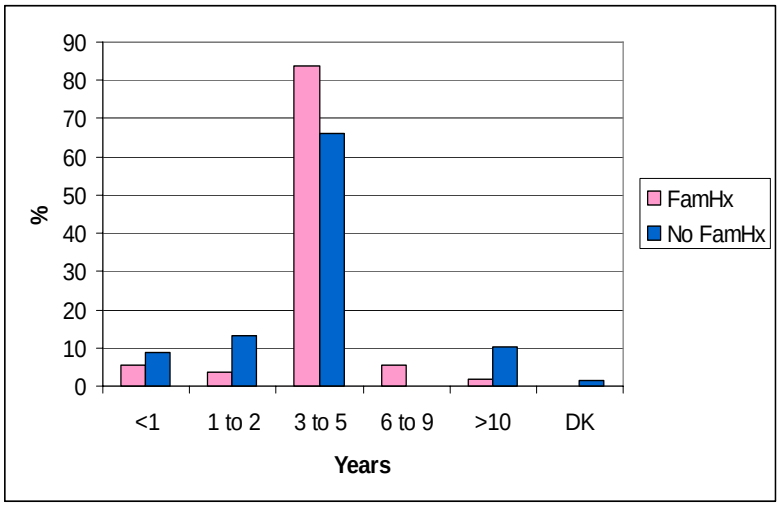


Figure 7: CRC family history status by when the participant was told to have their next colonoscopy among those who reported *positive test results* (n = 124)



4.3.3 Future CRC Screening

The majority of participants reported that they are very likely (n = 456, 72.8%) or somewhat likely (n = 94, 15.0%) to undergo another screening colonoscopy. For those who are not very likely (n = 50, 8.0%) or not at all likely (n = 26, 4.2%) the reasons why they would not undergo another screening colonoscopy are outlined in Table 11. The most common response was that the participant did not need another colonoscopy (37.4%). Among those who reported they did not need another colonoscopy 94.4% (n = 34) were aged 65 years or older.

Table 11: Reasons why those who are not very likely or not at all likely to undergo another screening colonoscopy (n = 76)

Reasons	Frequency (%) (n = 76)	% of total sample (n = 630)
Do not need another one	36 (37.4)	5.7
Test is too unpleasant	15 (19.7)	2.4
Other	14 (18.4)	2.2
Don't know	7 (9.2)	1.1
Too much of a time commitment	4 (5.3)	0.6

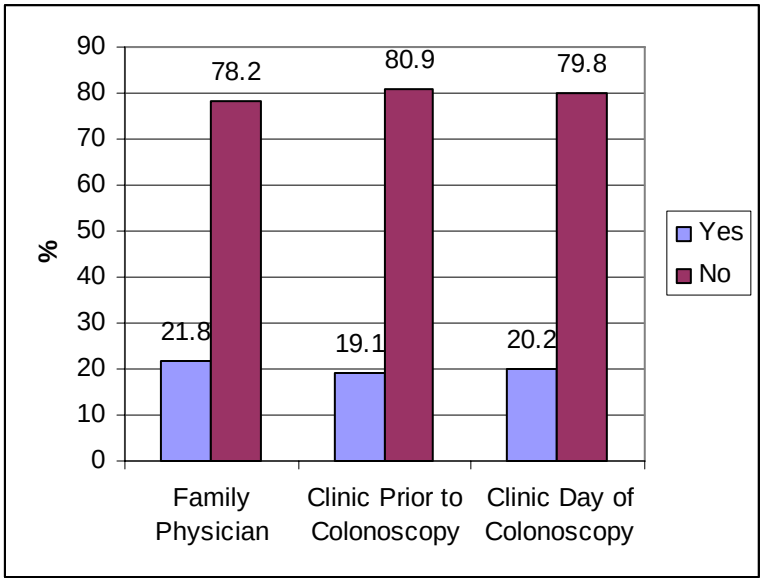
4.4 Additional Information Requested

4.4.1 Proportion of Participants Wanting Additional Information

Participants were asked if they wanted additional information from each stage of the screening process: from their family physician when referred for colonoscopy, from the GI Clinic prior to colonoscopy, and from the GI Clinic on the day of the colonoscopy. The proportion of participants who would have liked additional information from each stage of the screening process is illustrated in Figure 8. Overall, 38.8% (n = 245) of participants requested additional information. Among those participants, 58.4% (n =

143) requested information from one stage of the screening process, 31.4% (n = 77) requested information from two stages of the screening process, and only 10.2% (n = 25) requested information from all stages of the screening process. Thus, only of minority of participants were requesting information from all stages of CRC screening.

Figure 8: Proportion of participants who would have liked to receive more information, by stage of the screening process (n = 609)



Among those who requested additional information by stage of the screening process the majority were first-time CRC screeners (Table 12).

Table 12: Participants requesting more information by prior CRC screening experience

More information from:	Previously Screened	First-time Screeners
Family Physician	37 (28.0)	95 (72.0)
Clinic Prior to Colonoscopy	29 (25.4)	85 (74.6)
Clinic Day of Colonoscopy	48 (39.0)	75 (61.0)

There were no differences between education levels (high school or less, college/some university, and university/post graduate degree) and those requesting additional information (all $p>0.05$). Exploring the data by sex, females tended to request

additional information more often compared to males (60.6% versus 39.4% respectively) (p = 0.04). When comparing age groups (<50 years, 50 to 60 years, >60 years) those aged 50 to 60 were more inclined to want additional information from medical professional throughout the stages of screening compared to the other age categories (<50 years 28.6%, 50 to 60 years 44.5%, and >60 years 26.8%) (p = 0.03).

4.4.2 Type of Additional Information Participants Would Have Liked to Receive

4.4.2.1 Family Physician (Table 13)

When referred for colonoscopy the most common additional information participants would have liked to receive from their family physician was colonoscopy procedure information (n = 54, 40.6%). Participants would also have liked to receive information on different screening tests for CRC (n = 41, 30.8%) as well as general information on CRC (n = 34, 25.6%). A smaller proportion of participants would have liked information on risk factors (n = 4, 3.0%) and the general process of CRC screening (n = 8, 6.0%).

Table 13: Information participants would liked to received from their *family physician* when referred for colonoscopy (n = 133)

Type of information*	Frequency (%)	95% CI
Colonoscopy procedure	54 (40.6)	32.1, 49.4
Different screening test options	41 (30.8)	23.1, 39.4
General information on CRC	34 (25.6)	18.3, 33.8
Other information	31 (23.3)	16.4, 31.4
Process of CRC screening	8 (6.0)	2.6, 11.5
CRC risk factors	4 (3.0)	0.8, 7.5

*multiple responses allowed

4.4.2.2 GI Clinic Prior to Colonoscopy (Table 14)

The type of information participants would like to have received from the Clinic prior to their colonoscopy included what to expect during the procedure (n = 49, 42.2%), general information on CRC (n = 32, 27.6%), and different screening test options (n = 30, 25.9%). Participants also requested information on the risks of colonoscopy (n = 26, 22.4%) and what to expect after the procedure (n = 22, 19.0%).

Table 14: Information participants would have liked to received from the *Clinic prior to colonoscopy* (n = 116)

Type of information*	Frequency (%)	95% CI
What to expect during procedure	49 (42.2)	33.1, 51.8
General info on CRC	32 (27.6)	19.7, 36.7
Different screening test options	30 (25.9)	18.2, 34.8
Risks of colonoscopy	26 (22.4)	15.2, 31.1
What to expect after colonoscopy	22 (19.0)	12.3, 27.3
Other information	17 (14.7)	8.8, 22.4
Bowel preparation	12 (10.3)	5.4, 17.4
What the test is looking for	11 (9.5)	4.8, 16.3
Follow-up (how often the test is needed)	6 (5.2)	1.9, 10.9

*multiple responses allowed

4.4.2.3 GI Clinic on the Day of the Procedure (Table 15)

The most common information participants would have liked to obtain on the day of the procedure was related to colonoscopy test results. Sixteen percent desired test results, 28.5% (n = 35) wanted further explanation of test results, and 26.0% (n = 32) asked for a written copy of test results. Information on what happens during the procedure was also requested (n = 12, 9.8%) as well as follow-up information (n = 16, 13.0%). Some participants (n = 13, 10.6%) would liked to have received information from the GI Clinic when they were not sedated.

Table 15: Information participants would liked to have received on the *day of their colonoscopy* (n = 123)

Type of information*	Frequency (%)	95% CI
Further explanation of test results	35 (28.5)	20.7, 37.3
Written copy of test results	32 (26.0)	18.5, 34.7
Test results	20 (16.3)	10.2, 23.9
Follow-up	16 (13.0)	7.6, 20.3
Information when I was not sedated	13 (10.6)	5.7, 17.4
What happens during colonoscopy procedure	12 (9.8)	5.1, 16.4
Other	9 (7.3)	3.4, 13.4
What to expect after colonoscopy	8 (6.5)	2.8, 12.4
Preventive measures	5 (4.1)	1.3, 9.2

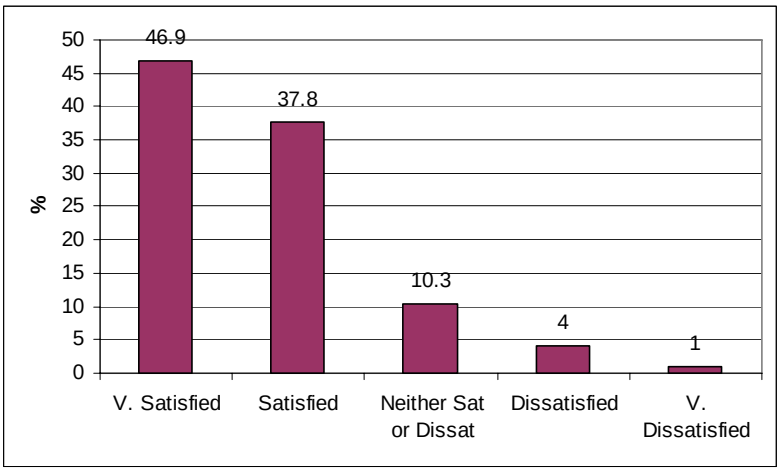
*multiple responses allowed

4.5 Overall Satisfaction and Usefulness of Information Received

4.5.1 Satisfaction

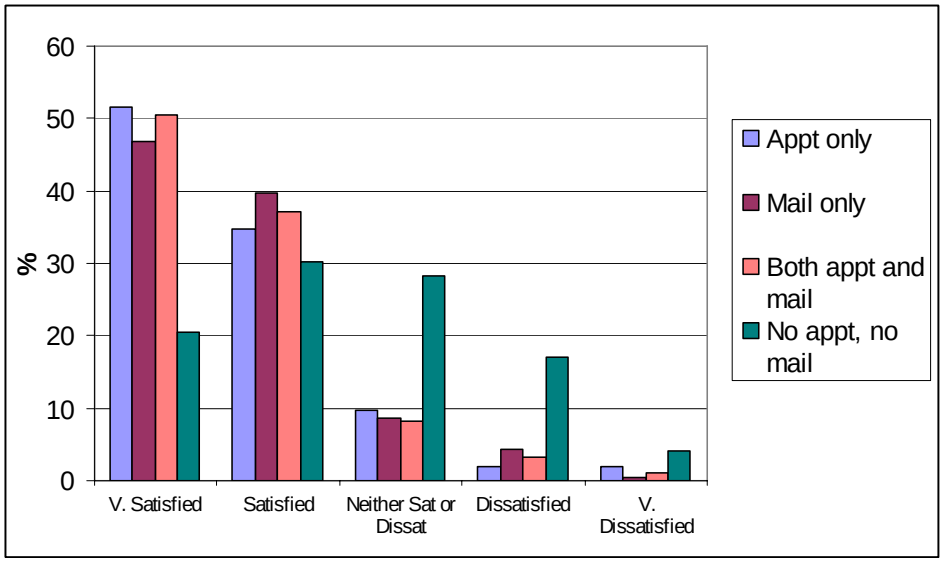
In general a large proportion of participants were satisfied with the information they received throughout each stage of screening and most found the information useful. Figure 9 represents overall satisfaction of participants regarding the information they received from medical professionals.

Figure 9: Overall satisfaction of participants with information they received throughout the process of CRC screening (n = 621)



When examining satisfaction of participants there were no differences between those who had been previously screened for CRC and first-time screeners ($p > 0.05$) and those with positive and negative test results ($p > 0.05$). In addition, there were no differences in satisfaction between gender, age, and education levels (high school or less, college/some university, and university/post graduate degree) (all $p > 0.05$). Reported satisfaction by type of contact with the GI Clinic prior to colonoscopy is illustrated in Figure 10. Those in the no appointment and no mail group were more likely to be either "neither satisfied or dissatisfied" or "dissatisfied" compared to the other groups.

Figure 10: Reported satisfaction with information received by type of contact with the GI Clinic prior to colonoscopy



There were differences in levels of satisfaction between those who wanted additional information throughout each stage of screening (from their family physician ($p < 0.01$), from the Clinic prior to colonoscopy ($p < 0.01$) and on the day of the procedure ($p < 0.01$)) compared to those who did not request more information (Table 16). However the source from which they requested additional information did not affect satisfaction. In

general, those who did not want more information reported being very satisfied more frequently than those who wanted more information. Also, those who requested additional information were more likely to be dissatisfied or neither satisfied or dissatisfied compared to those who did not ask for additional information.

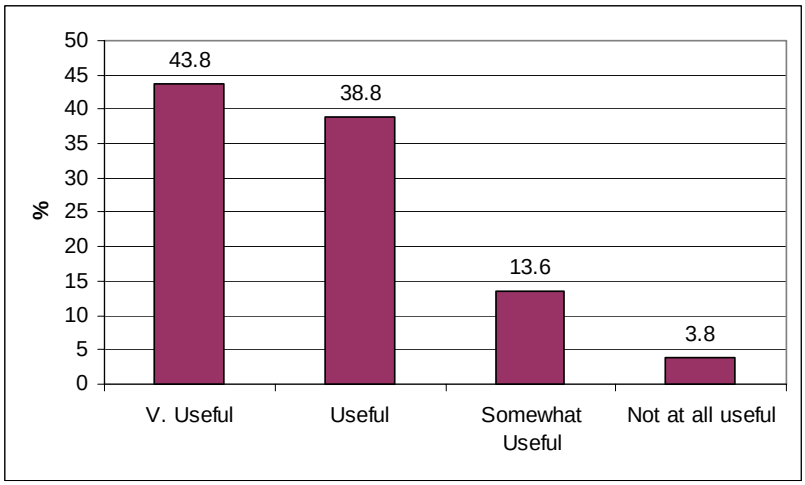
Table 16: Satisfaction levels among participants who requested additional information from their family physician and the GI Clinic.

Satisfaction	Requested additional information from:					
	Family Physician n (%)		Clinic prior to colonoscopy n (%)		Clinic on the day of procedure n (%)	
	Yes	No	Yes	No	Yes	No
Very satisfied	32 (24.6)	255 (54.1)	23 (20.5)	262 (53.5)	28 (23.1)	255 (53.2)
Satisfied	51 (39.2)	171 (36.3)	46 (41.1)	179 (36.5)	52 (43.0)	173 (36.1)
Neither	27 (20.8)	35 (7.4)	27 (24.1)	35 (7.1)	23 (19.0)	39 (8.1)
Dissatisfied	16 (12.3)	8 (1.7)	14 (12.5)	10 (2.0)	15 (12.4)	10 (2.1)
Very dissatisfied	4 (3.1)	2 (0.4)	2 (1.8)	4 (0.8)	3 (2.5)	2 (0.4)

4.5.2 Usefulness

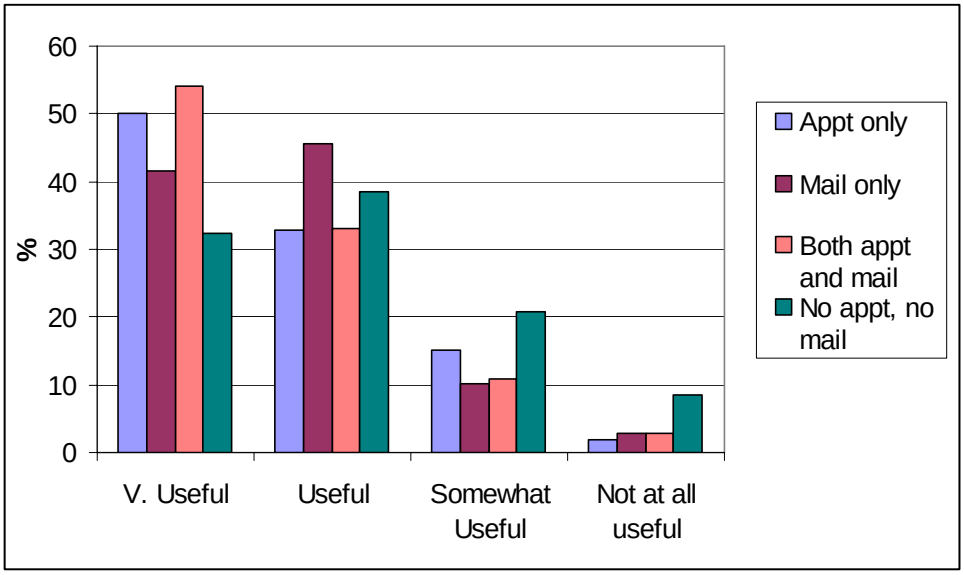
The overall usefulness of information the participants received is illustrated in Figure 11.

Figure 11: Overall usefulness of the information participants received throughout CRC screening (n = 609)



When exploring the overall usefulness of information received there were no differences (all $p>0.05$) between age groups, gender, test results, prior screening experience and education levels. Reported satisfaction by type of contact with the GI Clinic prior to colonoscopy is illustrated in Figure 12.

Figure 12: Overall usefulness of information received by type of contact with the GI Clinic prior to colonoscopy



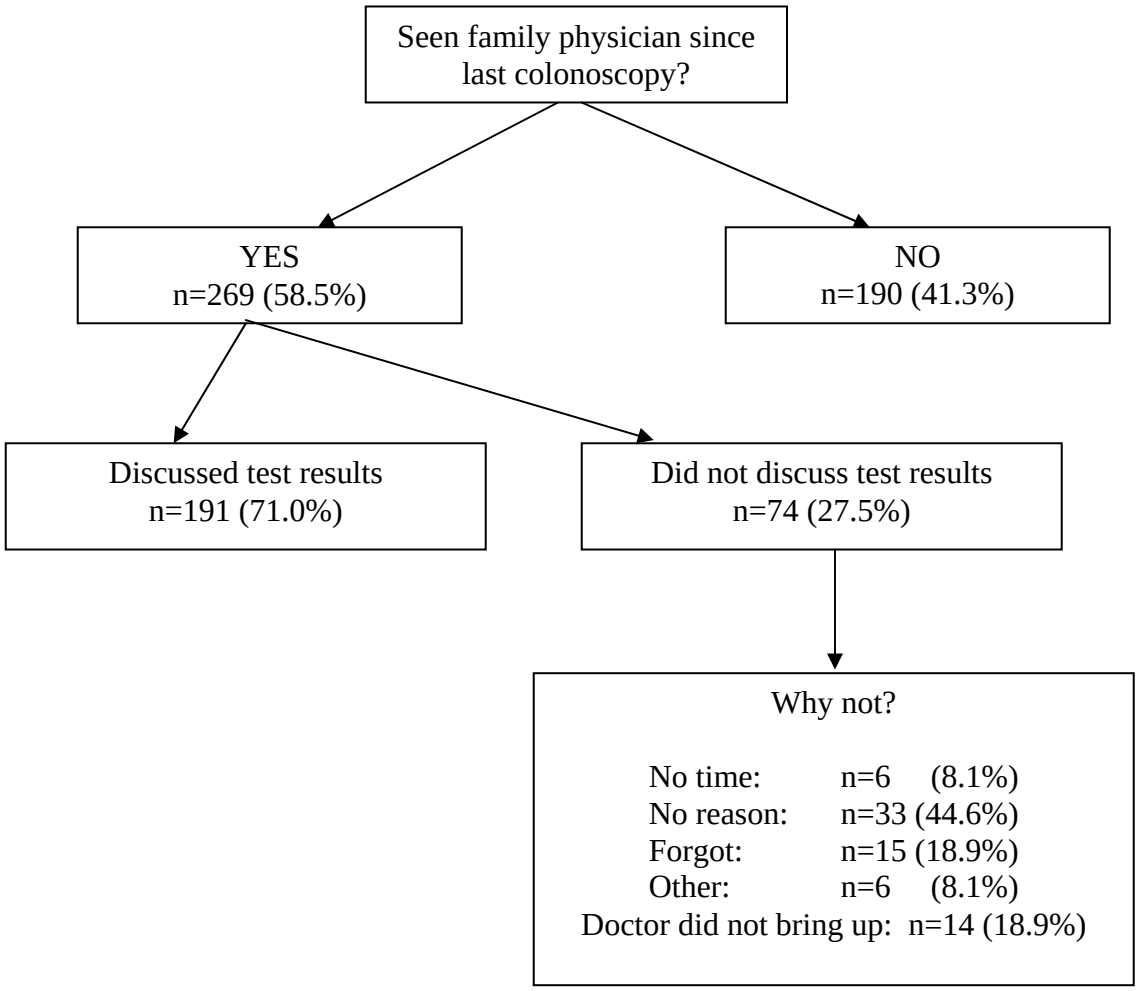
Similar to satisfaction, there were also differences in reported usefulness between those who wanted additional information throughout each stage of screening (from their family physician ($p<0.01$), from the Clinic prior to colonoscopy ($p<0.01$) and on the day of the procedure ($p<0.01$)) compared to those who did not request additional information. Those who requested additional information from medical professionals were more likely to find the information they received somewhat useful and not at all useful. Participants who did not request additional information were more likely to report the information very useful or useful.

4.6 Three Month Follow-up of Participants

A total of 574 (94.3%) participants agreed to be contacted again, therefore 574 follow-up questionnaires were mailed. 387 participants responded to the first mail-out within 3 weeks. Therefore, 187 reminder questionnaires were sent out and of those 80 were returned completed. In total, 460 completed questionnaires were returned with an overall 73.0% response rate (80.1% response rate among those who agreed to be contacted again).

The proportion of participants who visited their family physician since their colonoscopy is shown in Figure 13. Two-hundred and sixty-nine participants (58.5%) reported that they had seen their physician, and of them 191 (71.0%) reported they had discussed their colonoscopy test results. The most common reason participants did not discuss test results with their family physician was because there was no reason to bring it up. Only 9.4% of participants (n = 43) had gone back to the physician who performed their colonoscopy and 95.4% of those participants discussed their test results.

Figure 13: Post-colonoscopy family physician appointment (n = 460)



All participants who completed the follow-up questionnaire were asked what additional information they would liked to have received from the screening process overall. There were a variety of responses as depicted in Table 17. Some of the most common information requested included written copy of test results (41.5%), preventive measures for CRC (39.8%), and information on different screening tests for CRC (24.1%). One hundred and twenty-four participants (26.9%) requested no additional information.

Table 17: Information participants would have liked to receive throughout the process of CRC screening (n = 460)

Type of information*	Frequency (%)	95% CI
Written copy of test results	191 (41.5)	36.9, 46.2
Preventive measures	183 (39.8)	35.2, 44.4
None	124 (26.9)	22.9, 31.3
Different screening tests	111 (24.1)	20.3, 28.3
Risk factors for CRC	101 (21.9)	18.2, 26.0
General information on CRC	91 (19.8)	16.2, 23.7
Further explanation of test results	87 (18.9)	15.4, 22.8
When to have another colonoscopy	78 (16.9)	13.6, 20.7
Risks of colonoscopy	76 (16.5)	13.2, 20.2
What to expect after colonoscopy	45 (9.8)	7.2, 12.8
CRC statistics	43 (9.4)	6.8, 12.4
Bowel preparation	36 (7.8)	5.5, 10.7
What to expect during colonoscopy	35 (7.6)	5.4, 10.4
Other	16 (3.5)	2.0, 5.6

*multiple responses allowed

4.6.1 Comparison of Information Immediately Post-colonoscopy and 3-Months Post-colonoscopy

Similar results were obtained for the follow-up questionnaire as the initial questionnaire. Reported test results, when results were received, written copy of test results, when to have another colonoscopy, likelihood of undergoing another screening colonoscopy, and satisfaction of information received were comparable to the results of the first questionnaire. Differences between the questionnaires included who gave participants their test results and follow-up information, and reasons for not being likely to undergo another screening colonoscopy. In the follow-up questionnaire family physicians played a more important role in disseminating test results (15.4% versus 1.3%) and follow-up information (25.2% versus 15.3%). Among the 10.8% (n = 47) of participants who were not very likely or not at all likely to undergo another screening colonoscopy, 62.1% reported that the reason they are not likely to undergo another

screening colonoscopy was because their physician had not recommended it and 29.1% reported that they did not need another one.

Chapter Five: Discussion

The results of this study provide new and important knowledge about the type of information patients perceived to receive from medical professionals throughout the process of CRC screening using colonoscopy. This study has identified a number of informational gaps, such as medical professionals not providing patients with information on different CRC screening tests, the risks of colonoscopy, and appropriate follow-up screening intervals. Although research has shown that primary care physician recommendation is a strong predictor of acceptance of CRC screening (67), not everyone who is referred for screening actually undergoes the test. Thus, as this study involved patients who are actually undergoing CRC screening the results may provide an optimistic view because those not being screened may have different, and perhaps more informational needs.

5.1 Summary of findings

The primary research questions of this study were: (i) what type of information did patients report receiving throughout the process of screening; ii) what proportion of patient were aware of his/her colonoscopy test results and recommended follow-up; and (iii) what proportion of patients were satisfied with the information given and how many found the information useful. When addressing these questions this study found that most participants did not receive any information from their family physician when referred for colonoscopy. The most common information received from the GI Clinic prior to the procedure was what to expect during colonoscopy and less than half of participants were informed about the risks of colonoscopy. A large proportion of

participants were aware of his/her screening test results (93%) and the recommended follow-up (79%). Most participants were either very satisfied (47%) or satisfied (38%) with the information they received from and the majority found the information very useful (44%) or useful (39%).

Additional types of information patients would like to have received throughout each stage of screening was a secondary research question for this study. Approximately 39% of participants undergoing screening requested additional information from medical professionals. Information in relation to colonoscopy, what to expect during the procedure, different CRC screening test options, further explanation of test results, written copy of test results and preventive measures for CRC were commonly requested.

Colonoscopy is a particularly important aspect of CRC screening for both family physicians and GI Clinics as colonoscopy rates have increased in Alberta (96), colonoscopy is being recommended for screening by physicians (54;91), and a new Colon Cancer Screening Centre is being opened next year in Calgary, Alberta. Below, the results of this study will be discussed in relation to family physicians and GI Clinics.

5.1.1 Family Physician

This study found that a large proportion of participants reported that they did not receive any information from their family physician when referred for colonoscopy. Some patients received information about the procedure of colonoscopy and a small proportion of patients were given information about CRC in general. A study by Buchanan et al (2005) (98) found that the majority of patients going for a medical visit were interested in discussing different CRC screening modalities with their family physician but the results of this study showed that only 12% of participants recalled being

given information on different CRC screening tests. Most participants in this study who requested additional information from their family physician, including screening test options, general information on CRC and the procedure of colonoscopy, were first-time screeners.

Time constraints (99), the need to make multiple clinical decisions (100), and the need to adequately inform (101), and engage patients in decision-making represent challenges for family physicians trying to motivate, inform and counsel patients about CRC screening (102-104). In an Albertan survey of family physicians (105), the vast majority (95.6%) of physicians indicated a need for physician education about CRC screening including the current recommendations (87.2%) and pros and cons of each type of test available (including colonoscopy) (66.4%). Most (82%) Alberta family physicians indicated a need for resources to educate patients suggesting physicians would welcome resources to deal with informing and counselling patients about the issues surrounding CRC screening in their practice (105).

However, is it the responsibility of primary care providers to be up-to-date on all preventive tests and recommendations, including having expert CRC screening communication and counselling techniques? Over the past century, primary care has evolved from the idea of a family physician who tended to the medical, and at times the emotional and social needs of his/her patients, to a new and much richer and idealized concept that includes prevention, continuity of care, health maintenance, and death with dignity, among others (106). Increasing public and patient expectations and administrative and regulatory controls contribute to the perception of increased time pressures and erosion of autonomy among family physicians (107). Increasingly,

knowledgeable patients armed with a multitude of information from a variety of sources confront their family physicians with a bewildering array of new expectations and demands (107). Have we raised the bar too high and put too much responsibility on the shoulders of primary care? Studies have shown that high expectations and time constraints limit the ability of primary care physicians to comply with preventive services counselling and recommendations (108-110). Among Alberta physicians, 38% agreed that CRC screening was lower priority than other health issues due to time restrictions during a routine physical exam (105).

Is it the role of the GI specialist to be the main source of information instead of relying on primary care? A qualitative study of patient perspectives on CRC conducted in Toronto, Ontario (111) found that family physicians were not considered a primary information source but rather someone to fill in patients' gaps in understanding and to answer questions that patients had not had answered by their GI specialist. In our study we found that most participants did go back to their family physician within 3 months post-colonoscopy. Among those participants who were unlikely to undergo another screening colonoscopy, approximately one-third reported that the reason was because their family physician had not recommended them to be screened again. When patients attend a medical visit post-screening it may be an ideal time for family physicians to answer any outstanding questions that were not addressed by the GI Clinic and to ensure test result implications and screening follow-up recommendations are clear. However, in order to do this, family physicians need to work together with GI specialists and have educational strategies in place which will be discussed in section 5.3 below.

5.1.2 GI Clinic

Prior to the day of colonoscopy, 25% of participants had a GI Clinic appointment, 35% received information in the mail, 18% had both an appointment and received information in the mail, and 22% had neither an appointment or received mail. Our data suggests that having an appointment or both an appointment and mail is an important aspect of the screening process as those patients were more likely to receive pertinent information about CRC, different screening tests, and what to expect during the procedure compared to the other groups. However, it appears that the only way to receive information about the risks of colonoscopy is to have a Clinic appointment.

The results of this study showed that a minority of participants reported receiving information about the risks of colonoscopy from the GI Clinic prior to the procedure. This is alarming as it implies that informed consent is compromised if patients are either not being informed about the risks of the procedure or do not recall the risks. Valid consent requires that the patient has adequate information about the proposed course of action, its probable consequences, possible alternative and their consequences, and so on (112). It is the moral obligation of health professionals to disclose the necessary information to patients and it is essential that important concepts, such as uncommon risks of colonoscopy, be included in the process (88;112). Thus, in order for true informed consent, colonoscopy patients need to play an active role in the decision-making process and all the information about the steps of the screening process, along with their associated risks and complications must be presented at the outset (87). As the majority of participants did not report receiving information about the risks of colonoscopy this suggests the means the GI Clinic are using to transmit this information

is not effective and better methods need to be used to convey this information successfully.

Although the majority of participants reported being informed about when to have their next screening colonoscopy (79%) some may have received improper follow-up screening intervals. In this study 48% of participants with negative test results and no family history reported that they were recommended to have a repeat colonoscopy in 3 to 5 years rather than the 10 year interval commonly recommended by clinical practice guidelines (refer to section 2.2.1.1 above) (41). A screening interval of 10 years after a normal colonoscopy has been adopted based on the estimated timing of the polyp-cancer sequence. As the duration of decreased risk of CRC following a negative colonoscopy has remained a question in the literature a recent study in Manitoba, Canada (113) conducted a retrospective analysis to estimate risk for developing CRC after a negative colonoscopy. Using linked data from a population-based cancer registry and a medical-claims database, researchers identified 32 203 people who had negative screening colonoscopies, no prior history of CRC, colon resection or IBD. Follow-up after negative colonoscopy ranged from 6 months to 14 years. Compared with the general population, study participants had significantly lower risk for CRC for more than 10 years following the performance of a negative colonoscopy. Thus, for average risk individuals with negative colonoscopy test results a screening interval of 10 years appears to be reasonable.

5.2 Threats to Validity and Strengths and Delimitations of the Study

In any study it is important to assess whether the results could have been influenced by any sources of bias. Bias can be introduced through the methods used to identify and recruit subjects (selection bias), the measurement of information (information bias) or through confounding (114). Potential limitations of this study included selection and information bias including issues related to instrument validation.

Selection bias is error due to systematic differences in characteristics between those who are selected for a study and those who are not (26). In this study it is possible that those who did not consent and those who consented but did not return the questionnaire (non-responders) were different from the study sample. For example, they may have received less information from medical professionals throughout the process of screening and may have been less satisfied with the information received. This bias would distort measurement of the variable of interest; probably leading to an overestimation of the type of information received and reported satisfaction. Conversely, non-responders may have been very happy with their medical care, thus they did not engage in the study. This bias would distort measurement of the variable of interest; probably leading to an underestimation of the type of information received and reported satisfaction. However, given that only 9% of screening colonoscopies did not consent and 20% were non-responders, it was unlikely that selection bias would result in a significant change in the results.

Loss to follow-up occurs when study subject(s) do not complete participation in the study (26). In this study 94% agreed to participate in the 3-month follow-up questionnaire and among those people 20% were non-responders. Thus, combining those

who did not agree to participate in the 3-month questionnaire and those who were non-responders, gives an overall loss to follow up of 27%. Loss to follow-up bias occurs when there are differences in completeness of follow-up between comparison groups (26). When comparing baseline characteristics from the first questionnaire (age, sex, education level, relationship status, and smoking status) between those who were lost to follow-up and those who completed the study we found that the two groups were very similar. Further, the results of this study show that similar questions on the initial questionnaire and follow-up questionnaire were comparable therefore it is unlikely that loss to follow-up bias affected study results.

Information bias is defined as a flaw in measuring the exposure or outcome in a study that results in differential or non-differential quality (accuracy) of information between compared groups (26). In other words, it is systematic error in the measurement of information within a study. The measurement instruments used in this study were self-administered and participants were required to read, write and understand English. The retrospective study design had limitations related to the participants' ability to recall information asked of them in the questionnaires. Although self-administered questionnaires are often selected because they are relatively inexpensive, not labour intensive and have a rapid turnaround in data collection, there is little doubt that inaccurate recall is a disadvantage of this method (97). Recall bias is systematic error due to the differences in accuracy of completeness of recall of past events or experiences (26). This could have been present in this study if, for example, participants with positive screening test results were more likely to remember the type information and knowledge

they received from medical professionals compared to those with negative screening test results.

In addition, social-desirability, which is the tendency of an individual to convey an image in keeping with social norms and avoid criticism in a “testing” situation (115), is another disadvantage of self-administered questionnaires. However there was little opportunity for social-desirability to occur in this study due to the nature of the questions and participants were ensured that the information was confidential (information would not been seen by their physician(s) and would not affect their medical care).

Dillman et al (2000) (97) suggest that the inability to get adequate answers to open-ended questions is often identified as a chief limitation of self-administered questionnaires. The fundamental problem with questions of this nature is that the answer depends upon the extent to which respondents are willing to think hard about the question and write a complete answer. However, the open-ended questions in this study were viewed as “exploratory” and the goal was to get an idea of what type of additional information patients would have liked to receive from medical professionals throughout CRC screening using colonoscopy. In our follow-up questionnaire we used the information from our first questionnaire and created closed-ended questions to eliminate unintentional measurement error as explained above in section 3.4. Another disadvantage of self-administered questionnaires is that response rates tend to be lower (particularly mailed questionnaires) compared to personal interviews followed by telephone interviews, however, this was not the case for this study as we obtained a reasonably high response rate of 78% (116).

In order to evaluate measurement validity, face validity (114) was assessed by eight experts in the field of population health, family medicine and gastroenterology. Face validity is the extent to which a measurement appears reasonable on superficial inspection (26). For this study experts assessed the questionnaires to determine if the variables measured/criterion was logical and intuitive and after obtaining feedback, face validity of the revised questionnaires was assessed again by another gastroenterologist.

Despite the variety of approaches adopted to measure satisfaction, most studies evaluating patient satisfaction, including this one, report high levels of satisfaction (117). However it is argued that a literal interpretation of high satisfaction ratings is naïve. Among a wide range of sources of error, satisfaction ratings may be influenced by respondent characteristics such as age or educational attainment (118). However, this study found no differences in satisfaction between prior CRC screening experience, colonoscopy test results, or educational attainment.

The high level of satisfaction of information received throughout the process of screening found in this study could be explained by the “discrepancy” model (117) which argues that satisfaction is entirely relative, defined in large by the perceived discrepancy between patient’s expectations and actual experience. In 1994, Williams (119) further refined the theory to posit that dissatisfaction is only expressed when an extreme negative event occurs. In this way a positive response in satisfaction should not be interpreted as indicating that the factor under evaluation was “good” but simply that nothing “extremely bad” happened. Therefore, in this study patients may have reported being very satisfied or satisfied if they had received any type of information from medical professionals as opposed to receiving no information at all.

The strengths of this study include a large sample size and access to Endopro, the endoscopy database. To make reasonably precise estimates the sample size was targeted at 400 participants however this study went beyond with a study group of 630, ensuring precise estimates. Additionally, as we had a larger sample size than expected the chances of random error decreased (120). The major advantage of Endopro was the ability to confirm inclusion and exclusion criterion and to determine CRC family history.

5.3 Overall Colonoscopy Screening Implications and Recommendations for Practice

The professional relationship between primary care physicians and specialty physicians (known as 'specialists') is important as primary care is usually the first point of contact for patients and is the gatekeeper for clinic and hospital services in Canada. Effective communication between primary care physicians and specialists is important and some evidence has shown that closer integration of primary and specialist care improves health care for individual patients and for populations of patients (121;122). A study by Stille et al (2006) (122) investigated physician-reported communication between primary care physicians and specialists and found that communication was strongly associated with physicians reported ability to provide optimal care.

Partnership and communication between family physicians and the GI Clinic is important to ensure that patients receive consistent and accurate information throughout the screening process. Family physicians need to be informed about their patients colonoscopy test results and recommended follow-up in order to communicate information successfully to their patients. To disseminate information effectively we recommend that GI Clinics should consider mailing out test results, as well as

implications and recommended follow-up (according to clinical practice guidelines) to both family physicians and patients. By doing this, patients will receive a written copy of their test result and the information between all three parties will be consistent, reducing potential confusion and mixed messages. However, before this can be implemented we need to address why there are inconsistencies between the current GI Clinic follow-up recommendations and clinical practice guidelines which will be discussed in section 5.4 below.

Due to increasing pressures and time constraints placed on both family physicians and GI specialists, alternatives to providing patients with information and knowledge pertaining to CRC screening needs to be addressed. Educational strategies that are consistent across the Calgary Health Region need to be developed. To do this we recommend integrating health educators into the process of CRC screening. Health educators provide information to individuals and communities in an effort to promote, maintain, and improve healthy lifestyles. Their main objective is to promote healthy lifestyles and prevent disease through knowledge and behaviour change. We recommend that a health educator(s) be hired to collaborate with family physicians and GI specialists to design and develop brochures. A general brochure on CRC and brochures containing relevant information pre- and post-colonoscopy need to be developed. Educational material provided in the general CRC brochure should include information on CRC, the purpose of screening, and descriptions of different CRC screening test options. The brochure for patients prior to colonoscopy should include what to expect during and after the procedure, any risks associated with the procedure, general information on CRC and different screening test options. Educational material in the post-colonoscopy brochure

should include explanation of test results, recommended follow-up based on clinical practice guidelines, and preventive measures for CRC. The best method for distributing the brochures to patients needs to be evaluated. Another strategy to disseminate important information pertaining to CRC screening is having a health educator available to counsel and educate patients within the GI Clinic, especially for patients who are first-time screeners.

5.4 Future Research

This study identified two key knowledge gaps among those undergoing CRC screening using colonoscopy that need to be explored in future research.

The first knowledge gap is that the majority of participants did not report receiving information on the risks of colonoscopy. This means that participants are either: (1) not being told about the risks; (2) don't understand what the risks are; (3) are overloaded with information and are not being told at the appropriate time or; (4) do not recall the information. Thus, research needs to focus on where this problem lies and when that is resolved an intervention needs to be developed to tackle this issue.

The second knowledge gap is that some participants may have received improper information on follow-up screening intervals. To determine if participants reported the correct follow-up recommendation that they were given from health professionals, future research needs to compare the self-reported data to the Endoscopy Report filled out by the specialist performing the colonoscopy (which should include recommended colonoscopy follow-up). Another avenue of inquiry could include surveying GI specialists to assess what type of recommendations they are making and the reasons

behind them. This will determine if GI specialists are making recommendations according to clinical practice guidelines.

Additional research needs to be conducted to examine and evaluate if health education resources will aid family physicians and GI Clinics to work together effectively to convey adequate information to their patients throughout the process of CRC screening.

5.5 Summary

Through this study we have discovered the type of information patients receive throughout the process of screening using colonoscopy in Calgary Alberta, and their knowledge of important aspects of CRC screening. With this data we have identified informational gaps such as medical professionals not providing patients with information on the risks of colonoscopy or appropriate follow-up screening intervals. We recommend that health professionals utilize health education resources in order to disseminate important CRC screening information to patients.

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Appendix 1: CAG approach to (a) average risk screening (b) higher risk screening

(a)

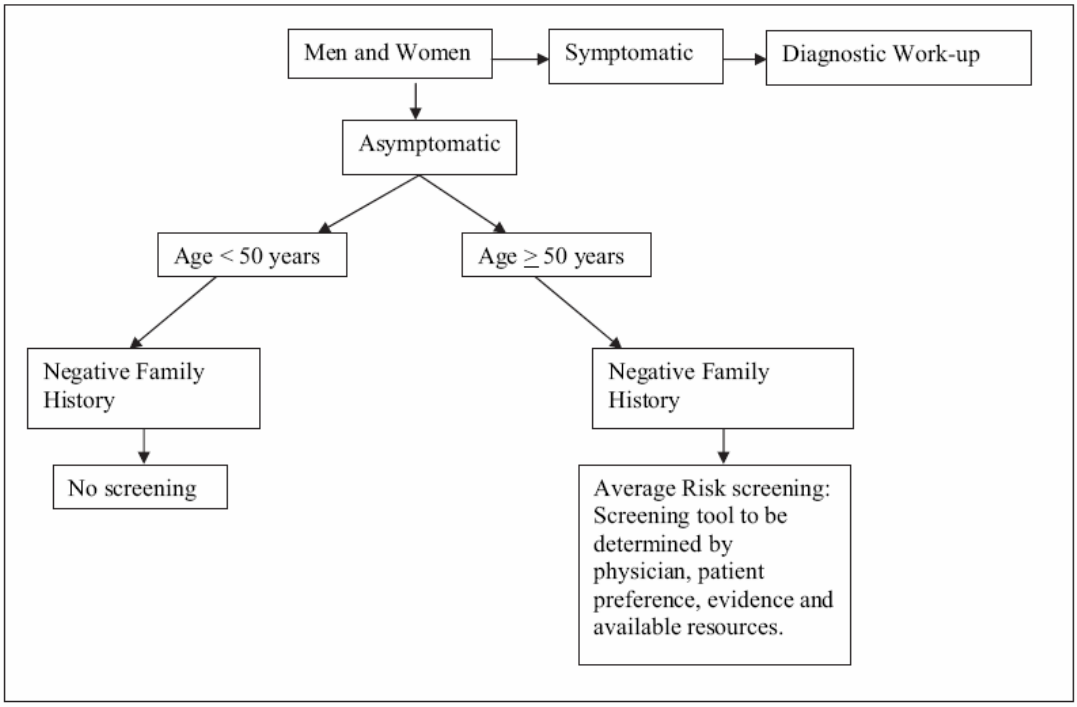


Figure 1) *Approach to average risk screening*

(b)

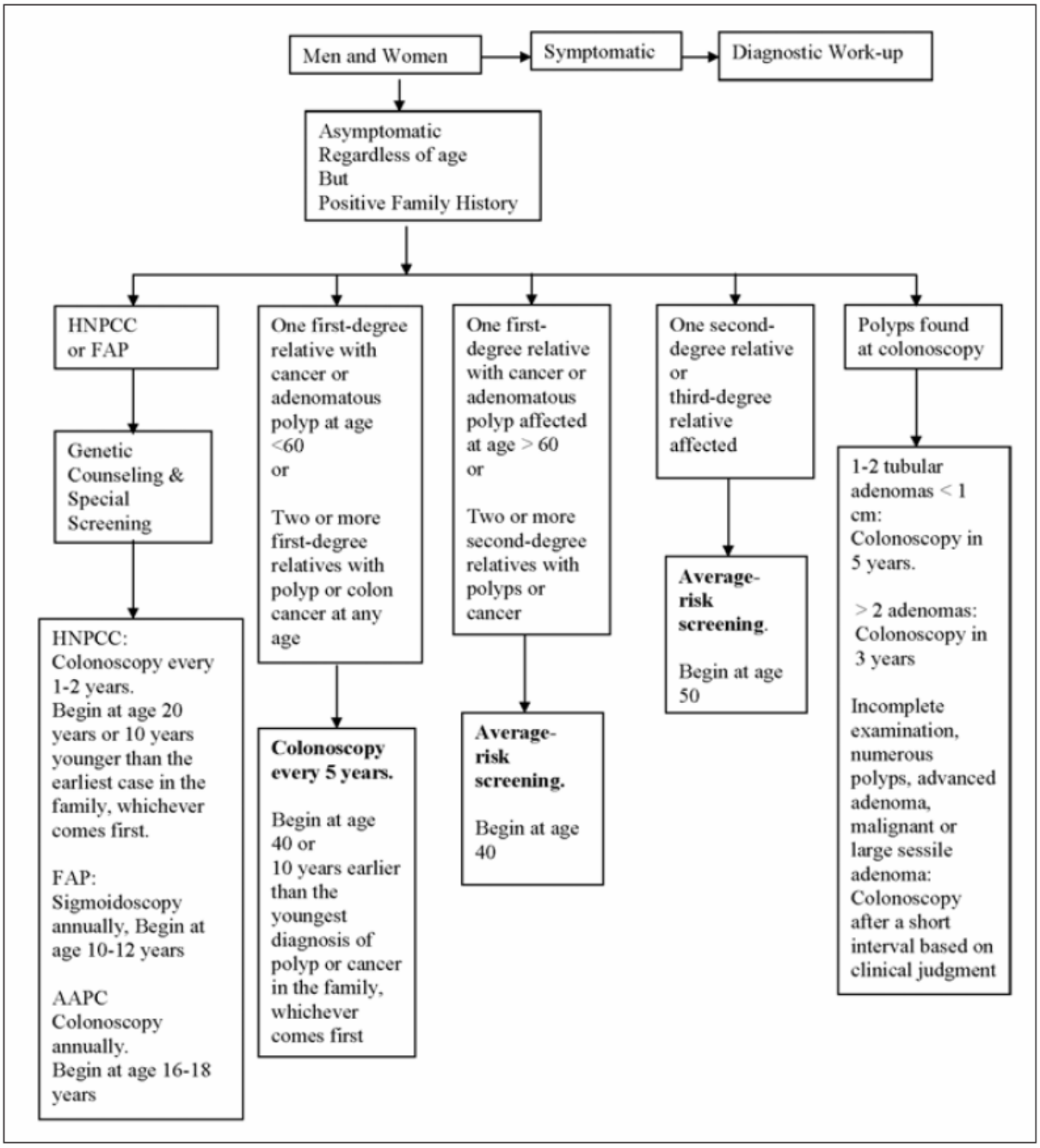
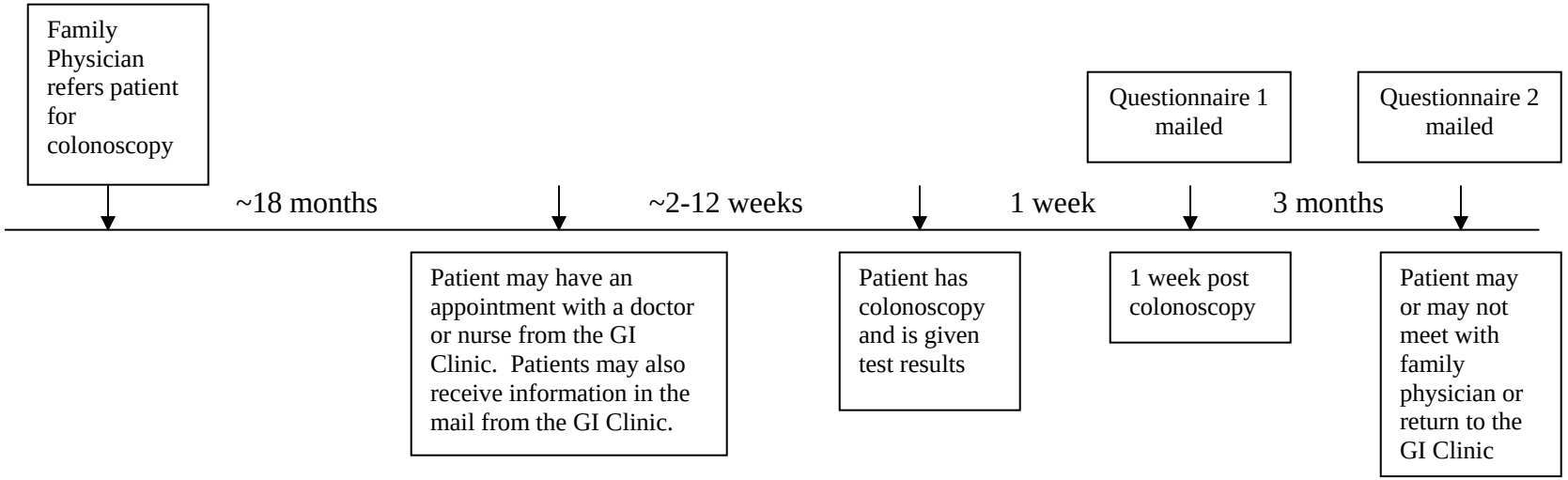


Figure 2) *Approach to higher risk screening. AAPC Attenuated adenomatous polyposis; FAP Familial adenomatous polyposis; First-degree relative Parents, siblings, children; HNPCC Hereditary nonpolyposis colorectal cancer; Second-degree Grandparent, aunt or uncle; Third-degree Great grandparent or cousin*

Appendix 2: Colonoscopy screening and data collection timeline



Appendix 3: CHREB Ethical Approval

FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

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2005-12-15

Dr. R. Hilsden
Department of Medicine
Room 1703 - HSC
University of Calgary
Calgary, Alberta

Dear Dr. Hilsden:

RE: Post-Colorectal Cancer Screening: Knowledge and Understanding

Grant ID: 18851

MSc Student: Walker, Robin

The above-noted proposal, including the Research Proposal, the Forms 1 and 2, the Cover Letters I and II and the Questionnaires 1 and 2 has been submitted for Committee review and found to be ethically acceptable.

Please note that this approval is subject to the following conditions:
(1) appropriate procedures for consent for access to identified health information has been approved;
(2) a copy of the informed consent form must have been given to each research subject, if required for this study;
(3) a Progress Report must be submitted by 2006-12-15, containing the following information:
- i) the number of subjects recruited;
- ii) a description of any protocol modification;
- iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
- iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
- v) a copy of the current informed consent form;
- vi) the expected date of termination of this project.

(4) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Glenys Godlovitch, BA(Hons), LLB, PhD

Associate Chair, Conjoint Health Research Ethics Board

GG/km/mh

c.c. Adult Research Committee Dr. J. Conly (information) Research Services Ms. R. Walker (MSc Student)
Office of Information & Privacy Commissioner

Appendix 4: Consent Form

Title: Post-Colorectal Cancer Screening: knowledge and understanding.
Investigators: Dr. Robert Hilsden, Dr. Elizabeth McGregor, Robin Walker

We are doing a survey about colon cancer and its detection. We hope to find out what information patients receive while undergoing colon cancer screening in Calgary, Alberta.

You may be one of the people who are chosen to participate in this study. By signing this form you are allowing us to find out why you are having this procedure done and to get your address to send you a short questionnaire in the mail. We will not be seeking any other information about you. Your response to this form will not be shown to your doctors. Your decision will not affect your medical care in anyway. If you allow us to send you a short survey in the mail you are under no obligation to return it.

Your signature on this form indicates that you have read and understood the information above and agree to the allowing us to find out why you are having your procedure done and to get your address to send you a short survey. If you wish further information you may contact the Study Coordinator, Robin Walker, at 403-210-9601.

After you have signed this form please GIVE THE FORM BACK TO THE RECEPTIONIST. Thank you.

_____
Signature

Please review your contact information above and make appropriate corrections.

PLEASE RETURN THIS FORM BACK TO THE RECEPTIONIST

Appendix 5: Physician/Nurse Form

Title: Post-Colorectal Cancer Screening: knowledge and understanding.
Investigators: Dr. Robert Hilsden, Dr. Elizabeth McGregor, Robin Walker

What is the purpose of this colonoscopy?

- ○ CRC Screening: **average risk** or **family history** (excluding those with IBD, HNPCC, FAP)
- ○ Other

If the purpose is screening, are there any reasons why we shouldn't send this patient a questionnaire?

- ○ Doesn't speak English
- ○ Other_____
- ○ No

UNIVERSITY OF CALGARY

Dept. of Community Health Sciences
HSC 1443, 3330 Hospital Drive N.W.
Telephone: 403-210-9601
Fax: 403-283-6151
Email: walkr@ucalgary.ca

Appendix 6: Cover letters

Date

Dear firstname lastname,

We are writing to invite your participation in a study on colon cancer and its detection through screening. In this study we hope to find out what information patients receive while undergoing colon cancer screening in Calgary, Alberta. On the day of your colonoscopy you gave us permission to find out why you had the procedure done and to send you a short questionnaire in the mail. We have identified that the reason you had your colonoscopy was for colon cancer screening purposes.

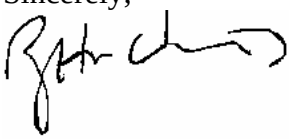
We hope that you will participate in this study by completing the enclosed questionnaire. The questionnaire will take approximately 10 minutes of your time. However you are under no obligation to complete this questionnaire. Your participation will not affect your future medical care. Your responses to this questionnaire will not be shown to your doctors, and all information you give will be kept strictly confidential.

Results from this study will be released in statistical form only, and it will not be possible to identify individual participants in the study. The results will help us to develop educational materials addressing the important health issue of colon cancer.

If you wish further information prior to completing this questionnaire you may contact the Study Coordinator, Robin Walker, at 403-210-9601. Please call collect if you are calling long distance.

Thank you in advance for taking the time to read this material and respond to the questionnaire. We appreciate your help.

Sincerely,



Robert Hilsden, MD, PhD, FRCP
Department of Medicine and Community Health Sciences
University of Calgary

UNIVERSITY OF CALGARY

Dept. of Community Health Sciences
HSC 1443, 3330 Hospital Drive N.W.
Telephone: 403-210-9601
Fax: 403-283-6151
Email: walkr@ucalgary.ca

Date

Dear firstname lastname,

You may recall participating in a questionnaire, on colon cancer approximately three months ago. We thank you for your participation in this study and taking the time to fill out the questionnaire. In the questionnaire you indicated that you were interested in receiving a letter about another short questionnaire for this study.

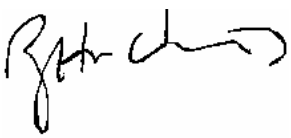
We are writing to invite you to participate in the final questionnaire for this study. The purpose of this questionnaire is to determine if colon cancer screening information has changed since the last time you filled out the questionnaire. This questionnaire will take less than 5 minutes of your time. However, you are under no obligation to complete this questionnaire. Your participation will not affect your future medical care. Your responses to this questionnaire will not be shown to your doctors, and all information you give will be kept strictly confidential.

Results from this study will be released in statistical form only, and it will not be possible to identify individual participants in the study. The results will help us to develop educational materials addressing the important health issue of colon cancer.

If you wish further information prior to completing this questionnaire you may contact the Study Coordinator, Robin Walker, at 403-210-9601. Please call collect if you are calling long distance.

Thank you for your time and willingness to participate in this study. We appreciate your help.

Sincerely,



Robert Hilsden, MD, PhD, FRCP
Department of Medicine and Community Health Sciences
University of Calgary

Appendix 7: Questionnaire 1

COLON CANCER SCREENING

What information have you received?

Thank you for your willingness to participate in this questionnaire.

This questionnaire is intended for people who underwent colonoscopy for cancer screening purposes. Colon cancer screening is tests performed on people who have no symptoms of colon cancer. We have identified that the reason you had your colonoscopy was for colon cancer screening purposes.

This questionnaire is not a test. Please answer the questions as best as you can. Please note that some questions allow for multiple responses. You may refuse to answer any questions. Your answers are completely confidential and will never be used in any way that could link them to you. Just to remind you that colon cancer, bowel cancer and colorectal cancer are all different terms for the same disease. In this questionnaire we will use the term colon cancer.

PART 1 – Screening test history

1. Prior to your recent colonoscopy, had you ever been screened for colon cancer?
   - O Yes
   - O No
   - O Don't remember

PART 2 - Now think back to when you were referred for colonoscopy by your family doctor.

2. How long ago did your family doctor refer you for colonoscopy?
   - O (1) Less than 6 months
   - O (2) 6 -12 months
   - O (3) 12-18 months
   - O (4) Greater than 18 months
   - O (5) Don't remember

3. Did you request to be screened for colon cancer or did your family doctor recommend it?
   - O (1) My doctor recommended it
   - O (2) I requested to be screened
   - O (3) Don't remember

4. Were you given any other test options (other than colonoscopy) to be screened for colon cancer?
   - ○ Yes ○ No ○ Don't remember

   ↳ **If Yes**, what was the **main** reason you choose colonoscopy? **(Please check only one)**
   - ○ (1) The accuracy of the test
   - ○ (2) You are not "awake" for the test (you are sedated)
   - ○ (3) The test is performed by a doctor in a clinic
   - ○ (4) You do not have to have the test every year
   - ○ (5) The test allows for the removal of polyps (precancerous growths)
   - ○ (6) My doctor recommended it
   - ○ (7) Other, please specify_____
   - ○ (8) I don't know why I choose colonoscopy

5. What type of information did you receive from your family doctor when you were referred for colonoscopy? **(Please check all that apply)**
   - ○ (1) Information on colon cancer
   - ○ (2) Information about different screening tests for colon cancer
   - ○ (3) Information about colonoscopy
   - ○ (4) I did not receive any information
   - ○ (5) I do not remember the information I received
   - ○ (6) Other information, please specify_____

6. Is there any other information you would have liked to receive from your family doctor when you were referred for screening?
   - ○ Yes ○ No

   ↳ **If Yes**, what information would you have liked to receive?
   _____
   _____

PART 3 - Now think back to a few weeks before your colonoscopy.

7. Prior to the date of your colonoscopy, did you have an appointment with a nurse or doctor from the clinic where you had your colonoscopy?
   - ○ Yes ○ No ○ Don't remember

8. Did you receive any information in the mail from the clinic where you had your colonoscopy?
   - ○ Yes ○ No ○ Don't remember

9. Prior to the date of your colonoscopy, what type of information did you receive from the doctor, nurse or clinic where you had your colonoscopy? (Please check all that apply)
   - ○ (1) Information on colon cancer
   - ○ (2) Information about different screening tests for colon cancer
   - ○ (3) Information on the risks of colonoscopy
   - ○ (4) Information on what to expect during colonoscopy
   - ○ (5) I did not receive any information
   - ○ (6) I do not remember the information I received
   - ○ (7) Other information, please specify_____

10. Is there any other information you would have liked to receive from the clinic prior to your colonoscopy?
   - ○ Yes ○ No

   ↳ **If Yes**, what information would you have liked to receive?
   _____
   _____

PART 4 - Now think back to the day of your colonoscopy.

11. On the day of your colonoscopy did you meet with the doctor who performed the colonoscopy after the procedure was complete?
   - ○ Yes ○ No ○ Don't remember

12. Have you been told the results of your colonoscopy?
   - ○ Yes ○ No ○ Don't remember

   ↳ **If Yes**, When did you receive your test results?
   - ○ (1) The day I had my colonoscopy
   - ○ (2) After the day I had my colonoscopy
   - ○ (3) I don't remember

   ↳ **If Yes**, What were the test results of your colonoscopy?
   - ○ (1) Positive (at least one polyps found)
   - ○ (2) Negative (no polyps found)
   - ○ (3) I don't remember

13. Who gave you your test results?
    - ○ (1) Doctor who performed the colonoscopy
    - ○ (2) Nurse at the clinic
    - ○ (3) Receptionist at the clinic
    - ○ (4) Family Doctor
    - ○ (5) No-one
    - ○ (6) Other, please specify_____
    - ○ (7) I don't remember

14. Did you receive a written copy of your test results?
    - ○ Yes ○ No ○ Don't remember

15. Is there any other information you would have liked to have on the day of your colonoscopy?
    - ○ Yes ○ No

        ↳ **If Yes**, what information would you have liked to receive?
        _____
        _____

PART 5 – Now think about the information you received throughout screening.

16. Overall, how satisfied are you with the information you received throughout the process of colonoscopy?
    - ○ (1) Very satisfied
    - ○ (2) Satisfied
    - ○ (3) Neither satisfied or dissatisfied
    - ○ (4) Dissatisfied
    - ○ (5) Very dissatisfied

17. Overall, how useful was the information you received throughout the process of colonoscopy?
    - ○ (1) Very useful
    - ○ (2) Useful
    - ○ (3) Somewhat useful
    - ○ (4) Not at all useful

PART 6 – The next set of questions relate to future screening.

18. Do you know when you should have your next colonoscopy?
    - ○ Yes ○ No ○ Don't know

    ↳ **If YES**, When?
    - ○ (1) Within the next year
    - ○ (2) 1 to 2 years
    - ○ (3) 3 to 5 years
    - ○ (4) 6 to 9 years
    - ○ (5) 10 years or more
    - ○ (6) Don't know

    ↳ **If YES**, where did you receive this information?
    - ○ (1) Doctor who performed the colonoscopy
    - ○ (2) Family Doctor
    - ○ (3) Nurse
    - ○ (4) Internet
    - ○ (5) Books/articles/news/radio
    - ○ (6) Friends/family
    - ○ (7) Other, please specify_____
    - ○ (8) Don't know

19. How likely is it that you will undergo another screening colonoscopy?
    - ○ (1) Very likely
    - ○ (2) Somewhat likely
    - ○ (3) Not very likely
    - ○ (4) Not at all likely

    ↳ **If Not very likely or Not at all likely**
    Why not?
    - ○ (1) The test is too unpleasant
    - ○ (2) It is too much of a time commitment
    - ○ (3) I do not need another one
    - ○ (4) Other, please specify_____
    - ○ (5) Don't know

PART 6 – Now a few questions about you.

20. Are you male or female?
    - ○ Male ○ Female

21. Have you smoked at least 100 cigarettes in your life?
    - ○ Yes ○ No ○ Don't know

    ↳ If Yes, At the present time, do you smoke cigarettes every day, occasionally, or not at all?
        - ○ (1) Everyday
        - ○ (2) Occasionally (less than every day)
        - ○ (3) Not at all
        - ○ (4) Don't know

22. What is your highest level of education? **(Check highest level completed)**
    - ○ (1) Elementary School
    - ○ (2) Some high school
    - ○ (3) High school diploma
    - ○ (4) Technical/community college
    - ○ (5) Some University
    - ○ (6) University degree
    - ○ (7) Post Graduate Training

23. What is your current relationship status?
    - ○ (1) Married
    - ○ (2) Living common-law or with partner
    - ○ (3) Separated or divorced
    - ○ (4) Widowed
    - ○ (5) Single (never married)

24. What age group are you in?
    - ○ (1) Less than 40 years of age
    - ○ (2) 40-44 years of age
    - ○ (3) 45-49 years of age
    - ○ (4) 50-54 years of age
    - ○ (5) 55-59 years of age
    - ○ (6) 60-64 years of age
    - ○ (7) 65-69 years of age
    - ○ (8) Greater than 70 years of age
    - ○ (9) Decline

25. Can we send you another short questionnaire in the future for this study?
    - ○ Yes ○ No

Thank you very much for taking the time to complete this questionnaire. Please return the questionnaire in the enclosed postage-paid, self-addressed envelope.

Appendix 8: Questionnaire 2

COLON CANCER SCREENING

Part II:
What information have you received?

Thank you for your willingness to participate in this questionnaire.

This questionnaire is intended for people who underwent colonoscopy for cancer screening purposes. Colon cancer screening is performed on people who have no symptoms of colon cancer. We have identified that the reason you had your colonoscopy was for colon cancer screening purposes.

This questionnaire is not a test. Please answer the questions as best as you can. Please note that some questions allow for multiple responses. You may refuse to answer any questions. Your answers are completely confidential and will never be used in any way that could link them to you. Just to remind you that colon cancer, bowel cancer and colorectal cancer are all different terms for the same disease. This questionnaire will use the term colon cancer.

1. Have you seen your family doctor since your last colonoscopy?
   - ○ Yes ○ No ○ Don't remember

   - ↳ **If Yes**, did you speak to your family doctor about your test results?
     - ○ No ○ Yes ○ Don't remember

     - ↳ **If No**, why didn't you speak to your doctor about your test results?
       - ○ (1) Not enough time
       - ○ (2) No reason to talk about it
       - ○ (3) My doctor did not bring it up
       - ○ (4) I forgot to talk to my doctor about it
       - ○ (5) Other_____

2. Since your last colonoscopy, have you gone back to meet with the doctor who performed your colonoscopy?
   - ○ Yes ○ No ○ Don't remember

   - ↳ **If Yes**, did you speak to the doctor about your test results?
     - ○ Yes ○ No ○ Don't remember

3. What were the test results of your colonoscopy?
   - ○ (1) Positive (at least one polyps found)
   - ○ (2) Negative (no polyps found)
   - ○ (3) I don't remember
   - ○ (4) No-one has told me

4. When did you receive your test results?
   - ○ (1) The day I had my colonoscopy
   - ○ (2) After the day I had my colonoscopy
   - ○ (3) I don't remember
   - ○ (4) I have not received my results

5. Who gave you your test results? **(Please check all that apply)**
   - ○ (1) Doctor who performed the colonoscopy
   - ○ (2) Nurse at the clinic
   - ○ (3) Receptionist at the clinic
   - ○ (4) Family Doctor
   - ○ (5) No-one
   - ○ (6) Other, please specify_____
   - ○ (7) I don't remember

6. Have you received a written copy of your test results?
   - ○ Yes ○ No ○ Don't remember

7. Do you know when you should have your next colonoscopy?
   - ○ Yes ○ No ○ Don't know
     - ↳ **If YES**, When?
       - ○ (1) Within the next year
       - ○ (2) 1 to 2 years
       - ○ (3) 3 to 5 years
       - ○ (4) 6 to 9 years
       - ○ (5) 10 years or more
       - ○ (6) Don't know

     - ↳ **If YES**, where did you receive this information?
     - ↳ **(Check all that apply)**
       - ○ (1) Doctor who performed the colonoscopy
       - ○ (2) Family Doctor
       - ○ (3) Nurse
       - ○ (4) Internet
       - ○ (5) Books/articles/news/radio
       - ○ (6) Friends/family
       - ○ (7) Other, please specify_____
       - ○ (8) Don't know

8. How likely is it that you will undergo another screening colonoscopy?
   - ○ (1) Very likely
   - ○ (2) Somewhat likely
   - ○ (3) Not very likely
   - ○ (4) Not at all likely

     ↳ **If Not very likely or Not at all likely**
     Why not?
     - ○ (1) The bowel preparation is too unpleasant
     - ○ (2) The test is too unpleasant
     - ○ (3) It is too much of a time commitment
     - ○ (4) I do not need another one
     - ○ (5) My doctor has not told me to have one
     - ○ (4) Other, please specify_____
     - ○ (6) Don't know
     - ○

9. Overall, how satisfied are you with the information you received throughout the process of colonoscopy?
   - ○ (1) Very satisfied
   - ○ (2) Satisfied
   - ○ (3) Neither satisfied or dissatisfied
   - ○ (4) Dissatisfied
   - ○ (5) Very dissatisfied

10. What other information would you have liked to receive throughout the process of screening? **(Please check all that apply)**
    - ○ (1) General information about colon cancer
    - ○ (2) Information about different screening tests for colon cancer
    - ○ (3) Information about the risks of colonoscopy
    - ○ (4) Information on risk factors for colon cancer (for example family history)
    - ○ (5) Information about preventive measures for colon cancer
    - ○ (6) Colon cancer statistics
    - ○ (7) Information about the bowel preparation for colonoscopy
    - ○ (8) Information on what to expect during colonoscopy
    - ○ (9) Information on what to expect after colonoscopy
    - ○ (10) Further explanation of test results (the implication of the results)
    - ○ (11) Written copy of test results
    - ○ (12) When/if I need another colonoscopy
    - ○ (13) None
    - ○ (14) Other, please specify_____
      _____

Thank you very much for taking the time to complete this questionnaire. Please return the questionnaire in the enclosed postage-paid, self-addressed envelope.

Dept. of Community Health Sciences
HSC 1443, 3330 Hospital Drive N.W.
Telephone: 403-210-9601
Fax: 403-283-6151
Email: walkr@ucalgary.ca

Appendix 9: Reminder cover letters

Date
Dear firstname lastname,

About three weeks ago we sent you a questionnaire to you that asked about what information you received while undergoing colon cancer screening. To the best of our knowledge, it's not yet been returned.

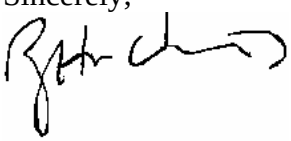
The comments of people who have already responded include a wide variety of information received throughout the process of colon cancer screening. We think the results are going to be very useful to develop educational materials addressing the important health issue of colon cancer.

We are writing again because of the importance that your questionnaire has for helping to get accurate results. Although we are sending questionnaire to people in Alberta, it's only by hearing from everyone in the sample that we can be sure that the results are truly representative.

Again, we want to emphasis that you are under no obligation to complete this questionnaire. Your participation will not affect your future medical care. Your responses to this questionnaire will not be shown to your doctors, and all information you give will be kept strictly confidential. Results from this study will be released in statistical form only, and it will not be possible to identify individual participants in the study. The results will help us to develop educational materials addressing the important health issue of colon cancer.

We hope that you will fill out and return the questionnaire soon, but if for any reason you prefer not to answer it, please let us know by returning a note or blank questionnaire in the enclosed stamped envelope. If you wish further information prior to completing this questionnaire you may contact the Study Coordinator, Robin Walker, at 403-210-9601. Please call collect if you are calling long distance.

Sincerely,



Robert Hilsden, MD, PhD, FRCP
Department of Medicine and Community Health Sciences
University of Calgary

UNIVERSITY OF CALGARY

Dept. of Community Health Sciences
HSC 1443, 3330 Hospital Drive N.W.
Telephone: 403-210-9601
Fax: 403-283-6151
Email: walkr@ucalgary.ca

Date

Dear firstname lastname,

You may recall participating in a questionnaire, on colon cancer. In the questionnaire you indicated that you were interested in receiving a letter about another short questionnaire for this study. Recently we had sent you a second questionnaire that asked you about what information you received while undergoing colon cancer screening. To the best of our knowledge the second questionnaire has not been returned.

We are writing to invite you to participate in the final questionnaire for this study. The purpose of this questionnaire is to determine if colon cancer screening information has changed since the last time you filled out the questionnaire. This questionnaire will take less than 5 minutes of your time. However, you are under no obligation to complete this questionnaire. Your participation will not affect your future medical care. Your responses to this questionnaire will not be shown to your doctors, and all information you give will be kept strictly confidential.

Results from this study will be released in statistical form only, and it will not be possible to identify individual participants in the study. The results will help us to develop educational materials addressing the important health issue of colon cancer.

If you wish further information prior to completing this questionnaire you may contact the Study Coordinator, Robin Walker, at 403-210-9601. Please call collect if you are calling long distance.

Thank you for your time and willingness to participate in this study. We appreciate your help.

Sincerely,

Robert Hilsden, MD, PhD, FRCP
Department of Medicine and Community Health Sciences
University of Calgary

Appendix 10: Pilot study feedback questions

1. Did the questionnaire take a reasonable time to complete?
   ○ Yes ○ No ○ Don't know

2. Approximately how long did the questionnaire take you to complete?
   _____min

3. Did you find that some questions had difficult wording?
   ○ Yes ○ No ○ Don't know

   ↳ **If YES**, Which question(s)?_____
   _____
   _____

4. Did you find that some questions were hard to understand?
   ○ Yes ○ No ○ Don't know

   ↳ **If YES**, Which question(s)?_____
   _____
   _____

5. Did the flow of the questionnaire (the order of the questions) make sense to you?
   ○ No ○ Yes ○ Don't know

   ↳ **If NO**, What order would you prefer?_____
   _____
   _____

6. Other comments or suggestions:_____
   _____
   _____
   _____

THANK YOU