UNDERSTANDING THE EPIDEMIOLOGY OF YOUNG-ONSET COLORECTAL CANCER AND INFORMATION NEEDS OF PATIENTS AND SURVIVORS

by

Khalid Saad El Din

B.Sc., University of Windsor, 2017

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

The Faculty of Graduate and Postdoctoral Studies

(Pharmaceutical Sciences)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

August 2019

© Khalid Saad El Din, 2019

The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, a thesis entitled:

UNDERSTANDING THE EPIDEMIOLOGY OF YOUNG-ONSET COLORECTAL CANCER AND INFORMATION NEEDS OF PATIENTS AND SURVIVORS

Submitted by Khalid Saad El Din in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE in Pharmaceutical Sciences.

Examining Committee:

Dr. Mary De Vera
Supervisor
Dr. Helen McTaggart-Cowan
Supervisory Committee Member
Dr. Annalijn Conklin
Supervisory Committee Member
Dr. Peter Loewen
Additional Examiner

Additional Supervisory Committee Members:

Dr. Jonathan Loree

Supervisory Committee Member

Dr. Sharlene Gill

Supervisory Committee Member

Abstract

Introduction: Recent evidence suggests that the risk of young-onset colorectal cancer (yCRC) is significantly increasing. Furthermore, the information needs of this population are not well understood. Unmet information needs are associated with ineffective disease self-management and negative health outcomes. Therefore, it is pertinent to understand the changing epidemiology of yCRC and the information needs of this population.

Objectives: This thesis aims 1) to systematically review the literature on the incidence and prevalence trends of yCRC; 2) to determine the information-seeking behaviours of individuals with yCRC; and 3) to determine the information needs of individuals with yCRC.

Methods: To address Objective 1, a systematic review was conducted. Databases were searched for studies that: used an epidemiologic design, assessed trends in yCRC incidence or prevalence, and published in English. To address Objective 2, descriptive statistics and proportions of information-seeking behaviours were reported. Lastly, Objective 3 was addressed by reporting proportions of information items unmet. Predictors of corresponding unmet information needs were assessed using multivariable logistic regression models.

Results: 1) The search returned 8,695 articles with 40 studies from 12 countries across five continents. Thirty-nine studies assessed trends in yCRC incidence and only one study prevalence trends. Noteworthy, 17 studies from North America and Oceania consistently reported increasing incidence trends in yCRC. Among studies assessing cancer site, nine (of 14) showed an increased risk of rectal cancer in adults less than 50 years. 2) A sample of 366 yCRC respondents, predominantly consisting of highly-educated white women, was analyzed. At respondents' most recent search of yCRC information (N=323), 143 respondents relied on the Internet. 3) Among 39 information need items, 26 unmet information needs were found.

Conclusion: This thesis provided evidence that risk of yCRC is increasing predominantly in North America and Oceania, driven by rising rectal cancers in younger adults over the past two decades. In addition, this thesis reports that the information needs of the recruited sample were substantially unmet.

Lay Summary

Colorectal cancer (CRC) is a disease common in older adults over the age of 50. However, there is accumulating evidence suggesting that the risk of developing CRC is increasing in adults under 50. I systematically searched and reviewed existing literature to establish the status of the increasing risk of young-onset colorectal cancer (yCRC). Overall, 40 studies among 8,695 identified, spanning 12 countries across five continents, were reviewed. Results extracted suggest that the risk of yCRC is increasing mostly in North American and Oceanic countries, driven by rising rectal cancers. Additionally, I analyzed survey results from 366 yCRC respondents to determine their unmet information needs. Results from this survey study suggest that respondents have 26 unmet information needs among 39 information items examined. Providing patients and survivors with sufficient and necessary information about their disease is a step towards helping them cope with their diagnosis and improving their quality of life.

Preface

This thesis, including the design, data collection, analyses, and written work, is the original work of Khalid Saad El Din. I would like to acknowledge the feedback and insight provided by my supervisor and committee members in drafting this thesis.

The studies conducted in this work were reviewed and approved by the University of British Columbia Behavioural Research Ethics Board (H18-02540).

A version of Chapter 2 has been submitted for publication.

Table of Contents

Abstractiii
Lay Summaryv
Prefacevi
Table of Contents
List of Tablesxi
List of Figuresxiii
List of Abbreviationsxiv
Acknowledgements xv
Dedicationxvi
Chapter 1: Introduction
1.1 Thesis Overview
1.1.1 Research Statement
1.2 Colorectal Cancer
1.2.1 Impacts of CRC
1.3 Changing Epidemiology of yCRC
1.4 Information Needs
1.4.1 Information Needs of Cancer Patients6
1.4.2 Information Needs of CRC Patients

1.5 Thesis Objectives and Overview	9
Chapter 2: Trends in the Incidence and Prevalence of Colorectal Cancer: A Worldwide	e Systematic
Review	11
2.1 Introduction	11
2.2 Methods	11
2.2.1 Search Strategy	11
2.2.2 Study Selection	
2.2.3 Data Extraction and Quality Assessment	
2.3 Results	
2.3.1 Trends in yCRC Incidence	
2.3.2 Trends in yCRC Prevalence	
2.3.3 Secondary Outcomes	
2.4 Discussion	
2.5 Conclusions	
Chapter 3: Information Needs and Seeking Behaviours Among Young-Onset Colorecta	al Cancer Patients
and Survivors	
3.1 Introduction	
3.1.1 Objectives	
3.2 Methods	
3.2.1 Study Design	
3.2.2 Inclusion Criteria	

3.2.3 Participant Recruitment and Ethical Approval	
3.2.4 Survey	
3.2.5 Data Audit	
3.2.6 Demographic and Clinical Variables	
3.2.7 Main Outcomes	
3.2.8 Statistical Analysis	
3.3 Results	
3.3.1 Participants	
3.3.2 Demographic Characteristics	
3.3.3 Clinical Characteristics	
3.3.4 Health-related Quality of Life	
3.3.5 Information Seeking Behaviours	
3.3.6 Information Needs	
3.3.7 Significant Predictors of Unmet Information Needs	
3.4 Discussion	
3.4.1 Complexities of yCRC, Ineffective Self-Management and Unmet Information Needs	s 67
3.4.2 Unmet Information Needs	
3.4.3 Significant Predictors of Unmet Information Needs	
3.4.4 Implications	
3.4.5 Limitations and Strengths	74
3.5 Conclusions	76

Chapter 4: Conclusion and Integrated Discussion
4.1 Key Findings
4.2 Integration of the Research
4.3 Limitations of the Research
4.4 Implications and Recommendations
4.4.1 Systematic Review
4.4.2 Cross-Sectional Survey Study
4.5 Future Research Directions
4.6 Conclusion
References
Appendix
Database search strategy91
Quality appraisal checklist
Reported incidence rates (per 100,000) for yCRC overall and according to sex among included
studies
CONNECT survey
The proportion of information items being unmet or met by yCRC respondents analyzed118

List of Tables

Table 1. Characteristics of Included Studies According to Continent/Region	16
Table 2. Characteristics of Included Studies According to Continent/Region Continued	17
Table 3. Characteristics of Included Studies According to Continent/Region Continued	18
Table 4. Characteristics of Included Studies According to Continent/Region Continued	19
Table 5. Characteristics of Included Studies According to Continent/Region continued	20
Table 6. Reported trends in incidence of yCRC incidence overall and according to sex	23
Table 7. Information domains for diagnosis, undergoing treatment, treatment-related, completing	
treatment, and impacts on life	40
Table 8. yCRC Respondent Demographic Characteristics	48
Table 9. Respondent yCRC and Treatment Characteristics	50
Table 10. Information Seeking Behaviours of yCRC Respondents at the Most Recent Time They Neede	ed
Information	52
Table 11. Information Seeking Behaviours of yCRC Respondents	53
Table 12a. Odds ratios and 95% confidence intervals for predictors of unmet information needs for	
information items at the time of yCRC diagnosis	61
Table 12a. Odds ratios and 95% confidence intervals for predictors of unmet information needs for	
information items at the time of yCRC diagnosis (continued)	62
Table 12b. Odds ratios and 95% confidence intervals for predictors of unmet information needs for	
information items for yCRC respondents currently undergoing treatment	63

Table 12c. Odds ratios and 95% confidence intervals for predictors of unmet information needs for
information items for yCRC respondents who have completed treatment and/or actively being followed-
up64
Table 12d. Odds ratios and 95% confidence intervals for predictors of unmet information needs for
information items for all yCRC respondents on the impacts of yCRC

List of Figures

Figure 1. Wilson's Second Model of Information Behaviour
Figure 2. PRISMA flow diagram for systematic review
Figure 3. Worldwide heatmap showing annual percent change in incidence (APCi) of yCRC across
countries included in the systematic review spanning from 1971 to 2013
Figure 4. Adapted version of the CaSUN questionnaire to assess the degree an information item has been
addressed
Figure 5. Flowchart of respondent recruitment and data cleaning for analysis
Figure 6a. Proportion of information items unmet among all respondents of yCRC at time of diagnosis54
Figure 6c. Proportion of information items unmet among respondents currently undergoing treatment 56
Figure 6d. Proportion of information items unmet among respondents who have completed treatment for
yCRC
Figure 6e. Proportion of information items unmet among all respondents on impacts of yCRC on life 57
Figure 7. Proposed framework on self-management, information needs, and information seeking

List of Abbreviations

- aHR-adjusted hazard ratio
- APC—Annual percent change
- APCi—Annual percent change in incidence
- APCp—Annual percent change in prevalence
- AAPCi—average APCi
- CDSMP—Chronic Disease Self-Management Program
- CI— Confidence interval
- CRC-Colorectal Cancer
- EAPCi—estimated APCi
- HRQoL—Health-related Quality of life
- NCDB—National Cancer Database
- OR Odds ratio
- PRISMA—Preferred Reporting Items for Systematic Reviews and Meta-Analysis
- SEER—Surveillance, Epidemiology, and End Results database
- US—United States of America
- UK—United Kingdom
- yCRC-Young-onset Colorectal Cancer

Acknowledgements

I would like to first acknowledge my amazing and supportive supervisor, Dr. Mary De Vera. Thank you for your continual support in my academic journey. I would also like to thank all the members of CORE for their help and support during my time at UBC. Thank you, Alex, Louise, Aly, Hallie, and Julia.

I must thank all my committee members for their feedback and experienced insights that accelerated my learning in conducting health service research.

Dedication

To my late grandfather that passed away from colorectal cancer, my supervisor that survived colorectal cancer, my caring family, and my better half, Lana.

Chapter 1: Introduction

1.1 Thesis Overview

1.1.1 Research Statement

Colorectal cancer (CRC) is the second most common cancer worldwide (1). CRC is associated with devastating impacts including increased discomfort and pain (2), reduced potential life years (3), and worsened HRQoL (4-7). In spite of the prevalence of CRC, it has been reported that CRC patients feel a lack of available information related to their cancer leading to feelings of frustration (8). Recent publications suggest an increasing incidence yCRC, or CRC among young adults diagnosed under the age of 50, which may suggest an epidemiological shift in CRC towards younger individuals (9-13). As such, it is important to systematically synthesize available evidence to better understand the epidemiology of yCRC. Assessing the trends in the risk and burden of yCRC can inform preventative and supportive efforts, respectively. Among this, helping yCRC patients successfully coping with their diagnosis involves having appropriate the information about their condition at various stages in the disease (i.e., diagnosis, treatment, survivorship) (14). This necessary information is critical in effective self-care and achieving optimal well-being. Unmet patient information needs are associated with difficulties managing ones' disease and suboptimal well-being (15, 16).

The objectives of this thesis are to explore the epidemiology of yCRC through a systematic review and to determine the information needs of yCRC patients and survivors through a descriptive cross-sectional health survey. This thesis will provide empirical evidence on the epidemiological incidence and prevalence trends of yCRC and could inform the allocation of health care services and resources. Further, this thesis will inform information needs of patients at diagnosis, during treatment, and into survivorship. It will also optimize the delivery of information to address the unmet information needs of yCRC patients and survivors.

1.2 Colorectal Cancer

CRC is a cancer in which polyps or tumours develop in the inner lining of the colon or rectum (17). Malignant tumours begin in the mucus-making glands that line the colorectum; 95% of cancers in this region are classified as adenomacarcinomas (17). Abnormal tissue growths, or polyps, in the colorectum region can become cancerous tumours and increase the chance of metastasis to other sites by spreading to lymph or blood vessels (17). Certain diets have been associated with an increased risk of CRC. For example, alcohol and high meat intakes have been associated with a 20% increased risk of CRC (18). Other common CRC risk factors include sedentary lifestyle, obesity, and diabetes mellitus, which are increasing among both younger and older age groups (19).

1.2.1 Impacts of CRC

The impact of CRC on patients includes discomfort, pain, and disability—both from the cancer itself and from treatment-associated side-effects (20). Treatment-associated side-effects include increased rates of fecal incontinence, anal bleeding, and mucus production, as well as significantly lower satisfaction with bowel function (20). Further ramifications of CRC include potential years of life lost (3), financial impact due to costs of treatment (21), and a social impact on relationships and family (22). Specifically, it has been estimated that CRC reduces the potential life of an afflicted individual by at least 15 years (3), reduces employment productivity by 13.6% (21), and leads to significantly higher levels of depression and anxiety (22). These significant impacts have prompted researchers to seek to improve health outcomes in CRC across the cancer care continuum (i.e., during diagnosis (23, 24), treatment, and posttreatment or survivorship (25, 26)).

1.3 Changing Epidemiology of yCRC

Traditionally, CRC has been associated with increasing age, with a marked increase in onset after the age of 50 (9). This led to routine CRC screening starting at the age of 50 (27, 28). Despite the attention towards CRC in older adults, 18% of rectal cancers and 11% of colon cancers actually present in adults

younger than the age of 50 (19, 29), for whom screening is not routine (11). With data suggesting an increasing incidence of yCRC (10-13, 30-34), it is crucial to confirm this rise and describe other epidemiological trends, clinical characteristics, and outcomes, as well as the risk factors for yCRC (19).

Exploring the emerging data on yCRC is necessary to guide this research. A cohort study conducted in the United States (US) undertaken by You and colleagues in 2012 aimed to examine the incidence trends, define the distinct clinicopathologic characteristics of yCRC, and establish key risk factors for this disease (11). Using the US National Cancer Database (NCDB), a hospital-based registry capturing approximately 75% of all incident cancer cases (19), 64,068 yCRC cases were identified, accounting for 11% of all CRC cases analyzed in the study by You et al. (11). Incidence trend analysis indicated decreasing age-adjusted incidence rates (annual percent change [APC], -2.1%; 95% confidence interval [CI], -3.0% to -2.0%) after 2001 for adults over the age of 50. Examining age-adjusted incidence rates of the yCRC cohort revealed a juxtaposed increasing incidence trend. There was a greater increase in rectal cancer (APC, 3.9%; 95% CI, 3.1% to 4.7%) among younger adults than older adults with CRC (APC, 2.7%; 95% CI, 2.0% to 3.3%). There was also a prominent predisposition of yCRC to situate in the distal colon, rectum, or splenic flexure (11). Relating to clinical characteristics, yCRC patients were diagnosed with notably more advanced-stage cancers. Young adults presenting with more advanced-stage yCRC or metastatic yCRC has been commonly observed in other epidemiological studies (10, 11, 29, 35, 36).

There is inconsistency among emerging data reporting the incidence trends of yCRC. A Canadian population-based cohort study published in 2002 examined temporal trends in the incidence of yCRC. The results suggested an APC of -0.43% (95% CI, -0.77 to -0.08) for men and a statistically significant APC of -1.39% (95% CI, -1.69 to -1.08) for women between 1969 and 1996 (37). Contrastingly, a US retrospective cohort study conducted in 2015 aimed to examine age-related disparities in the incidence trends of CRC (12). Using the Surveillance, Epidemiology, and End Results (SEER) database, a population-based registry collecting cancer incidence data for approximately 35% of the US population

(38), an APC of 2.0% (95% CI, 1.45 to 2.51) was observed for adults between 20 and 34 years of age diagnosed with yCRC? and about -1.0 (95% CI, -1.17 to -0.76) for adults between 50 and 74 years of age (12). The underlying cause of this increasing incidence of yCRC is not clear. Confirming the status of the incidence trend of yCRC is difficult given the inconsistency in reporting in population-based studies.

A systematic review of the literature on global epidemiological trends in yCRC is imperative to ascertain the current status of this issue. Systematically reviewing the temporal trends in the incidence and prevalence of yCRC is a step towards expanding awareness of CRC among younger adults and clinicians, implementing interventions, and allocating health care resources to reduce the burden of yCRC.

1.4 Information Needs

While confirming the epidemiology of yCRC is crucial to implementing early detection and potential preventative strategies (35), an individual patient's experience of yCRC can be affected substantially by an understanding of his/her own disease, treatment, and survival. Information management is an essential part of a patient's experience coping with an illness. Information management involves cognitive and communicative activities, such as seeking, avoiding, appraising, providing, and interpreting information (39). Information itself is defined as knowledge and details absorbed from the environment. A need for information emerges when a gap in one's state of knowledge is recognized (40). An individual that has a desire to fill this gap will undertake certain behaviours to gain the knowledge they seek (41, 42). Not fulfilling the desire to address a gap in one's state of knowledge leads to an unmet need for information. Collectively, the intentional-seeking of information and the passive behaviour of acquiring knowledge—as well as the avoidance of information—is defined as information behaviour (40). Information management becomes complex when individual's information behaviours vary over the course of their illness and depend on the availability and quality of information (39).

Many models of information-seeking exist, but there are seven main models that are more fully developed and include information needs as an integral component (40). From these seven models, Wilson's second model is the most complex; it includes explicit theories on why certain information

needs are sought more than others, why some information sources are used more than others, and why certain individuals may or may not successfully address an information need based on their self-efficacy (40). Wilson's second model is able to explain how information needs arise for individuals diagnosed with an illness and how specific factors influence an individual's decision making in seeking information, detangling the intricacy of information management (40). Refer to Figure 1 for a depiction of Wilson's Second Model of Information Behaviour. This model proposes why some needs are desired to be fulfilled more than others, why certain sources of information are prioritized, and why individuals vary in their information-seeking behaviours (40). Specifically, Wilson's model suggests that certain "activating mechanisms" act as motivators to drive an individual to search for information, determine how they search for it, and determine the amount of effort they invest into obtaining that information (40). Stressful situations that require coping can act as an activating mechanism and motivate an individual to seek information. These activating mechanisms are further influenced by five different types of intervening variables: demographic background, social role, environmental variables, characteristics of the information source, and psychological predispositions (40). These intervening variables are what differentiate individual's information-seeking behaviours. For example, an individual diagnosed with an illness might seek information about their diagnosis. The need to cope with this illness would act as an activating mechanism to seeking information. This would motivate an individual to seek information to help them better cope with their diagnosis. The information behaviours they undertake are dependent on intervening variables. This sought information is used to reduce the uncertainty of the individual's situation and help him/her to cope with the diagnosis (43). When an individual is diagnosed with an illness, they may seek information from friends, family, and health care professionals (43). Information regarding the etiology of diagnosis, symptoms, treatments options, and prognosis are common information needs that arise from patients. This information helps them comprehend their health state and make decisions regarding medical procedures and their new life situation (43).



Figure 1. Wilson's Second Model of Information Behaviour. Adapted from *Looking for Information:* A Survey of Research on Information Seeking, Needs, and Behavior (p. 137), by Case, D., 2007, London: Elsevier LTD. Copyright 2007 by Elsevier LTD.

1.4.1 Information Needs of Cancer Patients

The information needs of cancer patients is a dynamic area of literature contingent on the constantly evolving ways we receive and process information, especially with the substantial role of the Internet. Addressing the information needs of cancer patients can improve their HRQoL and is therefore an area that warrants attention (15). In general, cancer patients seek information regarding their specific cancer diagnosis, treatment options, associated side-effects, prognosis, and other relevant obstacles (44).

Successfully coping with a cancer diagnosis involves having necessary and sufficient information and understanding of the diagnosis, treatment, possible outcomes, and coping mechanisms (14). In this context, information needs can be defined as necessary or useful information for cancer patients to achieve optimal well-being (16). If information needs remain unmet, patients experience difficulties coping with their diagnosis. Unmet information needs may correspond with difficulty assessing one's efficacy and competence in adjusting to a cancer diagnosis, leading to negative perceptions of one's life situation and, as a result, to poorer psychosocial health (14). Specifically, a lack of information regarding one's cancer diagnosis has been linked to significantly increased levels of anxiety and stress (45). Effectively communicating what patients are required to know about their diagnosis—along with whom and when they receive this information during their cancer journey—is important in improving their health outcomes (44). A study conducted by Lorig et al. in 1999 aimed to determine the effectiveness of a community-based patient self-management course, The Chronic Disease Self-Management Program (CDSMP) (46). In a six-month randomized control trial, including 952 patients with various chronic conditions (i.e., heart disease, stroke, lung disease, or arthritis), findings suggest the CDSMP was effective in improving the health status of patients and in reducing the number of hospitalizations (46). The study by Lorig et al. highlights the importance of educating patients with sufficient information on disease management and the associated positive health outcomes.

Providing sufficient information to patients is necessary for achieving optimal well-being (15, 16) and improving health outcomes such as HRQoL (14). For example, a study conducted in Japan in 2015 aimed to determine the unmet information needs of young breast cancer survivors (mean age: 44.8 years, age range: 21 to 64 years) and the relationship between these needs and quality of life (QoL) (15). QoL was measured using the Japanese version of the World Health Organization Quality of Life Instrument-Short Form (15). A 26-item questionnaire on a four-point Likert scale was used to measure the unmet information needs of the survivors by inquiring about their satisfaction regarding the information they received from medical professionals (15). The relationship between QoL and unmet information needs was assessed using the Mann-Whitney U test. Overall, 50 participants, accounting for 31% of the sample, were unsatisfied with the communication they had with medical professionals, and this significantly corresponded to their QoL (15). It was also found that the unmet information needs of young breast cancer survivors included particular age-specific needs, such as fertility and premature menopause issues (15). This highlighted study suggests an important area in research where determining the unmet information needs of patients is a step towards improving their QoL during their disease journey and survivorship (15).

1.4.2 Information Needs of CRC Patients

Despite CRC being the second most common cancer (1), the extent to which the information needs of this population are met is not well understood (47). This area is also poorly understood for the yCRC subset of the population. With scarce literature examining the information needs of yCRC, literature on CRC that was inclusive of yCRC individuals has been referenced. Specifically, a population-based survey composed of breast cancer (N = 678), prostate cancer (N = 651), and CRC patients (N = 681) reported that CRC patients consistently seek less information than prostate and breast cancer patients (8). One possible explanation for this difference in information-seeking between cancer types may be that CRC treatment is associated with fewer long-term side-effects and less follow-up care (8). An alternative argument is that CRC receives considerably less public and scholarly attention, especially after screening, compared to other cancers, such as breast and prostate (8). This inattention may have led to considerably less information reaching CRC patients during their cancer diagnosis and survivorship and is translated as less information-seeking behaviour (47).

A scoping review conducted by van Mossel et al. in 2011 included 239 articles and aimed to determine what information individuals with CRC need across their disease continuum, as well as the information they are provided from health care professionals (47). The rationale of this scoping review was to identify literature gaps regarding the information needs of people with CRC (47). Examination of the literature revealed that information needs included staging of cancer, survivorship, diet/nutrition, treatment, and bowel management (47). Only 27% of articles included in this review directly acquired CRC patient input (47). Further, of the articles that did consult CRC patients, none were based on a comprehensive study that addressed the timing and type of information needs of CRC patients across the cancer care continuum (i.e., during diagnosis, treatment, and survivorship) (47). Notably, this scoping review revealed that the existing literature is focused on information-seeking rather than needs and uncovered a literature gap around the information needs of CRC and yCRC patients.

As supported by Wilson's second model of information behaviour, studying important patient characteristics such as age is pivotal in determining whether the information needs of CRC patients will be met. Specifically, it has been suggested that younger patients require more information from their health care professionals than is currently supplied (43, 48). Furthermore, research on the information needs of young adults with cancer suggests that they experience unique impacts regarding physical and psychosocial factors (49-54). Furthermore, research on the information needs of young adults with cancer suggests that they experience unique impacts of young adults with cancer suggests that they experience unique impacts regarding physical and psychosocial factors (49-54). Furthermore, research on the information needs of young adults with cancer suggests that they experience unique impacts regarding physical and psychosocial factors (49-54). Furthermore, research on the information needs of young adults with cancer suggests that they experience unique impacts regarding physical and psychosocial factors (49-54). Furthermore, research on the information needs of young adults with cancer suggests that they experience unique impacts regarding physical and psychosocial factors (49-54). yCRC is associated with more advanced-stage cancers (10, 11, 29, 35, 36) and similar five-year survival proportions as later-onset CRC (64.9% young vs. 61.5% old) (19), yet there is a lack of research into the information needs of individuals diagnosed with yCRC. This research will fill this gap by surveying yCRC patients about both their information needs and information-seeking behaviours.

1.5 Thesis Objectives and Overview

The overall aim of this thesis is to better understand the epidemiology of yCRC and the information needs of yCRC patients and survivors. The set objectives of this thesis are:

- To systematically review and synthesize the literature on the incidence and prevalence trends of yCRC.
- 2. To determine the information-seeking behaviours of individuals with yCRC.
- **3.** To determine the information needs of yCRC patients and survivors at different disease stages and how they vary according to patient and survivor characteristics.

Chapter 2 systematically reviews the existing literature on the trends in the incidence and prevalence of yCRC and addresses Objective 1. Studying the temporal epidemiological trends of yCRC calls for an exhaustive identification of published studies, standardized selection processes and appraisal, and a synthesis of the extracted research evidence, all of which will be provided by a systematic review(55).

After examining the temporal epidemiology of yCRC, further determining the information needs of yCRC patients and survivors is a step towards improving disease management and optimal well-being.

Chapter 3 addresses Objectives 2 and 3 through a descriptive cross-sectional survey. Chapter 3 presents an analysis of the differences in information needs at different disease stages and how information needs vary by sex, age, and cancer stage.

Finally, Chapter 4 presents an integrated discussion consisting of the key findings of each chapter, integration of the research, strengths and limitations of the research, and the implications and future directions of this thesis work. The ensuing thesis chapters addressing the set objectives are highlighted.

Chapter 2: Trends in the Incidence and Prevalence of Colorectal Cancer: A Worldwide Systematic Review

2.1 Introduction

Colorectal cancer, a heterogeneous disease of the colon and rectum predominantly arising from adenomatous polyps or adenomas (56), is the second most common cancer and cause of cancer mortality globally (1). Colorectal cancer is associated increased levels of discomfort, pain, disability (20); decreased life expectancy (57); and increased negative financial (58) and social impacts (59).

Reported incidence rates of CRC per 100,000 ranged 83 in Australia (36) in 2008, 28 in China in 2010 (60), and up to 41 in 2010 in the US (61). Nonetheless, reported an annual percent change in incidence (APCi) of -1.65 (p<0.05) in China (60) and -1.6 (p<0.05) in the US (30), suggest declining incidence of CRC, which has largely been attributed to population screening programs, with many countries recommend beginning at age 50 (62, 63).

While CRC has long been considered a disease of older adults (9), recent data suggest an increasing incidence of young-onset CRC (yCRC) (12, 13). In 2018, the American Cancer Society lowered the recommended age for average-risk adults to initiate screening from 50 to 45 years (64). The objective of Chapter 2 was to conduct a systematic review of observational studies assessing temporal trends in the incidence and prevalence of yCRC. Confirming whether the incidence of yCRC is increasing globally and estimating the magnitude of this increasing risk is warranted to inform treatment needs, survivorship support, and long-term impacts of yCRC.

2.2 Methods

2.2.1 Search Strategy

An information scientist searched Medline (1946-), Embase (1974-), and Cochrane Database of Systematic Reviews (2005-) on the Ovid platform, and CINAHL (1982-) and PsycINFO (1880-) on Ebscohost. Two separate but complementary searches were combined: first, concepts of "colorectal cancer", "prevalence", and "incidence" were used to identify articles on the epidemiology of CRC across all ages from which data could be extracted for individuals with yCRC; second, concepts of "young age" and "early" were incorporated to identify articles that specifically examined yCRC. Database dependent subject headings (e.g., Medical Subject Headings in Medline) and keywords were used (see "Database search strategy" in Appendix). Database searches were conducted on January 17, 2018, and then updated on December 3, 2018. Additionally, reference lists of included studies were hand searched. The protocol is registered with the PROSPERO international prospective register of systematic reviews (ID: CRD42018082151). The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) was applied to the reporting.

2.2.2 Study Selection

I used the following inclusion criteria: original study using epidemiologic design; full-length article or letter; patient population with CRC or yCRC; and published in English. Studies must report measures of trends in the incidence and prevalence (e.g., APC) of yCRC, with or without incidence rates or prevalence proportions. While yCRC has been consistently defined in individuals under 50 years (10, 30, 65, 66), this may not be the cut-off used in studies and thus, I considered any cut-off. Given the interest in peer-reviewed articles, I did not consider grey literature or reports (e.g., annual reports) from cancer registries as they may not routinely report on yCRC.

2.2.3 Data Extraction and Quality Assessment

I extracted information on country, data source, sample size, sex distribution, age cut-off for yCRC, and cancer site (e.g., colon, rectum). The primary outcome was measures of trends in the incidence (e.g., APCi) and prevalence (e.g., APCp) of yCRC. Where available from the included studies, I also extracted reported incidence rates. As some of the studies meeting inclusion criteria additionally reported on outcomes such as yCRC mortality and/or survival, I considered these as secondary outcomes and extracted relevant information. Two researchers (KS and MDV) independently screened titles and abstracts, reviewed manuscripts, and extracted data, resolving any discrepancies by consensus.

The quality of included studies were assessed with a checklist adapted for this systematic review based on the Joanna Briggs Institute Prevalence Critical Appraisal Tool, developed to address the lack of critical appraisal tools for systematic reviews of studies reporting prevalence (67), and the Appraisal tool for Cross-Sectional Studies, developed to address study design, reporting quality and risk of bias in epidemiologic studies of disease prevalence (68). I selected relevant criteria from each to create a checklist involving 20 items, with each item scored as 1 ("demonstrated in the study") or 0 ("not demonstrated in study" or "unclear") ("Quality appraisal checklist" Appendix). Item scores were summed with higher scores indicating studies of higher quality. The quality scores of each article are reported in Tables 2 to 6.

2.3 Results

The combined search strategies yielded 8,695 (6,612 with the broad search strategy and 2,083 with the specific search strategy) titles overall. After applying the inclusion criteria, I identified 40 studies—39 reported trends in yCRC incidence and one reported trend in yCRC prevalence. Figure 1 provides a PRISMA flow diagram. Table 1 summarizes characteristics and quality assessment scores of included studies, grouped according to continent/region. I report findings according to trends in yCRC incidence and prevalence below. The mean score from the quality assessment of articles is 18 with the minimum score being 9 and the highest score being 20.

2.3.1 Trends in yCRC Incidence

In contrast to prevalence, 39 studies evaluated trends in the incidence of yCRC (Table 2). In terms of year of publication, three were published before 2000 (69-71), five between 2000 and 2010, and 31 after 2010, with seven (72-78) of these published in the past year (2018) alone. Altogether, 31 studies defined yCRC based on a cut-off of diagnosis below the age of 50 years, two studies were based on a cut-off of 40 years (79, 80), three based on 45 years (37, 71, 81), and three based on 55 years (70, 74, 82). Incidence rates for yCRC were reported in 17 studies with six reporting overall (36, 61, 73, 75, 78, 80), seven reporting according to sex (69-71, 76, 83-85), and four reporting both overall and sex-specific incidence rates (30,

34, 77, 86) (see Appendix). With respect to the primary outcome of trends in yCRC incidence, included studies varied across reported trend measures—for example, APCi in 22 studies (10, 11, 30, 32-35, 66, 69, 72, 73, 77-81, 84-89), extensions of the APCi (average APCi [AAPCi], estimated APCi [EAPCi]) in 10 studies (37, 61, 70, 76, 82, 90-94), and other measures such as % changes in incidence rates, incidence rate ratios, and odds ratios (ORs) from regression models in seven studies (31, 36, 71, 74, 75, 83, 95). Studies also varied in how they reported these incidence trends – 15 provided overall estimates (11, 33, 35, 36, 61, 73-75, 78, 80, 86, 88, 89, 91, 95), 17 according to sex (10, 30, 31, 37, 69-72, 76, 79, 81-85, 90, 94), and seven provided both overall and sex-specific estimates (32, 34, 66, 77, 87, 92, 93). The heat map in Figure 2 graphically represents findings on trends in yCRC incidence worldwide, also based on the APCi as it was the most commonly reported trend estimate. In the following, a synthesis of findings on trends in yCRC incidence according to continents/regions with Table 2 summarizing reported trends.



Figure 2. PRISMA flow diagram for systematic review

Study	Country	Population /Data Source	Cancer Information			yCRC N age (yCRC cases)			Quality Score	
			Site	Definition	Stage	range (yr)		Primary/ Secondary	Incidence/Prevalence Trend	
North Ame	rica (n = 20	6 studies)								
Chow, 1991	US	Surveillance, Epidemiology, and End Results (SEER)-9	colon	ICD-O	not reported	<55	not reported	incidence	AAPC x sex x ethnicity	18
Polednak, 1994	US	Connecticut Tumor Registry	colorectal	ICD-O	not reported	0 to 44	not reported	incidence	% change in ASR x sex	18
Marrett, 2002	Canada	National Cancer Incidence Reporting System, Canadian Cancer Registry	colorectal	ICD-9	not reported	20 to 44	w: 2,692 m: 2,876	incidence	AAPC x sex	18
Cress, 2006	US	SEER-13	colorectal, rectum	ICD-O-3	in situ, invasive, localized, regional/distant	0 to 49	w: 6,893 m: 7,803	incidence	1. APC x sex 2. APC x sex x site	17
Siegel, 2009	US	SEER-13	colorectal	ICD-O-3	local, regional, distal	20 to 49	w: 9,733 m: 10, 913	incidence	APC x sex	16
Meyer, 2010	US	SEER-9	colon, rectum	not reported	not reported	<20 to 39	w: 3,662 m: 3,999	incidence	 APC x site APC x sex x site 	17

Table 1. Characteristics of Included Studies According to Continent/Region

Merrill, 2011	US	SEER-9	colorectal	ICD-O-2	not reported	30 to 49	not reported	incidence	% change in RAIR x sex x ethnicity	16
Ellison, 2012	Canada	Canadian Cancer Registry	colon, rectum	ICD-O-3	not reported	20 to 49	not reported	prevalence	APC x age	16

Table 2. Characteristics of Included Studies According to Continent/Region Continued

Giddings, 2012	US	California Cancer Registry	colorectal	ICD-O-3	localized, regional, distant	<50	w: 1,278 m: 1,259	incidence	APC x sex x ethnicity	19
You, 2012	US	National Cancer Database	colon, rectum	ICD-O-3	stage III, IV	<50	64,068	incidence	APC x site	18
Austin, 2014	US	CDC National Program for Cancer Registries	proximal colon, distal colon, rectum	ICD-O-3	local, regional, distal	<50	not reported	incidence	 APC x ethnicity APC x sex x ethnicity 	18
Siegel, 2014	US	SEER-13, CDC National Program for Cancer Registries	proximal colon, distal colon, rectum	ICD-O-3	local, regional, distal	<50	w: 6,250 m: 7,270	incidence mortality	APC x site	17
Singh, 2014	US	California Cancer Registry	proximal colon, distal colon, rectum	ICD-O-3	local, regional, or distant	20 to 49	20,520	incidence	BAPC x sex x age	19
Bailey, 2015	US	SEER-9	colon, rectum	not reported	localized, regional, distant	20 to 49	30,708	incidence	 APC x age APC x age x site 	18
Rahman, 2015	US	SEER-18, North American	colorectal	not reported	stage 0, I, II, II, IV	<50	60,023	incidence mortality	AAPC	17

		Association of Central Cancer Registries								
Patel, 2016	Canada	National Cancer Incidence Reporting System, Canadian Cancer Registry, Quebec Cancer Registry	colon, rectum	ICD-O-3	not reported	15 to 49	1969: 756 2010: 1,475	incidence	 APC x age APC x sex x age 	20

Table 3. Characteristics of Included Studies According to Continent/Region Continued

Koblinkski, 2017	US	SEER-18	colorectal	not reported	local, regional, distal	<50	not reported	incidence	percent change x ethnicity x stage	16
Sheneman, 2017	US	Colorado Central Cancer Registry	colorectal	ICD-O-3	early, late	<50	3,729	incidence	1. EAPC 2. EAPC x sex	18
Siegel, 2017	US	SEER-9, CDC National Program for Cancer Registries	proximal colon, distal colon, rectum	ICD-O-3	local, regional, distal	0 to 49	w: 6,650 m: 7,550	incidence mortality	1. AAPC x site 2. IRR x site	17
Siegel, 2017	US	SEER-9	proximal colon, distal colon, rectum	ICD-O-3	not reported	20 to 49	not reported	incidence	APC x age x site	19

Wang, 2017	US	Texas Cancer Registry	colorectal	ICD-O-3	localized, regional, distant	20 to 49	13,028	incidence mortality	APC x age	17
Ansa, 2018	US	SEER-18	proximal colon, distal colon, rectum	ICD-O-3	localized, regional, distant, or unstaged	0 to 49	57,938	incidence	APC x age	18
Crosbie, 2018	US	SEER-9	colorectal	ICD-O-3	not reported	20 to 49	w: 4,010 m: 4,578	incidence	APC x sex	19
Ellis, 2018	US	California Cancer Registry	colorectal	not reported	in situ, localized, regional, distant	20 to 49	w: 1,304 m: 1,276	incidence	TAPC x sex x ethnicity	18
Garcia, 2018	US	SEER-18, CDC National Program of Cancer Registries	colorectal	ICD-O-3	localized, regional, distant	20 to 49	not reported	incidence	relative change in IR	18

Table 4. Characteristics of Included Studies According to Continent/Region Continued

Jacobs, 2018	US	SEER-9	colon, rectum	ICD-O-3	Stage 0-2, 3, 4	<55	not reported	incidence	% change of IR	19
Oceania (n =	= 4 studies)								
Haggar, 2012	Australia	Western Australia Data Linkage Service	colorectal	ICD-O-3	not reported	15 to 39	500	incidence mortality	APC x sex	18
Boyce, 2016	Australia	New South Wales Central	colon, rectum	ICD-O-3 and ICD-10	localised, regional, distant	<30 to 49	w: 971 m: 1,030	incidence mortality	average annual linear trend in R	19

		Cancer Registry								
Gandhi, 2017	New Zealand	New Zealand Cancer Registry	proximal colon, distal colon, rectum	not reported	not reported	<50	not reported	incidence	rate of change of IR	19
Troeung, 2017	Australia	Western Australia Cancer Registry	colorectal	ICD-9 and ICD-10	tumour grade	15 to 39	w: 256 m: 261	incidence mortality	 APC overall APC x sex 	19
Europe (n =	= 3 studies)									
Zaridze, 1990	Russia	not well described	colon, rectum	not reported	not reported	<29 to 49	not reported	incidence	APC x type x sex x age	9
Larsen, 2010	Norway	Cancer Registry of Norway	colon, rectum	ICD-7	not reported	35 to 54	w: 1,739 m: 1,707	incidence	APC x age	18
Ullah, 2018	Ireland	National Cancer Registry of Ireland	colorectal	not reported	not reported	20 to 49	2,750	incidence	APC x age	18

Table 5. Characteristics of Included Studies According to Continent/Region continued

Asia (n = 6 studies)										
Nooyi, 2011	India	Indian Population- Based Cancer Registries	rectum	ICD-O	not reported	35 to 49	not reported	incidence	EAPC x sex x age	16
Wu, 2012	China	Shanghai Cancer Registry	colorectal	ICD-9	not reported	15 to 49	w: 312 m: 259	incidence	APC x sex	19
--------------------------	----------	---	------------------	--------------	-----------------------------	----------	----------------------	-----------	---	----
Zhou, 2015	China	Guangzhou Cancer Registry	colon, rectum	ICD-10	not reported	<50	not reported	incidence	1. APC 2. APC x sex	18
Nakagawaa, 2017	Japan	Japanese Population- Based cancer Registries	colon, rectum	ICD-10	not reported	<50	not reported	incidence	 APC x overall APC x site 	19
Sarakarn, 2017	Thailand	Khon Kaen Cancer Registry	colorectal	ICD-O	stage I, II, III, and IV	<50	w: 1,566 m: 1,798	incidence	 APC APC x sex 	17
Zhang, 2018	China	Hong Kong Cancer Registry	colon, rectum	not reported	not reported	20 to 49	8,829	incidence	APC x sex x type	20
Africa (n = 1	study)									
Hamdi Cherif, 2014	Algeria	Population- Based Cancer Registry of Setif	colorectal	ICD-O-3	not reported	15 to 44	not reported	incidence	APC x sex	19

Abbreviations: APC – annual percent change (in incidence or prevalence); AAPC – average annual percent change; ASR – age-standardized incidence rate; BAPC – biannual annual percent change; EAPC – estimated annual percent change; TAPC – triannual percent change; IR – incidence rate; w – women; m – men; yCRC – young-onset colorectal cancer; CDC – Centre for Disease Control; ICD-O – International Classification of Diseases for Oncology; ICD – International Classification of Diseases;

SEER-9 captures Atlanta, Connecticut, Hawaii, Iowa, New Mexico, Utah, Detroit, and San Francisco-Oakland, and Seattle;

SEER-13 captures Alaska Native population, Atlanta, Connecticut, Hawaii, Iowa, New Mexico, Utah, Detroit, San Francisco-Oakland, Seattle, Los Angeles, San Jose-Monterey, and rural Georgia;

SEER-15 captures Alaska Native population, Atlanta, Connecticut, Hawaii, Iowa, New Mexico, Utah, Detroit, San Francisco-Oakland, Seattle, rural Georgia, California, Kentucky, Louisiana, and New Jersey;

SEER-18 captures Alaska Native population, Atlanta, Connecticut, Hawaii, Iowa, New Mexico, Utah, Detroit, San Francisco-Oakland, Seattle, Los Angeles, San Jose-Monterey, rural Georgia, greater Georgia, California, Kentucky, Louisiana, and New Jersey.



Figure 3. Worldwide heatmap showing annual percent change in incidence (APCi) of yCRC across countries included in the systematic review spanning from 1971 to 2013.

*Where countries were reported in multiple studies, I included the most recent study; for the US, I included APCi's reported by Siegel et al., 2017 (45)

Table 6. Reported trends in incidence of yCRC incidence overall and according to sex

Study	Date Range	Overall	Women	Men	Finding§
North America					
Chow 1991	1976-1987	-	CC AAPC White: -2.0 (<0.05) CC AAPC Black: -1.3	CC AAPC White: -0.7 CC AAPC Black: +1.7	not consistent
Polednak, 1994	1965-1991	-	CRC % change ASR: -19 (p=0.153)	CRC % change ASR: -29 (p<0.05)	\downarrow CRC m
Marrett 2002	1969-1996	-	CRC AAPC: -1.39 (-1.69, -1.08)	CRC AAPC: -0.43 (-0.77, -0.08)	$\begin{array}{c} \downarrow \text{CRC w} \\ \downarrow \text{CRC f} \end{array}$
Cress, 2006	1992-2001	CRC APC: +1.1●	CRC APC: +1.4 RC APC: +3.6 (p<0.05)	CRC APC: +0.8 RC APC: +2.5 (p<0.05)	↑ RC w ↑ RC m
Siegel 2009	1992-2005	-	CRC APC: +1.6 (p<0.05)	CRC APC: +1.5 (p<0.05)	↑ CRC w ↑ CRC m
Meyer 2010	1973-2005	CC APC: -0.2 (-0.6, 0.3) RC APC: +2.6 (1.9, 3.3)	RC APC: +2.5 (1.8, 3.8)	RC APC: +2.5 (1.6, 3.4)	↑ RC
Merrill, 2011	2000-2007	-	CRC % change RAIR White: 21.7 CRC % change RAIR Black: 11.4	% change CRC RAIR White: 2.0 CRC % change RAIR Black: 0.4	↑ CRC w ↑ CRC m
Giddings, 2012	1998-2007	-	CRC APC Chinese: -1.8 (-3.9, 0.3) CRC APC Japanese: -0.1 (-3.6, 3.7) CRC APC Filipino: -0.1 (-2.2, 2.1) CRC APC Korean: +0.5 (-2.0, 3.1) CRC APC South Asian: - CRC APC Vietnamese: +2.2 (-0.8, 5.2)	CRC APC Chinese: -1.6 (-3.3, 0.1) CRC APC Japanese: +1.4 (-2.5, 5.6) CRC APC Filipino: +0.6 (-1.6, 2.9) CRC APC Korean: +3.4 (0.1, 6.7) CRC APC South Asian: +1.5 (-2.9, 6.2) CRC APC Vietnamese: +1.8 (-0.8, 4.4)	not consistent
You 2012	1998-2007	CRC APC: +2.1 (1.1, 3.1) CC APC: +2.7 (2.0, 3.3) RC APC: +3.9 (3.1, 4.7)	-	-	↑ CRC ↑ CC

					↑ RC
Austin 2014	1998-2009	CRC APC N Hispanic White: +1.69 (1.47, 1.91) Black: +0.44 (-0.03, 0.92) Asian: +0.61 (-0.41, 1.35) Hispanic White: +0.59 (-0.15, 1.33)	CRC APC N Hispanic White: +1.79 (1.46, 2.11) Blacks: +0.47 (-0.39, 1.34) Asian: +0.45 (-0.57, 1.49) Hispanic White: +0.76 (0.03, 1.5)	CRC APC N Hispanic White: +1.61 (1.35, 1.87) Blacks: +0.40 (-0.14, 0.93) Asian: +0.72 (-0.53, 1.99) Hispanic White: +0.42 (-0.63, 1.48)	not consistent
Siegel 2014	2001-2010	CRC APC: +1.1 (p<0.05) RC APC: +1.8 (p<0.05)	-	-	↑ CRC ↑ RC
Singh, 2014	1988-2009	-	CRC BAPC 20-29y: +3.8 (p< 0.011) CRC BAPC 30-39y: +4.5 (p< 0.001) CRC BAPC 40-49y: +2.6 (p< 0.001)	CRC BAPC 20-29y: +2.7 (p< 0.011) CRC BAPC 30-39y: +3.5 (p< 0.001) CRC BAPC 40-49y: +2.7 (p< 0.001)	↑ CRC w ↑ CRC m
Bailey 2015	1975-2010	CRC APC 20-34y: +1.99 (1.48, 2.51) CRC APC 35-49y: +0.41 (0.14, 0.69) RC APC 20-34y localized: +4.03 (p<0.001) regional: +3.05 (p<0.001) distant: +2.66 (p<0.001) RC APC 35-49y localized: +1.62 (p<0.001) regional: +1.37 (p<0.001) distant: +1.46 (p<0.001)	-	_	↑ CRC ↑ RC
Rahman 2015	1992-2009	CRC AAPC: +1.68 (p<0.05)	-	-	↑ CRC
Patel 2016	1997 to 2010	CRC APC 15-29y: +6.7 (4.3, 9.3) CRC APC 30-39y: +2.4 (1.5, 3.3) CRC APC 40-49y: +0.8 (0.3, 1.4)	CRC APC 15-29y: +7.9 (1.1, 15.1) CRC APC 30-39y: +2.3 (0.8, 3.7) CRC APC 40-49y: +0.6 (0.1, 1.2)	CRC APC 15-29y: +7.0 (3.7, 10.4) CRC APC 30-39y: +2.5 (1.5, 3.4) CRC APC 40-49y: +1.0 (0.4, 1.5)	↑ CRC
Koblinski 2017	2000-2010	CRC % change Hispanic localized: 177%; regional: 156%	-	-	↑ CRC

		distant: ↑57% CRC % change White localized:↑21%; regional: ↑18% distant: ↑41%			
Sheneman 2017	2003-2013	CRC EAPC: +1.7	CRC EAPC: +0.6	CRC EAPC: +2.7 (p<0.05)	↑ CRC m
Siegel 2017	2004-2013	CRC AAPC: +1.6 (p<0.05) CRC IRR: +1.22 (1.17, 1.28) RC AAPC: +2.0 (p<0.05) RC IRR: +1.22 (1.13, 1.31)	-	-	↑ CRC ↑ RC
Siegel 2017	1974-2013	CC APC 20-29y: +2.4 (1.6, 3.3) CC APC 30-39y: +1.0 (0.5, 1.5) CC APC 40-49y: +1.3 (0.7, 1.8) RC APC 20-29y: +3.2 (2.4, 3.9) RC APC 30-39y: +3.2 (2.7, 3.7) RC APC 40-49y: +2.3 (1.8, 2.7)	_	_	↑ CC ↑ RC
Wang 2017	1995-2010	CRC APC 20-39y: +1.82 (p<0.01) CRC APC 40-49y: +0.33 (p=0.08)	-	-	no consistent
Ansa, 2018	2000-2014	CRC APC <40: +2.7 (p<0.001) CRC APC 40-49y: +1.7 (p<0.001)	-	-	↑ CRC
Crosbie, 2018	1992-2014	CRC APC: +1.8 (p<0.05)	CRC APC: +1.8 (p<0.05)	CRC APC: +1.7 (p<0.05)	↑ CRC
Ellis, 2018	2010-2014	_	CRC TAPC Chinese: +0.1 (-2.1, 2.4) CRC TAPC Japanese: +0.5 (-3.1, 4.1) CRC TAPC Filipino: -0.6 (-3.5, 2.4) CRC TAPC Korean: +0.8 (-3.8, 5.5) CRC TAPC South Asian: +4.3 (-2.0, 10.9) CRC TAPC Vietnamese: -0.5 (-3.1. 2.2) CRC TAPC SEast Asian: - CRC TAPC SEast Asian: - CRC TAPC White: +1.9 (0.8, 2.9) CRC TAPC Black: +0.3 (-0.7, 1.4)	CRC TAPC Chinese: +0.4 (-2.0, 2.9) CRC TAPC Japanese: +1.5 (-2.0, 5.0) CRC TAPC Filipino: +1.1 (-1.1, 3.3) CRC TAPC Korean: +0.7 (-1.8, 3.3) CRC TAPC South Asian: -0.9 (-5.7, 4.2) CRC TAPC Vietnamese: +1.1 (-3.9, 6.2) CRC TAPC SEast Asian: -1.0 (-3.8, 1.9)	not consistent

			CRC TAPC Hispanic: +2.1 (1.2, 3.1)	CRC TAPC White: +0.9 (0.4, 1.4) CRC TAPC Black: -0.9 (-2.2, 0.4) CRC TAPC Hispanic: +1.6 (0.3, 2.9)	
Garcia, 2018	2001-2014	CRC relative increase IR: 24%	-	-	↑ CRC
Jacobs, 2018	1973-2014	CC % change IR: 41.5 (37.4, 45.8) RC % change IR: 9.8 (6.2, 13.6)			↑ CRC ↑ RC
Oceania					
Haggar 2012	1982-2007	-	CRC APC: +1.4 (0.1, 2.7)	CRC APC: -0.4 (-1.7, 1.0)	↑CRC w
Boyce 2016	2001-2008	CRC OR: 1.03 (0.99, 1.07)	-	-	no change
Gandhi 2017	1975-2012		RC IRR: 1.13 (1.2, 1.26)	RC IRR: 1.18 (1.06, 1.32)	↑ RC w ↑ RC m
Troeung 2017	1982-2007	CRC APC: +3.0 (0.7, 5.5)	CRC APC: +3.4 (1.1, 5.7)	CRC APC: +2.6 (-0.9, 5.2)	↑ CRC w
Europe					
Zaridze, 1990	1971-1987		CC APC <29y: -0.1 (-14.2, 14.3) CC APC 30-39y: -1.3 (-7.4, 5.1) CC APC 40-49y: +8.2 (4.6, 11.9) RC APC <29y: -13.7 (-26.4, 0.2) RC APC 30-39y: -9.1 (-18.3, 1.2) RC APC 40-49y: +4.3 (0.5, 8.3)	CC APC <29y: -9.1 (-17.2, -0.3) CC APC 30-39y: -2.9 (-9.7, 4.5) CC APC 40-49y: +3.2 (-0.1, 6.6) RC APC <29y: -16.5 (-29.3, -1.5) RC APC 30-39y: -11.1 (-16.4, -5.4) RC APC 40-49y: +3.7 (-1.4, 9.1)	no consistent
Larsen 2010	1992-2006		proximal CC EAPC: ≥-2 distal CC EAPC: -1 RC EAPC: <+1	proximal CC EAPC: <1 distal CC EAPC: ≥-2 RC EAPC: <+1	no change w no change m
Ullah, 2018	1994-2012	CRC APC 20-29y: +9.17 (p<0.03) CRC APC 30-39y: +4.6 (p=0.1) CRC APC 40-49y: +0.83 (p=0.45)			not consistent
Asia					

Nooyi, 2011	1983-2002		RC EAPC 35-39 y: - RC EAPC 40-44y: +1.7 (p=0.35) RC EAPC 45-49y: +0.4 (p=0.83)	RC EAPC 35-39y: +3.1 (p=0.12) RC EAPC 40-44y: +1.8 (p=0.29) RC EAPC 45-49y: +1.4 (p=0.41)	no change w no change m
Wu 2012	1973-2005		CRC APC: -0.3 (-0.9, 0.3)	CRC APC: 0.1 (-0.4, 0.4)	no change w no change m
Zhou 2015	2005-2011	CRC APC: -3.07 (p<0.01)	CRC APC: -2.56 (p=0.21)	CRC APC: -3.45 (p=0.06)	↓ CRC
Nakagawa 2017	1987-2004	CRC APC: -0.8 (-1.7, 0.1) RC APC: -1.9 (-2.6, -1.1)			↓ RC
Sarakarn 2017	1989-2012	CRC AAPC: +5.7	CRC AAPC: +5.7 (p<0.05)	CRC AAPC: +3.2 (p<0.05)	↑ CRC w ↑ CRC m
Zhang, 2018	1983-2012		CC APC: -1.56 (-1.73, -1.39) RC APC: -0.17 (-0.40, 0.05)	CC APC: -1.11 (-1.32, 0.90) RC APC: +0.60 (0.37, 0.84)	not consistent
Africa					
Hamdi Cherif, 2014	1986-2010		CRC APC: -2.1 (-6.3, 2.3)	CRC APC: -0.8 (-4.7, 3.3)	no change w no change m

•- obtained from authors after contacting them; §-key finding(s) indicate consistent trends identified from each study

Abbreviations: CRC – colorectal cancer; RC – rectal cancer; CC – colon cancer; APC – annual percent change; AAPC – average annual percent

change; ASR - age-standardized incidence rates; EAPC -estimated annual percent change; RAIR - risk-adjusted incidence rate; BAPC - biannual

percent change; TAPC - triannual percent change; IRR - incidence rate ratio; OR - odds ratio;

North America

With 25 included, the majority of studies in this systematic review are from North America. Among 23 studies from the US, 12 reported overall estimates and consistently showed increasing incidence of yCRC, largely driven by rectal cancer in 8 studies (11, 30, 33, 36, 61, 74, 80, 89). The earliest of these studies by Meyer et al. (2010) analyzed data from the SEER between 1973 and 2005 to report an APC of +2.6 (95% CI, 1.9 to 3.3) for rectal cancer and -0.2 (95% CI, -0.6 to 0.3) for colon cancer (80). In 2012, You et al. used the United States National Cancer Database to report 64,068 yCRC cases from 1997 to 2007 and APCis of +3.9 (95% CI, 3.1 to 4.7) for rectal cancer and +2.7 (95% CI, 2.0 to 4.7) for colon cancer (11). Also a noteworthy finding from this study is the median age of yCRC onset as 44 years with the majority (75.2%) of diagnoses occurring between 40 to 48 years (11). In 2015, Bailey et al. used SEER-9 data to report APCis for vCRC among 20 to 34 year-olds as +1.99 (95% CI, 1.48 to 2.51) and 35 to 49 year-olds as +0.41 (95% CI, 0.14 to 0.69) between 1974 and 2010 (35). In further analyses according to stage and location, they highlighted the increasing risk of rectal cancer, particularly in patients aged 20 to 34 years, with APCis of +4.03 (p<0.001) for localized, +3.05 (p<0.001) for regional, and +2.66 (p< 0.001) for distant disease (35). Furthermore, they estimated that incidence rates of rectosigmoid and rectal cancers for patients under 50 years are expected to increase up to 124.2% by 2030 (35). Siegel et al. published one study in 2009 (10), one in 2014 (33), and 2 in 2017 (8, 18), all using data from SEER and consistently showing the contributions of rectal cancer to the increasing risk of yCRC. For example, in their most recent study in 2017, authors showed that the age-adjusted proportion of incident cases in adults 55 years and younger increased from 14.6% (95% CI, 14.0% to 15.2%) to 29.2% (95% CI, 28.5% to 29.9%) for rectal cancer (18).

Studies from the US also allowed for evaluation of sex-specific and ethnicity-specific trends in yCRC incidence. Eight included studies reported estimates according to sex with four showing increasing incidence of yCRC in both women and men (10, 30, 31, 94); and, three reported both overall and sex-specific estimates with one study reporting an increase in yCRC among men (93) and one reporting an

28

increase in yCRC in both women and men (77). Finally, ethnicity-specific trends were reported in 17 US studies (10, 11, 31, 61, 70, 74-78, 80, 84, 86, 87, 91, 93-95). I observed consistently reported increases in yCRC incidence among non-Hispanic White women and men (10, 61, 87). Increasing incidence was also reported among White patients (31, 80, 95) as well as Blacks (80). I could not draw consistent findings from two studies that specifically evaluated yCRC incidence among Asian ethnicities (76, 84).

I also identified 2 studies from Canada. In 2002, Marrett et al. used the National Cancer Incidence Reporting System and the Canadian Cancer Registry and reported decreasing incidence of yCRC with APCis from 1969 to 1996 of -1.39 (95% CI, -1.69 to -1.08) for women between 20 and 44 years and -0.43 (95% CI, -0.77 to -0.08) for same-aged men (37). However, more recently, Patel et al. used National Cancer Incidence Reporting System, Canadian Cancer Registry, and the Quebec Cancer Registry data and reported APCi values ranging from +0.6 (95% CI, 0.1 to 1.2; 40 to 49 years) to +7.9 (95% CI, 1.1 to 15.1; 15 to 29 years) for women and from +1.0 (95% CI, 0.4 to 1.5; 40 to 49 years) to +7.0 (95% CI, 3.7 to 10.4; 15 to 29 years) for men (32).

Oceania

Four studies from Oceania were included. Three studies from Australia largely showed an increasing risk of yCRC (34, 36, 79), particularly among women (34, 79). In 2012, Haggar et al. showed this increasing trend in yCRC among women (APCi, +1.4; 95%, 0.1 to 2.7) but not for men (APCi, -0.4; 95%, -1.7 to 1.0) in their analyses using 1982 to 2007 data for 15 to 39 year-olds in Western Australia (79). In 2017, Troeung et al. similarly found increasing risk of yCRC among women (APCi, +3.4; 95% CI, 1.1 to 5.7) but not among men (APCi, +2.6; 95% CI, -0.9 to 5.2) (34). In New Zealand, Gandhi et al. retrieved all cases of CRC and yCRC from the New Zealand Cancer Registry from 1995 to 2012 (83). Calculating incidence rate ratios (IRR) to estimate trends of yCRC incidence, authors reported an increased risk of rectal cancer for both women 1.13 (IRR 1.13; 95% CI, 1.2 to 1.26) and men (IRR 1.18; 95% CI, 1.06 to 1.32) less than 50 years (83).

Europe

Three studies from Europe were included (69, 73, 82). In a Russian study, Zaridze et al. reported APCis according to sex, cancer type, and age group but no consistent trends in yCRC epidemiology were noted (69). In their 2010 study using the Cancer Registry of Norway, Larsen and Bray did not show significant changes in yCRC incidence among 35 to 54 year-olds, with an APCi between -2 and +1 for both women and men (82). The most recent study using the National Cancer Registry of Ireland reported inconsistent findings with APCi of +9.17 (p<0.03) for 20 to 29 year-olds, +4.6 (p=0.1) for 30 to 39 year-olds, and +0.83 (p=0.45) for 40 to 49 year-olds (73).

Asia

Six studies from Asia showed varying trends in yCRC incidence (66, 72, 85, 88, 90, 92). The only increasing trend for yCRC was found in Thailand by Sarakarn et al. who reported an AAPCi of +5.7 between 1989 and 2012 for patients under 50 years overall, and significant trends for both women (AAPCi, +5.7; p<0.05) and men (AAPCi, +3.2; p<0.05) (92). In contrast, a decreasing trend for rectal cancer in patients less than 50 years was reported in Japan (APCi, -1.9; 95% CI, -2.6 to -1.1) (88). Finally, three studies from China reported conflicting findings. Zhou et al. (2015) reported a decrease in incidence with an APCi of -3.1 (p<0.05) for yCRC in patients under 50 using the Guangzhou Cancer Registry (66); Wu et al. reported no change in incidence with APCis of -0.3 (95% CI, -0.9 to 0.3) in women and +0.1 (95% CI, -0.4 to 0.4) in men aged 15 to 49 years (85); while Zhang et al. did not show consistent findings (72).

Africa

One included study from Africa used the Cancer Registry of Setif, Algeria from 1986 to 2010 and reported no change in yCRC incidence with APCis of CRC among patients 15 to 44 years of -2.1 (95% CI, -6.3 to 2.3) for women and -0.8 (95% CI, -4.7 to 3.3) for men (81).

2.3.2 Trends in yCRC Prevalence

A 2012 Canadian study by Ellison et al. evaluating trends in the prevalence of various cancers reported APCps of yCRC of +2.6 (p<0.01) among 20-39 year-olds and +1.8 (p<0.01) among 40-49 year-olds, suggesting an increasing burden over the study period of 2002 to 2008 (96).

2.3.3 Secondary Outcomes

Among included studies, 7 reported additional information on survival (36, 86, 91) or mortality (33, 34, 61, 79) in yCRC. With respect to survival, Rahman et al. (2015) reported 5-year relative survival for yCRC in the US for Non-Hispanic Whites as 65.5%, African Americans as 56%, Hispanics as 62%, Asians as 66%, and Pacific Islanders, American Indians, and Alaska Natives as 60% (91). In 2017, Wang et al. examined yCRC among Hispanics in the US and reported a 5-year survival proportion of 62% among 20 to 39 year-olds and 64% among 40 to 49 year-olds (86). In Australia, Boyce et al. showed that the 5-year survival was higher in those with yCRC (<50 years) as compared to those with CRC (\geq 50 years) (67%; 95% CI, 65% to 70% versus 56%; 95% CI, 55% to 56%, p <0.001) and, compared to patients with CRC, those with yCRC had a 33% lower risk of disease-related death (adjusted hazard ratio [aHR], 0.67; 95% CI, 0.61 to 0.74) (36). With respect to trends in yCRC mortality, Haggar et al. reported APCs in age-adjusted mortality rates (per 100,000) from 1982 to 2005 in Western Australia of -2.3 (95% CI, -3.7 to -0.8) among women and -2.1 (95% CI, -4.0 to -0.1) among men (79). However, in the US, Siegel et al. reported a 13% increase in mortality rates for yCRC patients from 2000 to 2014 (61).

2.4 Discussion

Forty studies were identified spanning 12 countries across five continents evaluating temporal trends in the incidence and prevalence of yCRC ranging from the years 1965 to 2014. An increasing incidence of yCRC in North America and Oceania was found, particularly the United States, Australia, and Canada with reported overall APCis up to 7.9 (95% CI, 1.1 to 15.1) (32) and nearly 30% increased incidence over 20 years (10, 12). These trends appear to be driven by increased rectal cancers, with site-specific APCis up to 4.03 (p<0.001) (35). With comparatively fewer studies and inconsistent findings, similar conclusions cannot be drawn for studies from Europe, Asia, and Africa.

To my knowledge, this is the first systematic review assessing the changing epidemiology of yCRC. While narrative reviews of yCRC have been published (97-99), the only prior systematic review specific to yCRC was by O'Connell et al. in 2004, which included 55 studies based on clinical samples of patients (100). Altogether, studies in this prior systematic review contributed 6,425 patients allowing authors to describe clinical characteristics of yCRC including common presenting symptoms (abdominal pain and rectal bleeding), observed delays in diagnosis exceeding six months, and treatment patterns (100). A specific finding from O'Connell et al.'s prior systematic review that the rectum and sigmoid colon were the most frequent sites (54% of tumours) is consistent with findings on the contribution of rectal cancer to the increased incidence of yCRC at the population level. Interestingly, the authors found no difference in the sex distribution of yCRC with 49% in male and 51.4% in female (100). These findings have implications for efforts in raising awareness for both women and men on the increasing risk of yCRC, raising awareness on the importance of screening, and considering biological differences between sexes as well as gender differences, such as, differences in health care seeking.

The increasing incidence of yCRC across a number of jurisdictions seen in this systematic review may indeed signal a recent epidemiological shift in CRC. Indeed, the majority of included studies (N = 31) have been published since 2010 with seven published in the past year alone. Reviewing these published, peer-reviewed evidence including quality assessment brings areas for attention based on key

32

findings. One of the key findings is the contribution of findings from North America and Oceania, particularly the US, Australia, and Canada to the worldwide increased risk of yCRC. Future research examining reasons for this increasing risk is important to inform preventive efforts. Indeed, among included studies in the systematic review, only one evaluated population-level determinants of yCRC (11). Specifically, in addition to examining trends in the incidence of yCRC in the US, You et al. also reported independent determinants or risk factors for advanced stage yCRC (Stage III/IV) which included: 1) younger age (aHR for 18 to 29 year-olds: 1.4, 95% CI, 1.2 to 1.6; aHR for 30 to 39 year-olds: 1.21, 95% CI, 1.1 to 1.4, compared to 40 to 49 year-olds); 2) African-American ethnicity (aHR, 1.2, 95% CI, 1.1 to 1.3, compared to White); and 3) insurance status (compared to those with insurance, aHR for those without insurance was 1.2, 95% CI, 1.1 to 1.3; and for those on Medicaid, 1.6, 95% CI, 1.5 to 1.8) (11). Although they did not evaluate direct associations with yCRC, Patel et al. evaluated trends in lifestyle factors among Canadians less than 50 years to elucidate if there may be parallel increases with yCRC incidence trends. With a parallel increase in the prevalence of being overweight or obese in adults younger than 50 years, authors described obesity as a potential lifestyle factor influencing the increasing risk of yCRC in Canada (32), which may be consistent in similar North American and Oceanic countries. Aside from lifestyle factors, there may also be psychosocial factors. For example, the increasing risk of yCRC may be associated with a delay in seeking medical care from young adults (101). Also noteworthy, the observed risk of yCRC may be an under-representation of the true risk due to clinicians dismissing symptoms that may be consistent but not be specific to CRC (11).

It is also important to discuss knowledge gaps identified from this systematic review. Notably, only one included study evaluated trends in the prevalence of yCRC (96). Particularly, only one included study evaluated trends in the prevalence of yCRC (96). It is important to understand the burden of yCRC in terms of trends in prevalence as it is only through population-level examinations of the number of people who have been previously diagnosed with yCRC that can be counted and used to characterize survivors and ultimately inform the long-term impacts of yCRC.

33

Understanding trends in survival and mortality in yCRC is another area identified in this systematic review requiring further investigation to inform contemporary knowledge of this disease. While comparable 5-year survival rates were noted among 2 US studies (86, 91), a comparison of mortality data suggests conflicting evidence. Specifically, in terms of mortality trends in yCRC, an Australian study indicated that it has decreased for both sexes from 1982 to 2005 in Western Australia (79) while Siegel et al. reported that it has increased from 2000 to 2014 in the US (11). Subsequent to the latter article, the same authors published a letter reporting an increasing mortality trend for yCRC in patients 20 to 54 years from 1970 to 2014 (APC_{mortality},+1.0; 95% CI, 0.7 to 1.4) (89).

Strengths and limitations of this systematic review deserve discussion. Combining two separate but complementary searches was a unique feature and strength of this study that maximized the capture of eligible studies; however, the inclusion of relevant studies may have been limited by publication bias as in any other systematic review. Reports or data from national cancer registries were not considered unless they have been published as peer-reviewed studies and reported trend estimates of yCRC incidence and/or prevalence, in line with inclusion criteria. I must also comment on the fact that the majority of the included studies were from the US, particularly using SEER data. As shown in Table 1, there was variability in SEER databases (e.g., SEER-9, SEER-18) used with or without linkage to other data sources (e.g., CDC National Program for Cancer Registries). There was also wide variation in reporting of trends (e.g. overall, according to women and men, according to sites) and as such, the inability to account for potential overlap between studies evaluating yCRC trends over similar time periods with SEER data is an important limitation of this systematic review. Nonetheless, drawing more nuanced information on yCRC such as sex- and ethnicity-specific trends is only possible with consideration of all included studies from the US.

2.5 Conclusions

Our systematic review highlights increasing yCRC risk in western countries driven by rising rectal cancer incidence in younger adults over the past two decades. This systematic review also reveals the lack of studies examining prevalence trends. Implications of this systematic review include raising awareness on both the increasing risk of yCRC and the importance of screening. Lastly, there is a wide variation in reporting incidence trends of yCRC, as such, it is important for future literature to report these trends uniformly to facilitate pooling.

Chapter 3: Information Needs and Seeking Behaviours Among Young-Onset Colorectal Cancer Patients and Survivors

3.1 Introduction

The increasing incidence of yCRC, as described in Chapter 2, has resulted in a growing patient population. Assisting this population with coping with yCRC at diagnosis, during treatment and into survivorship, is imperative. With cancer being a chronic disease, effective patient self-management is critical to effective self-care (102). Self-management encompasses all tasks that are undertaken to cope with a disease including monitoring health status, managing the impacts of the disease, interacting with the health care system, and health care-related decision-making (102). Information is necessary and helpful for yCRC patients in coping with physical and psychological complications (15). If information needs remain unmet, patients will continue to have difficulties managing their disease and achieving optimal well-being (15, 16). Some studies have suggested that the ramifications of unmet information needs include negative perceptions of one's life situation, increased levels of anxiety and depression (22, 45), decreased HRQoL, and other adverse health outcomes (14). It is, therefore, important to evaluate the information needs of yCRC patients.

Examining the literature on the information needs of young adults with cancer can help explain the effect that age has on the information needs of adults with yCRC. As discussed in Chapter 1, there is a scarcity of research investigating the information needs of CRC and yCRC patients. The literature gap about the information needs of individuals with yCRC will be addressed in this chapter. By examining unmet information needs and the extent to which these needs vary, this study investigates how supportive care could be improved through the provision of necessary, reliable, and sufficient information.

3.1.1 Objectives

A cross-sectional Web-based survey was used to examine the information needs of individuals diagnosed with yCRC. The objectives of this chapter are to determine

- 1. the information-seeking behaviours of respondents.
- the unmet information needs of individuals diagnosed with yCRC during diagnosis, treatment, and survivorship, and
- 3. the respondent characteristics associated with information needs being unmet.

3.2 Methods

3.2.1 Study Design

This was a cross-sectional study using data gathered from a Web-based survey. Convenience sampling was used to recruit individuals from the target population, individuals that have received a CRC diagnosis. For the purposes of this study, respondents currently undergoing treatment were categorized as "patients"; those who completed treatment and actively being followed up were categorized as "follow up"; and respondents who were past follow up with more than five years since last treatment were categorized as "survivors".

3.2.2 Inclusion Criteria

Individuals were eligible to complete the survey if they had ever, at any age, received a diagnosis of CRC (self-reported). Respondents must have been able to complete the survey in English, French, Spanish, or Mandarin. For the purposes of this study, only respondents that received a diagnosis under the age of 50 were included in the analysis.

3.2.3 Participant Recruitment and Ethical Approval

The survey was promoted both offline and online to obtain an accurate sample estimate and reduce possible non-coverage bias. Noncoverage bias manifests when respondents who opted to complete the survey may not be representative of the target population (103). Offline recruitment of participants included having poster adverts at St. Paul's Hospital, BC Cancer – Vancouver Centre, and the University of British Columbia (UBC) Hospital. Offline promotion also included features in community newspapers (i.e., The Globe and Mail, Abby News, UBC News, Canadian Filipino) and media appearances in news shows (i.e., Global News). Online promotion of the survey included making posts on major social media platforms including Facebook, Twitter, and Instagram. The survey was additionally promoted using Facebook Ad campaigns for 52 days by targeting individuals that have shown an interest for CRC and cancer pages. Successful recruitment involved individuals first viewing survey promotions online or through poster adverts and then making a decision to opt into the survey by accessing the survey website link. The survey was completed once and included no follow-up measures. The survey was incentivized with an opportunity to enroll in a raffle to win one of two iPads. Recruitment began on November 17, 2018 and ended on March 6, 2019. This study was approved by the UBC Behavioural Research Ethics Board (H18-02540). All respondents were required to agree to a consent form. This study was hosted on the UBC's Survey Tool provided by Qualtrics (104), with survey data being anonymously secured, stored, and backed up in Canada, adhering to the Freedom of Information and Protection of Privacy Act.

3.2.4 Survey

Data were collected on specific types and sources of information that yCRC patients felt they had needed or tried to obtain. The specific types of information assessed are referred to as information (need) items within this thesis. Survey development consisted of deriving information items from existing literature and utilizing the response format of an empirically standardized questionnaire—the Cancer Survivors Unmet Needs (CaSUN)—to assess the degree to which respondents' information needs were met (105). In the development of the survey, patients and oncologists piloted and provided direct feedback on the questions regarding their readability, clarity, terminology, and applicability. To expand the survey's reach, it was translated into French, Spanish, and Mandarin using Qualtrics' translation service (106). The survey was back-translated to English to ensure the accuracy of the translations.

38

The survey consisted of the following six sections, which will be described in detail below:

- Sociodemographic characteristics
- Characteristics of CRC
- Quality of life
- Information need items
- Information-seeking behaviours
- Potential eHealth resource features

Sociodemographic characteristics and the **CRC diagnosis** sections of the survey included questions about country of residence, current age, age at diagnosis, gender, CRC information (e.g., type, stage, treatment), education level, residence status (i.e., rural, urban, suburban), marital status, and ethnicity. Questions from sections were based on a prior survey in 2015 among patients with yCRC, the *Never Too Young Bowel Cancer UK Report*, which was designed to collect information on the experiences of individuals diagnosed with bowel cancer under the age of 50 (107).

Respondents were also asked about their health status in the **quality of life** section of the survey. This section included questions from the EQ-5D-5L instrument (108). The EQ-5D-5L instrument was used to measure HRQoL across five dimensions including: mobility, self-care, usual activities, pain/discomfort and anxiety/depression (109, 110). Among each dimension, respondents were presented with five levels including: no problems, slight problems, moderate problems, severe problems and extreme problems (109, 110). Respondents indicated their health status in each of these dimension by selecting one of the five levels (109, 110). Furthermore, a general health question was used to assess the participants' perceived HRQoL. The general health question probed the overall health of respondents at the time of completing the survey. Respondents selected health statuses on a five-point Likert scale from "Terrible" to "Excellent".

The **information domains** section of the survey was designed to determine topics and concerns relevant to individuals with yCRC. The information items presented in this survey were guided by the scoping review by van Mossel (47). Additional feedback and direction from oncologists aided in determining the applicability of the information items included in the survey. A total of 39 information items were included in the survey. The information items were grouped into the following five domains: 1) information items among all respondents on yCRC <u>at time of diagnosis</u>; 2) information items among respondents <u>currently undergoing treatment for yCRC</u>; 3) information items among all respondents regarding <u>treatment</u>; 4) information items among respondents <u>who had completed treatment and/or are actively being followed-up</u>; and 5) information items among all respondents on the <u>impacts of yCRC on life</u>. Respondents were presented with information domains depending on their treatment status. The specific information items in each domain and to which respondents these are applicable to can be referenced in Table 7.

Table 7. Information domains for diagnosis, undergoing treatment, treatment-related, completing treatment, and impacts on life

Information domain sections	Applicable respondents	Information items
Information items among all respondents on yCRC at time of diagnosis	- All respondents	 Cancer stage Cancer location Chances of surviving the cancer Cause of cancer Risk of cancer to family members Clinical trials for new cancer treatments Specialized cancer tests (i.e., biomarkers)
Treatment-related information	- All respondents	 What to expect with radiation? What are the side-effects with radiation? How to deal with the side-effects of radiation How does surgery work?

		 What to expect with surgery? What are the side-effects with surgery? How to deal with the side-effects of surgery How does surgery work? How does chemotherapy work? What to expect with chemotherapy? What are the side-effects with chemotherapy? How to deal with the side-effects of chemotherapy How does chemotherapy work? How to deal with the side-effects of chemotherapy How does chemotherapy work? How does chemotherapy work? How does chemotherapy are available
Information items for respondents currently undergoing treatment	- Patients	 Alternative/complementary treatments Clinical trials for new treatments What are the chances of the cancer coming back after treatment? Exercise/physical activity during treatment Nutrition/diet during treatment Bowel activity during treatment Other patients' experiences during treatment
Information items for respondents who have completed treatment and/or actively being followed-up for yCRC	- Survivors - Follow-up patients	 Dealing with a stoma Exercise/physical activity after treatment Nutrition/diet after treatment Bowel activity after treatment Other patients' experiences after treatment
Information items for all respondents on impacts of yCRC on life	- All respondents	 Sexual activity Fertility Work and cancer Parenting with cancer Mental health and cancer Bowel activity after cancer Long-term side-effects of treatment

Information items were collected using the response format of the Cancer Survivors Unmet Needs (CaSUN) questionnaire (105). The CaSUN is a 35-item self-report survey developed by Hodgkinson et al. in 2007 to assess the unmet supportive care needs of cancer survivors (this is a free to use questionnaire with permission granted from the author). The instrument also included an open-ended question permitting respondents to report additional needs. Information items presented using the adapted response

format of the CaSUN questionnaire were presented in a matrix table on a five-point Likert scale. The CaSUN questionnaire response options for each item can be referenced in Figure 1. To appropriately investigate the objectives of this survey, questions were dynamically presented to respondents depending on their yCRC characteristics. Because skip logic patterns were programmed into the survey, respondents were only presented with relevant information items or sections depending on the treatment(s) they received and their treatment status. This was devised to present relevant information items that respondents would find applicable depending on their treatment and current stage in their disease continuum. For example, an individual who had completed treatment or was being actively followed-up would only be presented with information items from the following domain: respondents who had completed treatment and/or are actively being followed-up for yCRC. The responses of participants regarding information items from the treatment type (i.e., radiation, surgery, chemotherapy). For example, the information item from any of the following treatment received categories: ("surgery only", "chemotherapy and surgery", "radiation and surgery", "chemotherapy, radiation, and surgery").

	This information need <u>has not</u> <u>been met</u> . How strong is your information need? WEAK	This information need <u>has not</u> <u>been met</u> . How strong is your information need? MEDUIM	This information need <u>has not</u> <u>been met</u> . How strong is your information need? STRONG	This information need <u>has been</u> <u>met</u>	This information need <u>is not</u> <u>applicable</u> because it is not a need for you	Not sure
Information item #1						
Information item #2						
Information item #3						
Information item #4						
Information item #5						

Figure 4. Response format of the CaSUN questionnaire adapted to survey questions to assess the degree an information item has been addressed. Adapted from "*The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: TheCaSUN (Cancer Survivors' Unmet Needs measure)*", by Hodgkinson, K. et al., 2007, *Psychooncology, 16*(9), 796-804. Copyright 2007 by John Wiley & Sons, Ltd. Adapted with permission.

The **information-seeking behaviours** section of the survey included 17 items. These items were extracted from the Health Information National Trends Survey (HINTS) developed by the National Cancer Institute and administered to cancer patients to collect information on the use of health-related information and their health-related perceptions, knowledge, and behaviours (111). For purposes of this thesis, two information-seeking questions were included for analysis: 1) at the most recent time, what source did participants use to find yCRC information? (recent search) and 2) how often were specific information sources used? (source use). Respondents indicated how frequently they used specific information sources on a five-point Likert scale ranging from "Never" to "Always" in the source use question. The **potential eHealth resource features** section consisted of items querying respondents on

what features they would desire in a potential eHealth resource. The survey included in this study can be referenced in the Appendix.

3.2.5 Data Audit

Data were exported from the Qualtrics system as an Excel file and imported into SAS software, Version 13. The imported Excel dataset consisted of all individuals diagnosed with CRC, regardless of their age. For the purpose of this study, only respondents diagnosed with yCRC (i.e., under the age 50) were included for analysis. The data cleaning process removed responses from individuals that accessed the survey and provided responses only to the country and gender questions (N = 318), as they lacked to answer any questions relating to the objective of the survey. Such incomplete surveys may have occurred because this was a Web-based survey, and website visitors may have inspected the survey by answering these questions and made a decision not to complete the survey thereafter. Patterns of missing data and invalid responses were analyzed during data cleaning. A total of three invalid responses were excluded from analysis. Response patterns and survey completion time (Mean= 24 minutes; SD=114 minutes) were assessed to identify the difference between respondents that skipped certain questions (N = 0).

3.2.6 Demographic and Clinical Variables

Participants were asked about their cancer type (i.e., colon, rectal, or colon and rectal cancer), cancer stage, and the type of treatment received. Age at the time of the survey, age at diagnosis, gender, marital status, ethnicity, education, country of residence, neighbourhood status (urban, rural, or suburban), and HRQoL were obtained. The mean scores from the EQ-5D-5L were used to computed mean HRQoL of the sample. The value set used to compute the mean HRQoL from the EQ-5D-5L were in accordance with the societal preferences in Canada derived by Xie et al. in 2016 (112). For this study, a HRQoL equal to and above the mean HRQoL of 0.84 was categorized as "Good" and below as "Poor". How often the analyzed sample used the Internet was coded as a separate variable (Internet use) from the source use question.

3.2.7 Main Outcomes

There were two main outcomes of this chapter, determining the information-seeking behaviours of yCRC respondents and their information needs. Respondents' information-seeking behaviours were inferred from the recent search and source use information-seeking questions analyzed. Regarding information needs, information items applicable to respondents, previously outlined above, based on treatment status were assessed. For each of the 39 information need items, I determined whether respondent information need was met ("this information need has been met") or unmet if any of the following responses were indicated: "this information need has not been met (weak need)"; "this information need has not been met (moderate need)"; and "this information need has not been met (strong need)". Proportions of information items being a weak unmet need, medium unmet need, strong unmet need, a met need, or not applicable are presented in the Appendix. Responses indicating "not sure", "do not know", "prefer not to answer", and "not applicable" were excluded, particularly given they represented low proportions of the responses. The overall need for each information item was then declared **unmet** if at least 50% (\geq 50%) of respondents indicated that the information need has not been met. Conversely, overall need for each information item was declared **met** if less than 50% (< 50%) of respondents indicated that information has not been met. In the absence of prior studies in yCRC (and CRC) assessing whether information needs were met, a conservative cut-off was applied based on the rationale on the importance of serving at least half of patients and survivors of yCRC (and CRC) and to pinpoint underserved information items for this population. For information items declared unmet, I conducted bivariate and further multivariable analyses to determine respondent characteristics that predict the odds of unmet information needs. Categorical variables with subgroups of small sample sizes were dichotomized to accommodate conducting statistical analyses. The following variables were collapsed: marital status (married, nonmarried), ethnicity (white, non-white), country (Canada, United Kingdom, US, Other), and general health status (good, poor).

45

3.2.8 Statistical Analysis

Descriptive statistics included means and standard deviations for continuous variables and proportions for categorical variables. Respondents' information needs and information-seeking behaviours were characterized using descriptive statistics. To determine significant predictors of unmet information needs, separate cross-tabulations and Pearson's chi-square tests were used to evaluate associations between having unmet information needs and predictor variables. Predictor variables included age at diagnosis, age at the time of survey completion, gender, cancer site, cancer stage, treatment status (i.e., patient vs. sur), country, neighbourhood status, education, marital status, ethnicity, HRQoL and Internet use. The reference groups set within each variable included: 40-49 years-old for age at diagnosis, 40-49 years-old for age at the time of survey completion, male for gender, colon for cancer site, stage 3 for cancer stage, patients for treatment status, US for country, urban for neighbourhood, postsecondary education for education, married for marital status, white for ethnicity, good for HRQoL, and never for Internet use. Predictors with significant bivariate associations with an unmet information need were then simultaneously entered into a single multivariable logistic regression model. This process was repeated for each unmet information need outcome separately. Unmet information needs with multiple significant predictors are reported as multivariable adjusted logistic models in Tables 12a-d. Multivariable associations between unmet information items and predictors were reported as ORs with 95% CI.

3.3 Results

3.3.1 Participants

A total of 1,272 individuals signed the consent form of this survey, of whom 851 (67%) completed the survey for analysis. Individuals diagnosed with yCRC over the age of 50 were excluded from analysis in this survey based on the exclusion criteria. Altogether, 366 indicated that they had received their diagnosis before the age of 50 and thus met the inclusion criteria and comprised the analytical survey sample (response rate = 29%). Refer to Figure 5 for the flowchart of respondents included in and

46

excluded from analysis. A comparison the yCRC sample analyzed and later-onset CRC respondents recruited in this survey can be referenced in the Appendix.



Figure 5. Flowchart of respondent recruitment and data cleaning for analysis

3.3.2 Demographic Characteristics

Analyzing demographic characteristics of the analytic sample revealed that respondents were, on average, women (69.9%, N = 256), 40-49 years old at completion of the survey (41.8%, N = 153), and ethnically White (84.9%, N = 256). Respondents' demographic characteristics are summarized in Table 8. The mean age at diagnosis was in the 40-49 age group (55.7%, N = 204). The sample was composed of 34% (N = 119) patients and 65% (N = 224) survivors.

	Number of yCRC respondents (%)
Current Age	
<20	3 (0.8)
20-29	15 (4.1)
30-39	90 (24.6)
40-49	153 (41.8)
50-59	87 (23.8)
60-69	15 (4.1)
70-79	2 (0.6)
>80	1 (0.3)
Total	366 (100)
Gender	
Men	110 (30.1)
Women	256 (69.9)
Prefer not to answer	0
Total	366 (100)
Marital status	
Widowed	3 (0.9)
Common-law	22 (7.14)
Single, never married	31 (9.9)
Separated/divorced	33 (10.6)
Married	220 (70.5)
Total	312 (85.2)
Prefer not to answer	3 (0.9)
Missing	54 (14.8)
Education level	
Elementary or primary school	1 (0.3)
High school or secondary school	54 (17.3)
Postsecondary (university, college)	253 (81.1)
No schooling completed	0
Prefer not to answer	4 (1.3)
Total	312 (85.2)
Missing	54 (14.8)
Residence	
Rural	67 (21.5)
Urban	99 (31.7)
Suburban	141 (45.2)
Do not know	2 (0.6)
Prefer not to answer	3 (0.9)
Total	312 (85.2)
Missing	54 (14.8)
Ethnicity	
Middle Eastern	1 (0.3)
Native/Aboriginal	3 (0.9)
Other	5 (1.6)
Asian	8 (2.6)

	Table 8.	yCRC Res	pondent I	Demographic	Characteristics
--	----------	----------	-----------	-------------	-----------------

	Number of yCRC respondents (%)
Hispanic	10 (3.2)
Mixed ethnicity	14 (4.5)
White	265 (84.9)
Black	2 (0.6)
Prefer not to answer	4 (1.3)
Total	312 (85.2)
Missing	54 (14.8)
Country	
Other	13 (3.6)
UK	38 (10.4)
Canada	104 (28.4)
US	211 (57.7)
Total	366 (100)

3.3.3 Clinical Characteristics

Analysis of clinical characteristics of the respondents analyzed revealed that, most respondents reported with Stage III (42.9%, N = 157) in the colon (58.2%, N = 213). The most common treatment prescribed to respondents was a combination of chemotherapy and surgery (39.8%, N = 145). Furthermore, 34.4% (N = 119) of respondents were undergoing treatment at the time of the survey, and the remainder had completed treatment and were actively being followed-up (64.7%, N = 224). Young-onset CRC and treatment characteristics are summarized in Table 9.

	yCRC	
Age at diagnosis		
<20	4 (1.1)	
20-29	31 (8.5)	
30-39	127 (34.7)	
40-49	204 (55.7)	
Total	366 (100)	
Cancer site		
Colon	213 (58.2)	
Rectum	108 (29.5)	
Both sites	42 (11.5)	
Prefer not to answer	3 (0.8)	
Total	366 (100)	
Cancer stage		
Stage 0	8 (2.2)	
Stage I	27 (7.4)	
Stage II	54 (14.8)	
Stage III	157 (42.9)	
Stage IV	105 (28.7)	
Do not know	15 (4.1)	
Prefer not to answer	0	
Total	366 (100)	
Treatment received/receiving		
Chemotherapy and surgery	145 (39.8)	
All (radiation, chemotherapy, surgery)	124 (34.1)	
Surgery only	40 (10.9)	
Chemotherapy only	22 (6.0)	
Radiation and chemotherapy	13 (3.6)	
Radiation only	3 (0.8)	
Radiation and surgery	1 (0.3)	
None	0	

 Table 9. Respondent yCRC and Treatment Characteristics

	yCRC
Other	16 (4.4)
Total	364 (99.5)
Missing	2 (0.5)
Phase of treatment	
Currently undergoing treatment	119 (34.4)
Completed treatment and actively being followed up	151 (43.6)
More than 5 years from last treatment	73 (21.1)
Do not know	3 (0.9)
Total	346 (94.5)
Missing	20 (5.5)

3.3.4 Health-related Quality of Life

The mean HRQoL of respondents was 0.84 (standard deviation [SD] = 0.074) with a minimum HRQoL of 0.62 and a maximum HRQoL of 0.95. Overall, 39.4% of respondents reported "Good" HRQoL and 60.6% "Poor", using the set categories from the HRQoL values from the EQ-5D-5L. Computing the descriptive statistics of the general health question indicated that 35% reported "Good" health and 65% "Poor" at the time of survey completion.

3.3.5 Information Seeking Behaviours

At the most recent search for yCRC information, 44% (N = 143) of respondents used the Internet, 29% (N = 94) asked doctors or other medical professionals, and 15% (N = 48) queried cancer organizations. Refer to Table 10 for the information sources respondents used most recently to find yCRC information. Respondents relied on doctors or other medical professionals, the Internet, and cancer organizations to obtain yCRC information, with 74%, 47%, and 46% of respondents "always" or "usually" using these sources, respectively. Refer to Table 11 for the frequency with which respondents used information sources to find yCRC information.

Table 10. Information Seeking Behaviours of yCRC Respondents at the Most Recent Time They

Needed Information

Source	Frequency (%)
Books	6 (1.9)
Brochures, pamphlets, etc.	2 (0.6)
Cancer organizations	48 (14.9)
Do not know	1 (0.3)
Doctors or other medical health professionals	94 (29.1)
Family members or friends	2 (0.6)
Government health agencies	4 (1.2)
Internet	143 (44.3)

Source	Always (%)	Usually (%)	Sometimes (%)	Never (%)	Missing (%)
Books	9 (2.5)	13 (3.6)	153 (41.8)	140 (38.3)	49 (13.4)
Brochures, pamphlets, etc.	9 (2.5)	27 (7.4)	198 (54.1)	84 (23.0)	48 (13.1)
Cancer organizations	60 (16.4)	107 (29.2)	136 (37.2)	16 (4.4)	47 (12.8)
Doctors or other medical health professionals	152 (41.5)	119 (32.5)	44 (12.0)	5 (1.4)	46 (12.6)
Family members or friends	9 (2.5)	26 (7.1)	156 (42.62)	124 (33.9)	47 (12.8)
Government health agencies	13 (3.6)	39 (10.7)	143 (39.1)	115 (31.4)	48 (13.1)
Internet	77 (21.0)	93 (25.4)	121 (33.1)	26 (7.1)	48 (13.1)
Magazines	2 (0.6)	9 (2.5)	92 (25.1)	207 (56.6)	49 (13.4)
Newspapers	1 (0.3)	3 (0.8)	75 (20.5)	232 (63.4)	49 (13.4)

Table 11. Information Seeking Behaviours of yCRC Respondents

3.3.6 Information Needs

Of the 39 information items, 26 (67%) were classified as unmet using the 50% cut-off. Information items are reported below according to the information domains predefined at diagnosis, regarding treatment, during treatment, after treatment, and on the impacts of yCRC.

3.3.6.1 Information items among all yCRC respondents analyzed at the time of diagnosis

Items pertaining to information needs at the time of diagnosis were described for all respondents of the study sample, with five out of seven items deemed unmet. Figure 6a presents the proportion of information items unmet among all respondents analyzed with yCRC at the time of diagnosis. Notably, 82% (N = 277) of respondents had an unmet information need regarding the cause of cancer with 32% (N = 117) of those respondents indicating that the cause of their cancer was a strong unmet need for them. Additional unmet information needs included research clinical trials for yCRC (79% of responses unmet, N = 234), specialized tests (63%, N = 212), chances of surviving cancer (52%, N = 177), and the risk of cancer to family (51%, N = 176).



Figure 6a. Proportion of information items unmet among all respondents of yCRC at time of diagnosis

3.3.6.2 Treatment-related information needs

Similarly, information need items related to treatment were reported by respondents depending on the treatment regimen they received, and it was found that 5 out of 13 items were unmet. Three unmet information needs pertained to how to deal with the side-effects of chemotherapy, surgery, and radiation; 51% (N = 58), 54% (N = 61), and 57% (N = 66) of respondents analyzed had these information needs unmet, respectively. Further, 51% (N = 59) of respondents analyzed indicated that they had an unmet need concerning how radiation works. Lastly, 50% (N = 56) respondents analyzed reported that they did not have sufficient information on the available types of chemotherapy. Refer to Figure 6b for the proportion of information items unmet among all respondents with yCRC regarding treatment.



Figure 6b. Proportion of information items unmet among all respondents with yCRC regarding treatment

3.3.6.3 Information needs while currently undergoing treatment

Information items relevant to respondents with yCRC currently undergoing treatment were probed among 119 respondents, and all seven of the items were deemed unmet. Specifically, alternative/complementary treatments had the greatest proportion unmet, with 85% (N = 92) of respondents reporting insufficient information relating to this topic. The information item on clinical trials was an unmet need, with 83% (N = 88) of respondents reporting this information need unmet. Figure 6c illustrates the proportions of the

information items unmet among respondents with yCRC currently undergoing treatment at survey completion.



Figure 6c. Proportion of information items unmet among respondents with yCRC currently undergoing treatment

3.3.6.4 Information needs after completing treatment

Among the 223 yCRC survivor respondents, four out of the five queried information items were unmet. The greatest unmet need among these respondents was regarding other patients' experiences after treatment, with 72% (N = 136) of respondents analyzed reporting that this was an unmet need for them. Analyzing information items by the sublevels of unmet need reveals that the information item of post-treatment nutrition and diet was the strongest unmet need (44% responding with strong unmet need). By contrast, stoma management was an information need met, with 40% (N = 40) stating that they had sufficient information on this topic. The remaining participants found stoma management not applicable to them (43%; N = 97), or they were not sure what it was (8%; N = 17). Refer to Figure 6d for an illustration of the proportion of information items unmet among yCRC respondents who had completed treatment and/or were actively being followed-up.


Figure 6d. Proportion of information items unmet among yCRC respondents who have completed treatment and/or were actively being followed-up

3.3.6.5 Information needs on the impacts of yCRC on life

The information need items concerning the impacts of yCRC on life were investigated among all yCRC respondents analyzed. All information items in this information domain were unmet. The long-term side-effects of treatment was reported unmet by 79% (N = 246) of respondents. Notably, bowel activity after cancer was reported unmet by 66% (N = 199), managing work with cancer by 63% (N = 182), and sexual activity information by 67% (N = 200). Figure 6e presents the proportion of information items on the impacts of yCRC on life unmet among all respondents.



Figure 6e. Proportion of information items unmet among all yCRC respondents on impacts of yCRC on life

3.3.7 Significant Predictors of Unmet Information Needs

It was revealed that 18 of the 26 unmet information needs (five unmet needs for all respondents at diagnosis, five unmet needs for patients currently undergoing treatment, seven unmet needs regarding yCRC treatment, four unmet needs for those who had completed treatment, seven unmet needs for all respondents on the impacts of life) were significantly associated with multiple predictors. Among the 13 predictors examined, nine appeared to be significantly associated with unmet information needs across all

five information domains. Tables 12a-d present the adjusted multivariable associations between multiple predictors associated with each unmet need. Predictors significantly positively associated with unmet needs—suggesting that individuals are more likely to have their needs unmet—include cancer site, country, marital status, and Internet use. Predictors that were inversely associated with unmet information needs include treatment status, age at survey completion and ethnicity.

Cancer site

The site of yCRC was significantly associated with the unmet information need regarding the risk of cancer to family. The odds of having an unmet information need regarding the risk of cancer to family members was 150% greater for those diagnosed with rectal (adjusted OR, 2.50; 95% CI, 1.11 to 5.00) or colon and rectal cancer (adjusted OR, 2.50; 95% CI, 1.43 to 5.00) compared to those diagnosed with colon cancer (refer to Table 12a).

Country of residence

Country of residence also was associated with the information needs of risk of cancer to family members and specialized cancer tests being unmet. For individuals from the United Kingdom (UK), an adjusted OR of 3.33 (95% CI, 1.43 to 10.00) was reported, compared to those from the US. The odds of having an unmet information need regarding specialized cancer tests was 100% (adjusted OR, 2.0; 95% CI, 1.25 to 5.00) greater for individuals from Canada than for those from the US (refer to Table 12a).

Marital status

Respondents' marital status was significantly associated with the information need of the chances of surviving the cancer; those who were not married had a 67% (adjusted OR, 1.67; 95% CI, 1.00 to 3.33) greater possibility of having this information need unmet than married individuals (refer to Table 12a).

Internet use

Further, how often respondents used the Internet was significantly associated with the information needs of the cause of cancer, work and cancer, bowel activity after cancer, and long-term side-effects of treatment. Individuals who indicated that they "always", "sometimes", or "usually" used the Internet to search for CRC information had a 400% (adjusted OR, 5.0) increased chance of having their information need on the cause of cancer unmet than those who never searched the Internet (refer to Tables 12a-d).

Health-related quality of life

HRQoL was significantly associated with several unmet information needs, with individuals in poor health having a greater chance of unmet needs than those in good health. These information needs span across all yCRC respondents, yCRC respondents undergoing treatment, and those who completed treatment and/or actively being followed-up. With regards to unmet needs across all respondents, poor HRQoL was associated with work and cancer, parenting and cancer, and mental health and cancer. For respondents undergoing treatment at survey completion, poor HRQoL was associated with a greater chance of the following information needs being unmet: nutrition/diet, exercise/physical activity, and clinical trials for new treatments. Lastly, poor HRQoL was associated with a greater chance of the information need on bowel activity being unmet (refer to Tables 12a-d).

Treatment status

The current treatment status of respondents was significantly associated with the information need regarding the chances of surviving cancer, where adjusted ORs of 0.53 (95% CI, 0.3 to 0.91) and OR of 0.5 (95% CI, 0.25 to 1.0) were reported for respondents analyzed who were being followed-up and were survivors, respectively (compared to respondents who were current patients) (refer to Table 12a).

Current age

Age was a significant predictor of information needs where being a younger respondents at the time of completing the survey was inversely associated with having information needs regarding the cause of cancer, sexual activity, and the long-term side-effects of treatment being unmet. An adjusted OR as low as 0.15 (95% CI, 0.035 to 0.63) was reported for individuals between 20-29 years having an unmet information need in the cause of cancer, compared to those between 40-49 years (refer to Tables 12a, d).

Ethnicity

Furthermore, respondents' ethnicity was significantly associated with having the information need on clinical trials for cancer treatments, where those of non-White ethnicities had an adjusted OR of 0.42 (95% CI, 0.18 to 0.91) when compared to those of a White ethnicity (refer to Table 12a).

Table 12a. Odds ratios and 95% confidence intervals for predictors of unmet information needs for information items at the time of

yCRC diagnosis

	Surviving Cancer	Cause of cancer	Risk of cancer to family	Clinical trials	Specialized tests	Dealing with the side-effects of radiation
Age diagnosed						
20-29 yr					0.63 (0.18, 2.5)	
30-39 yr					0.52 (0.27, 1.11)	
40-49 yr (ref)					1.0	
Current age						
20-29 yr		0.15 (0.035, 0.63)*			1.66 (0.28, 10.0)	
30-39 yr		1.43 (0.53, 3.33)			1.11 (0.53, 2.5)	
50-59 yr		1.428 (0.526, 3.33)			2.0 (1.0, 3.33)	
60-69 yr		2.0 (0.30, 10.0)			0.45 (0.13, 1.67	
40-49 yr (ref)		1.0			1.0	
Gender						
women vs men					0.77 (0.40, 1.30)	
(rei)						
			250(11150)*			
colon and rectal			$2.30(1.11, 3.0)^{*}$			
rectal			$2.30(1.43, 3.0)^{+}$			
CRC stage			1.0			
stage 0		0.035 (0.0069, 0.36)*	0.91 (0.12, 10.0)			
stage 1		0.56 (0.18, 1.67)	0.63 (0.26, 1.43)			5.0 (0.0, 0.40)
stage 2		0.53 (0.21, 1.43)	0.59 (0.29, 1.25)			2 (0.67, 10.0)
stage 4		1.66 (0.63, 5.0)	1.43 (0.83, 2.50)			1.67 (0.59, 5.0)
stage 3 (ref)		1.0	1.0			1.0

Note. Each column represents a multivariable logistic regression model with the outcome as unmet information need for the corresponding item p < 0.05

Table 12a. Odds ratios and 95% confidence intervals for predictors of unmet information needs for information items at the time of

vCRC	diagnosis	(continued)	
JOILO	anagnosis	(commutu)	

	Surviving Cancer	Cause of cancer	Risk of cancer to family	Clinical trials	Specialized tests	Dealing with the side-effects of radiation
HRQoL						
poor		1.67 (0.91, 3.34)	1.43 (0.91, 2.50)	2.5 (1.43, 5.0)*	1.67 (1.0, 2.50)	
good (ref)		1.0	1.0	1.0	1.0	
Treatment status						
follow-up	0.53 (0.30, 0.91)*	0.91 (0.37, 2.50)				
survivor	0.50 (0.25,1.0)*	0.5 (0.17, 1.67)				
patient (ref)	1.0	1.0				
Country						
Canada			1.0 (0.59, 1.67)	1.25 (0.59, 2.50)	2 (1.25, 5.0)*	
Other			0.71 (0.22, 2.50)	0.77 (0.19, 3.33)	1.43 (0.38, 5.0)	
UK			3.33 (1.43, 10.0)*	0.59 (0.20, 1.66)	1.67 (0.71, 3.33)	
US (ref)			1.0	1.0	1.0	
Marital status						
non-married vs married (ref)	1.67 (1.0, 3.33)*	2.0 (0.77, 5.0)				0.24 (0.087, 0.67)
Ethnicity						
non-white vs white (ref)				0.42 (0.18, 0.91)*		
Internet use						
always		5.0 (1.43, 10.0) *				
usually		5.0 (0.0, 1.67)*				
sometimes		5.0 (1.25, 10.0)*				
never (ref)		1.0				

Note. Each column represents unmet information needs as dependent variables in separate multivariable adjusted logistic models. Only significantly associated variables in each model are reported.

**p*<0.05

 Table 12b. Odds ratios and 95% confidence intervals for predictors of unmet information needs

 for information items for yCRC respondents currently undergoing treatment

	Clinical trials for new treatments	Exercise and physical activity during treatment	Nutrition and diet during treatment	Other patients' experiences about treatment
HRQoL				
poor	5 (1.25, 10)*	2.5 (1.0, 10.0)*	3.33 (1.43, 10.0)*	2.0 (0.77, 5.0)
good (ref)	1.0	1.0	1.0	1.0
Country				
Canada	1.11 (0.22, 5.0)			3.33 (1.0, 10.0)
Other	0.38 (0.019, 10.0)			0.24 (0.024, 2.50)
UK	Ť			Ť
US (ref)	1.0			1.0
Ethnicity				
non-white vs white (ref)	4.0 (0.80, 18.90)			
Internet use				
always		10.0 (0.0, 0.83)	0.0 (0.0, 2.50)*	
sometimes		3.33 (0.37, 0.0)	10.0 (0.91, 0.0)	
usually		3.33 (0.43, 0.0)	0.0 (0.0, 2.0)*	
never (ref)		1.0	1.0	

Note. Each column represents unmet information needs as dependent variables in separate multivariable adjusted logistic models. Only significantly associated variables in each model are reported. *p < 0.05

† - Quasi-complete separation

Table 12c. Odds ratios and 95% confidence intervals for predictors of unmet information needs for information items for yCRC respondents who have completed treatment and/or actively being

	Exercise and physical activity after treatment	Bowel activity after treatment
CRC stage		
stage 0	1.43 (0.20, 10.0)	
stage 1	0.20 (0.052, 0.77)*	
stage 2	1.11 (0.50, 2.50)	
stage 4	1.0 (0.38, 2.50)	
stage 3 (ref)	1.0	
HRQoL		
poor	1.43 (0.77, 2.50)	2.50 (1.25, 5.0)*
good	1.0	1.0
Internet use		
always		3.33 (1.11, 10.0)*
sometimes		Ť
usually		2 (0.71, 5.0)
never (ref)		1.0

followed-up

Note. Each column represents unmet information needs as dependent variables in separate multivariable adjusted logistic models. Only significantly associated variables in each model are reported. *p < 0.05

† - Quasi-complete separation

Table 12d. Odds ratios and 95% confidence intervals for predictors of unmet information needs for information items for all yCRC

	Sexual activity	Work and cancer	Parenting with cancer	Mental health and cancer	Bowel activity after cancer	Long-term side- effects of treatment
Current age						
20-29 yr	0.5 (0.15, 1.67)		0.91 (0.16, 5.0)			0.53 (0.12, 2.50)
30-39 yr	1.0 (0.50, 2.0)		0.63 (0.29, 1.43)			0.34 (0.16, 0.77)*
50-59 yr	0.77 (0.38, 1.43)		0.83 (0.38, 2.0)			0.50 (0.23, 1.11)
60-69 yr	0.19 (0.034, 1.0)*		0.12 (0.0090, 1.67)			0.19 (0.048, 0.77)*
40-49 yr (ref)	1.0		1.0			1.0
Gender						
women vs men				1 (7 (0 01 2 22)	1 (7 (0 01 2 22)	
(ref)				1.07 (0.91, 5.55)	1.07 (0.91, 5.55)	
CRC stage						
stage 0	0.40 (0.054, 3.33)				0.16 (0.012, 2.0)	
stage 1	0.50 (0.166, 1.43)				0.83 (0.29, 2.50)	
stage 2	0.91 (0.40, 2.0)				0.91 (0.43, 2.0)	
stage 4	1.0 (0.53, 1.67)				0.16 (0.012, 2.0)	
stage 3 (ref)	1.0				1.0	
HRQoL						
poor vs good (ref)	1.67 (0.91, 2.50)	2.50 (1.67, 5.0)**	2.0 (1.0, 3.33)*	2.0 (1.11, 3.33)*	2.50 (1.25, 5.0)*	2.0 (1.0, 3.33)
Country						
Canada				1.0 (0.56, 1.67)		2.0 (0.91, 5.0)
Other				0.33 (0.086, 1.25)		0.56 (0.086, 3.33)
UK				1.25 (0.45, 3.33)		0.63 (0.23, 1.67)
US (ref)				1.0		1.0
Internet use						
always	2.0 (0.67, 5.0)	5.0 (5.0, 10.0)*	3.33 (1.0, 10.0)		3.33 (1.0, 10.0)*	2.0 (0.59, 5.0)
sometimes	1.25 (0.42, 3.33)	+	2.0 (0.67, 5.0)		3.33 (0.91, 10.0)	1.67 (0.56, 5.0)
usually	2.50 (0.91, 10.0)	1.67 (0.71, 5.0)	2.50 (0.91, 10)		2.50 (0.77, 10.0)	3.33 (1.11, 10.0)*
never (ref)	1.0	1.0	1.0		1.0	1.0

respondents on the impacts of yCRC

Note. Each column represents unmet information needs as dependent variables in separate multivariable adjusted logistic models. Only significantly associated variables in each model are reported.

**p*<0.05

† - Quasi-complete separation

3.4 Discussion

This descriptive cross-sectional study investigated the information-seeking behaviours and information needs of individuals diagnosed with yCRC. It has been indicated that yCRC respondents heavily relied on the Internet to find yCRC at their most recent search for yCRC information. Among the sample analyzed, 74%, 47%, and 46% of respondents relied on doctors or other medical professionals, the Internet, and cancer organizations to obtain yCRC information, respectively. To date, this is the first investigation to examine the information-seeking behaviours of a yCRC sample.

Among the 39 information need items surveyed, 26 unmet information needs were found across the five information domains explored. Specifically, there were five out seven of unmet information needs in the time of diagnosis domain, five out of 13 unmet needs regarding the treatment domain, seven out of eight unmet needs in the currently undergoing treatment for yCRC domain, four out five unmet needs in the completed treatment and/or actively being followed-up domain, and seven out of seven unmet needs in the impacts of yCRC on life domain. Furthermore, this study identified significant predictors of various unmet information needs, including cancer type, cancer stage, treatment status, HRQoL, country of residence, ethnicity, marital status, and Internet use. These predictors may aid in identifying and allocating resources to subpopulations more likely to experience unmet information needs.

To date, this is the first known report to empirically document the information needs of adults with yCRC at diagnosis, during treatment, and into survivorship. A recent literature search uncovered a 2019 cross-sectional survey study that evaluated the unmet information needs of CRC survivors (113). As in this study, the outcome (unmet information needs) was measured using the CaSUN questionnaire (113). Survivor characteristics associated with unmet information needs were measured using negative binomial regression models (113). Explanatory variables included were age at diagnosis, time since diagnosis, cancer type (colon or rectal), and treatment status (113). Vu et. al recruited 99 CRC survivors (58 with colon cancer, 41 with rectal cancer) undergoing surveillance (113). The mean age of colon cancer survivors was 60 (SD: \pm 12) and 56 (SD: \pm 11) for rectal cancer survivors (113).

The study by Vu et al. found that about 67% of recruited colon cancer survivors and 90% of rectal cancer survivors had at least one unmet information need (113). It was also revealed that higher rates of treatment-related problems were reported among rectal cancer patients (113). Multivariable analysis suggests that receiving radiation treatments is significantly associated with greater treatment-related needs (113). The results of the study by Vu et al. are consistent with this thesis work. That is, examining the association between unmet information needs and cancer site in this thesis work revealed that rectal cancer respondents had a greater chance of having an unmet information need regarding the risk of cancer to family. These findings highlight the importance of assessing patient characteristics and their association with patient information needs in the design and implementation of targeted patient and survivor resources.

3.4.1 Complexities of yCRC, Ineffective Self-Management and Unmet Information Needs

Individuals with diagnosed yCRC have to contend with numerous dimensions of disease burden, including symptoms, treatment-associated side-effects, and uncertainty (102). Applying this concept of self-management, all the information items probed by this survey (physical, social, and emotional impacts of yCRC) assessed different dimensions of self-management. Ose et al. proposed three complexities an individual diagnosed with a disease encounters that run parallel to the self-management dimensions: complexity of the disease, complexity of care, and complexity of the treatment data (102). Complexity of the disease is associated with the physical and psychological impacts of the disease, as well as treatment-associated side-effects (102). Complexity of care is associated with interactions with health care professionals, personal and social interactions, long-term care, and home care (102). Lastly, complexity of treatment data relates to how longer durations of treatment, survival, and follow-up are associated with larger amounts of information that patients must manage (102).

The inability of individuals diagnosed with yCRC to self-manage is significantly associated with lower HRQoL and well-being (14-16, 102). Effective self-management is composed of the following processes: identifying disease information needs, navigating resources to obtain information needs, and

further implementing the information to address needs (102, 114). As the gap between the complexities and an individual's capacity to address them increases, the ability to self-manage is compromised (102). Effective self-management requires the ability to seek support and guidance, search for information, and then disseminate information (102). It can be inferred, then, that the inability to self-manage corresponds with difficulties seeking and managing information needs. As such, I have proposed a framework to aid in the interpretation of my findings. This framework adapted both from the concept of self-management from Ose et al. and Wilson's Second Model of Information Behaviour Model was used to explain how the complexity of a yCRC diagnosis affects self-management and, in turn, specific information needs and information-seeking behaviours, as well as how intervening variables confound this pathway (see Figure 7 for the proposed framework). An individual's capacity to address the complexities of yCRC, along with their information-seeking behaviours, are dependent on their personal characteristics. This relates to Wilson's Second Model of Information Behaviour, where intervening variables including demographic background, social role, environmental variables, and psychological predispositions play a role in information seeking (40). Relating to yCRC, individuals with a complex diagnosis may not be able to effectively self-manage by identifying, obtaining, and implementing the information they need, which results in unmet information needs. This association has been reinforced in this study; it was found that individuals with more advanced stages of yCRC (increased complexities) are more likely to have unmet information needs.



Figure 7. Proposed framework on self-management, information needs, and information seeking. Adapted from *Looking for Information: A Survey of Research on Information Seeking, Needs, and Behavior (p. 137),* by Case, D., 2007, London: Elsevier LTD. Copyright 2007 by Elsevier LTD.

3.4.2 Unmet Information Needs

Respondents of this survey demonstrated unmet information needs regarding diet/nutrition, physical activity/exercise, bowel management, and psychosocial aspects (i.e., mental health, sexual activity, work, parenting), all considered self-management activities. Responses signaled a need for information on new treatments. There were substantial unmet information needs on clinical trials at diagnosis and alternative treatments while undergoing treatment. Interestingly, analysis of the treatment-related items revealed that respondents desired counselling on "dealing with" treatment-associated side-effects regardless of the treatment they received. Treatment-associated side-effects of yCRC have substantial physical (20) and psychosocial (22) morbidities. According to Ose et al., such treatment-associated side-effects increase the complexity of the disease. This unmet information need and increased disease complexity may contribute to the other unmet information needs around self-management including bowel activity, mental health, sexual activity, work and cancer, diet and nutrition, and exercise and physical activity.

3.4.3 Significant Predictors of Unmet Information Needs

The importance of determining significant associations between unmet information needs and sociodemographic characteristics is a step towards targeting patients and survivors who report unmet needs. Such targeting may be effective in informing health care practitioners on what specific supportive care, informational resources, and services to provide to specific subpopulations with yCRC. Overall, 18 multivariate logistic regressions were conducted between specific items of unmet information needs and potential predictors. It was revealed that unmet needs appeared to have strong associations with respondents' cancer characteristic (i.e., cancer type, cancer stage, treatment status), HRQoL, country, and Internet use.

Cancer characteristics

Individuals diagnosed with rectal or both colon and rectal cancer had a 150% greater chance of having an unmet information need on the risk of cancer to family members than those diagnosed only with colon cancer. This observed association may be a reflection of the increase complexities associated with rectal cancer compared to colon cancer. That is, rectal cancer patients are more likely to have ostomies and develop infections compared to colon cancer—leading to rectal cancer patients requiring more information to self-management and more possible unmet needs. Furthermore, rectal cancer is generally less prevalent, with around 25 cases per 100,000, compared to around 37 cases per 100,000 for colon cancer (1). Moreover, rectal cancer is associated with a lesser mortality rate, with around 3 cases per 100,000, compared to around 5 cases per 100,000 for colon cancer (1). This lower prevalence and mortality of rectal cancer may correspond with less public and scholarly attention and possibly lead to fewer resources and supportive care. This relative disparity in resources and supportive care may explain the observed unmet information needs for individuals with cancer in the rectum.

With respect to cancer staging, those with less advanced staging had lower odds of having unmet information needs than those with more advanced staging. This may be explained by the fact that less

advanced yCRC stages are associated with less aggressive treatment and fewer complications and, therefore, potentially fewer information needs. Similarly, it has been suggested that survivors have a lower chance of having unmet information needs than patients undergoing treatment. Generally, survivors are years beyond diagnosis and treatment, and accordingly, have better quality of life and fewer activating mechanisms or motivators that drive the search for necessary information.

Health-related quality of life

Sufficient information on disease management is necessary for optimal well-being (15, 16); a lack of this information is associated with decreased HRQoL (14). Individuals with good HRQoL in the analyzed sample were less likely to have unmet information needs at their current disease stage than those with a poor HRQoL. The observed association between HRQoL and unmet information needs in this study has been reiterated in other studies (15, 49). This finding was also observed in a US study by Zebrack (2009) that investigated the supportive care needs of young adult cancer survivors (49). Results of this highlighted study indicated that survivors reporting good health were less likely to report unmet information needs (49). This finding suggests that clinicians should monitor patients' and survivors' HRQoL and enquire about any information needs for those with poor HRQoL.

Country of residence

Given the international nature of the survey, I assessed differences in information needs by geographic location. I noted that country of residence was also associated with having certain information needs met or unmet. Individuals from Canada had a higher chance of having an unmet information need on specialized cancer tests compared to individuals from the US. This may be explained by the inherent differences in the two countries' health care systems. Specifically, specialized colorectal cancer testing, and targeted therapy may be more common in the US, with its private health care system. The uptake of targeted therapy may be comparatively lower in Canada, leading to less unmet information needs.

Internet Use

The Internet is the predominant source of information respondents analyzed sought when looking for yCRC information at their most recent search. Furthermore, Internet use was a significant predictor of unmet information needs. In particular, Internet use was associated with a greater chance of information needs being unmet for individuals that "always" or "usually" used the Internet to find yCRC information, compared to those who "never" used it. The Internet has the potential to be an excellent source of health information; however, it does have several shortcomings (115). For instance, difficulties finding and understanding information online, the variable quality of information, and the potential for overconsumption are drawbacks that could explain the greater odds of information needs being unmet (115-117). Both a US and UK survey reported that individuals with yCRC report difficulties finding ageappropriate information (107, 118). Correspondingly, yCRC respondents who rely on the Internet to fulfill information needs may find a lack of age-appropriate information, explaining the increased odds of having information needs unmet for individuals who regularly use the Internet. In addition, greater Internet use may correspond with more questions arising, whereas with less Internet use, more targeted questions may be sought and answered by physicians or other sources, having needs met. In other words, more Internet use could increase information needs, thus raising the odds of those needs being unmet. Residence status may act as a confounder where individuals from remote locations have poor Internet use and, in turn, different information needs. However, the inclusion of the neighborhood status did not affect the association between Internet use and any unmet needs.

3.4.4 Implications

The findings of this study may improve patient-clinician care and communication by informing health care practitioners about the supportive care, informational resources, and services to provide to specific subpopulations with yCRC. For instance, there are large proportions of individuals diagnosed with yCRC that have unmet information needs regarding self-management (i.e., diet/nutrition, physical activity/exercise, bowel management, mental health, etc.). Guidance and counselling regarding the specific needs within self-management could be implemented to address such needs. In particular, 71% of the sample analyzed that were undergoing treatment and 64% of those who completed treatment had an unmet information need regarding diet and nutrition. Further, the implementation of psychological support for individuals with yCRC is crucial; 70% of respondents reported a need for more information regarding mental health and cancer.

Gender bias has repercussions in research and warrants consideration. Notably, the majority of the analytic sample were women (70%) for whom information needs were largely unmet. This result may reflect a possible gender bias in the health care where women receive less guideline-based care compared to male patients. Gender bias in disease management has been observed in different diseases. Specifically, it has been indicated that women with myocardial infarction (119) and heart failures (120) receive less guideline-based diagnosis (121). It is possible that women with yCRC also receive less guideline-based care. Colorectal cancer, similar to other chronic diseases, is a complex diagnosis (102) with established disease management guidelines and evidence-based recommendations (122). The unmet information needs reported in this study may allude to the presence of gender bias where women do not receive the information they need for effective self-management. Moreover, the analytic sample was comprised predominantly of women who have completed a post-secondary education. Studies have suggested a possible association between education attainment and health literacy (123). As such, women in this analytic sample may be more inclined to need information because of their higher literacy but are actually receiving less disease management information—leading to greater unmet information needs. However,

this finding may also be a consequence of participant bias. There is substantial evidence suggesting that women are more likely to participate in scientific research (124-129). That is, the majority of the recruited sample being women may a by-product of this participant bias. Bivariate analysis examining the differences in all unmet information needs between men and women reveals that indeed there is no statistically significant difference in unmet needs between both genders.

Lastly, this research recognizes the relevance of serving patients and survivors with online resources. The increased odds of having information needs unmet for those that regularly use the Internet may signify a lack of appropriate resources or access for patients and survivors. Additionally, the Health on Net survey (2005) suggests that 90% desire reliable online resources recommended by their health care providers (115). Results from this survey reinforce this: around 46% of respondents reported "always" or "usually" using the Internet to find yCRC-related information, and 44% searched for yCRC-related information at the most recent time they had an information need. Further, 81% of respondents expressed interest in a future eHealth resource that provides reliable yCRC information. Patients and survivors of vCRC reported desiring information on other patients' experiences with vCRC. As reported in a 2015 UK survey, 33% of respondents with vCRC felt that existing resources were intended for older patients, and half noted a lack of peer support with "no one their age with bowel cancer to talk to" (130). Also, unmet information needs were also observed among respondents who have completed treatment. A 2017 US survey similarly reported struggles with finding age-appropriate support and subsequent feelings of isolation in yCRC patients (118). These findings were consistent with my findings: 72% of survivor respondents reported an unmet need regarding other patients' experiences with yCRC. This supports the implementation of a future eHealth resource that provides reliable and appropriate yCRC information along with a platform for connecting patients and survivors.

3.4.5 Limitations and Strengths

There were several limitations of this study. This study employed a Web-based survey that used convenience sampling, a form of nonprobability sampling where the probability of a respondent

completing the survey is indeterminate, leading to noncoverage bias (103). The choice to complete a survey is at the discretion of the respondents, and it is thereby non-random. Further, due to the lack of information on those who opted out of completing the survey, assessing the magnitude of the bias is beyond reach (103). Efforts were made to reduce non-convergence bias through local promotion of the study using non-Internet recruitment methods. However, with predominantly online recruitment, the sample is biased to individuals that have Internet access. This bias may have inflated estimates of Internet information-seeking behaviours and the degree to which information needs are met. Nonresponse bias is also inherent to Internet surveys. To elaborate, individuals who have access to the Internet but are unwilling to participate may be meaningfully different than individuals who have completed the survey. The noncoverage and nonresponse biases limit the generalizability of the findings from this survey-based study. The generalizability is further compromised by the composition of the recruited sample, which was predominantly White women with postsecondary education. Because of the cross-sectional design of survey, it is difficult to make casual inferences from findings (131)—a further limitation of this study. It is possible those of poor HRQoL are frustrated and dissatisfied with their current health state and their unmet information needs may be a proxy of their frustration and dissatisfaction with their current state. Relating to this, the construct validity of whether this survey truly a measure of unmet information needs has not been validated—an area of future research. However, the piloting of this survey among clinicians and patients to reduce measurement error and to improve the face validity of the survey was conducted as a means to mitigate this. Additionally, the survey lacked criteria to validate if respondents were truly diagnosed with yCRC.

Strengths of this study include the involvement of patient engagement groups, patients, and clinicians in the development and piloting of the survey, which improved internal validity. Prior established surveys were adapted to further improve the internal validity of the survey. Specifically, integrating questions from the HINT survey and the EQ-5D-5L were strengths in assessing information-seeking behaviours and HRQoL, respectively. Moreover, the global coverage achieved through the online

promotion of this survey is indeed a strength of this study. Lastly, the broad range of information items and sources inquired in this study allowed for the careful investigation of the set research objectives.

3.5 Conclusions

There are several unmet information needs for those afflicted by yCRC regarding different aspects of selfmanagement. The findings of this study may inform the need for cultivating effective patient-clinician care, communication, and patient education—to address unmet information needs. This study also highlights the need for further examining how unmet information needs arise as well as the predictors and ramifications of unmet needs.

Chapter 4: Conclusion and Integrated Discussion

This thesis contributes to a greater understanding of yCRC by exploring the epidemiology and information needs of patients with this disease. This concluding chapter will discuss the key findings of the thesis, the results from Chapters 2 and 3, the strengths and limitations of the work, and the implications and future directions of this research.

4.1 Key Findings

The objective of **Chapter 2's** systematic review was to confirm whether the incidence of yCRC is increasing globally, estimate the magnitude of this increasing risk, and examine prevalence trends. This systematic review revealed that the risk of yCRC is increasing in North American and Oceanic countries, driven by rising rectal cancers in younger adults over the past two decades. It also highlighted a need for more data on incidence trends of yCRC in less represented countries; there are comparatively fewer studies from Europe, Asia, and Africa than from North America. In particular, there were 25 studies identified from North America, three from Europe, six from Asia, and only one from Africa. Furthermore, this review identified the literature gap of a lack of population-level studies evaluating determinants and trends in the burden of yCRC.

Chapter 3, a descriptive cross-sectional survey study, aimed to determine the unmet information needs of individuals diagnosed with yCRC. A total of 39 information items was assessed, 26 of which were unmet in at least 50% of respondents. A need for more information on self-management and alternative treatments was reported across the yCRC disease continuum. With the majority of respondents seeking information from doctors, possible explanations for unmet needs may be due to deficits in health care systems or difficulties in self-management strategies from disease complexities. A proposed explanatory model was constructed to depict the complex relationship between a yCRC diagnosis, self-management, information needs and information-seeking behaviours. The final explanatory model is illustrated in Figure 7.

Lastly, investigating the associations between significant predictors and information needs revealed that respondents with rectal cancer, advanced stages of yCRC, or greater Internet seeking behaviours were significantly associated with a greater odds of having unmet information needs.

4.2 Integration of the Research

This thesis integrated a systematic review (**Chapter 2**) with a descriptive cross-sectional survey study (**Chapter 3**) to describe the information needs of individuals with yCRC. The results from Chapter 2 underscored the need to conduct the study presented in Chapter 3. This thesis has empirically established a growing risk associated with yCRC: a patient population with substantial unmet information needs.

4.3 Limitations of the Research

The limitations of this collective research affect the conclusions that can be derived. A common recurrence presented in both Chapters 2 and 3 is the preponderance of White ethnicity and English language. Namely, the increasing risk of yCRC was predominantly presented in North American and Oceanic nations, particularly the United States, Australia, and Canada. Among the 40 articles included in the systematic review, 29 articles (73%) were from North American and Oceanic nations—where the White ethnicity is common, and English is the first language. Similarly, 87% of respondents analyzed from the cross-sectional study were from North American and Oceanic nations. This dominance of North American and Oceanic nations in both chapters compromises the generalizability of the conclusions that can be drawn from this thesis work. This compromise also limits the ability to examine social inequalities related to yCRC trends and unmet information needs. In particular, it is possible that certain ethnicities may have certain characteristics (i.e., lifestyle and predisposing genetic factors) that are driving the increasing incidence of yCRC. Furthermore, it is also likely that these ethnicities are less likely to utilize health care services (i.e., cancer screening services) as visible minorities (132). Therefore, understanding the social inequalities and ethnic differences in incidence trends of yCRC is pertinent given the rise in international tourism and its effects on global public health (133).

Cultural and language barriers are also important factors in health care (134). This becomes complex as western medicine has evolved into a subculture itself with a unique language, history and methodology (134). Language is crucial in how patients define, perceive, and react in health care situations (i.e., yCRC diagnosis). This is a key limitation in the systematic review with only English articles being included. In an effort to expand the reach of the survey, the inclusion criteria in the crosssectional study was open to individuals who can complete the survey in English, French, Spanish, or Mandarin. However, the number of respondents that completed the survey in non-English languages was very small (N = 3). As such, a key limitation of this research is the restricted number of languages involved in both the systematic review and cross-sectional survey study—limiting the data collected and the overall findings. However, acknowledgement of such key limitations throughout this thesis can inform the design of future studies.

4.4 Implications and Recommendations

Researching the epidemiology of yCRC can be used to guide and evaluate strategies in the management of the yCRC population. Overall, by synthesizing findings from peer-reviewed, epidemiologic studies, Chapter 2's systematic review provides empirical evidence that confirms the increasing incidence of yCRC, particularly in North American and Oceanic countries, driven by an increase in rectal cancers. Continued efforts for awareness and education to address this increasing risk are warranted. The specific implications and recommendations from the results of this systematic review are discussed.

4.4.1 Systematic Review

The first implication of the included systematic review is that the incidence of yCRC is increasing, predominantly in North America. The first recommendation to address this implication would be to raise awareness of the signs and symptoms of yCRC, asymptomatic yCRC, risk factors of yCRC, and the necessity of periodic screening. This can be achieved by creating and distributing educational resources sourced from research articles and clinicians. Incorporating patient-engagement groups in the development of educational resources would improve the applicability and comprehension of resources to

patients. Highlighting patient experiences and stories may be an effective strategy in educating the population. Lastly, population education can be accomplished through public health interventions distributed through television, brochures, and online platforms.

The second recommendation is to develop initiatives to aid in sensitizing medical practitioners to the signs and symptoms of yCRC in order to improve detection and diagnosis. It has been indicated that yCRC patients are diagnosed with more advanced-stage cancer (10, 11, 29, 35, 36). Two possible explanations for this may be 1) a delay in seeking medical care in young adults and 2) the dismissal of symptoms consistent but nonspecific to yCRC in young adults by clinicians (11). The first recommendation would aid in spreading awareness of yCRC in young adult populations, addressing the former explanation. It is, however, important to spread awareness of the increasing risks and symptoms of yCRC to health care professionals. Providing similar educational resources described in recommendation 1 tailored towards medical practitioners would aid in sensitizing medical practitioners. The last recommendation would be to initiate routine CRC screening starting at younger ages. This practice was suggested by the American Cancer Society in 2018; the recommended age for average-risk adults to initiate screening was lowered from 50 to 45 years (64). Applying the same change in routine CRC screening is recommended for the Canadian health care system, where yCRC is also on the rise (32, 37).

A further implication that can be drawn from the systematic review is the that incidence of rectal cancer is increasing in young adults. As a by-product of this increase, it is recommended to change the current screening guidelines to increase the number of endoscopies performed on patients presenting with symptoms of rectal cancer, such as rectal bleeding (80). Similarly, a flexible sigmoidoscopy would also be suggested in settings where rectal cancer symptoms are presented (80).

4.4.2 Cross-Sectional Survey Study

The urgency to improve the outcomes and supportive care of yCRC has escalated with the established increasing incidence highlighted in this thesis, along with improved survival from advancements in both detection and treatment (19). As more individuals are being diagnosed with yCRC and both the patient

and survivor populations are increasing, assessing their respective information needs is a step towards improving outcomes, such as quality of life.

The main implication of the cross-sectional survey study is that the information needs of individuals with yCRC are largely unmet. Therefore, cultivating effective patient-clinician care and communication could aid in patient education and subsequently in addressing patient information needs. It has been indicated that improvements in patient-clinician care and communication are associated with improved treatment adherence, patient satisfaction, and self-management (135). As suggested throughout this thesis, poor self-management may be a consequence of unmet information needs. Hence, educating patients on effective self-management strategies and providing relevant resources would allow patients to better cope with their disease complexities—potentially reducing unmet information needs. In other words, patient education is crucial to effective self-management and would reduce the potential of unmet information needs.

The analysis of respondents' characteristics suggests that individuals with rectal cancer, advanced-stage cancer, and poor HRQoL are more likely to have unmet information needs. It is recommended to identify and further enhance care and communication for these individuals, as well as provide support for developing effective self-management techniques. It was also indicated that yCRC patients would find an eHealth resource with reliable cancer information useful. As such, developing an eHealth resource that provides reliable and appropriate yCRC information along with a platform for connecting patients and survivors would be helpful. As many patients seek information online, an eHealth resource would also assist in disseminating appropriate information. Lastly, the final implication drawn from the survey study of this thesis is that individuals that regularly use the Internet to find yCRC-related information are more likely to have unmet information needs. Organizing information through an eHealth resource could provide reliable information to patients and also reduce the possibility of patients encountering contradictory or unhelpful information and overconsuming information; therefore, reducing the potential of unmet information needs.

4.5 Future Research Directions

This thesis provides a description of the incidence trends of yCRC and the information needs of individuals diagnosed with this disease. This work has identified several areas for future research. One direction for future research pinpointed by this thesis work is the need to examine reasons for the increasing risk of yCRC and is important to inform prevention efforts. Indeed, among the studies included in the systematic review, only 1 evaluated population-level determinants of yCRC. As such, a direction for future research would be to conduct population-level examinations of the burden of yCRC in terms of trends in prevalence. It is only through population-level examinations of the number of people who have been previously diagnosed with yCRC that can be counted and used to characterize survivors and ultimately inform the long-term impacts of yCRC. Investigating the trends in survival and mortality in yCRC is another area for future research identified in the systematic review. These investigations would inform the contemporary knowledge of this disease. Furthermore, future research should assess the trends of yCRC using the web-based platform by WHO International Agency for Research on Cancer (IARC), which collects and presents data from cancer registries from all over the world. Lastly, there is inconsistency and heterogeneity in reporting trends of yCRC identified through this research. One direction for future research would be to report findings in a manner that facilitates pooling results with other studies. For example, reporting results APC by 5- or 10-year periods would make it amendable to pool results from other studies. Similarly, reporting results according to ethnicities in future studies would allow for examination of trend differences between ethnicities.

Though there are inherent limitations of the descriptive cross-sectional survey, this work lays a path for several directions for future research. For instance, designing a longitudinal study would be valuable in evaluating the casual relationships between predictors and unmet information needs. Investigating the information needs of individuals diagnosed with yCRC via a qualitative study would be beneficial in providing more detail and depth on the experiences of patients and survivors. Conducting a qualitative investigation would also elucidate the levels of communication between yCRC patients and

their health care providers (136). An additional future direction for research would be to ascertain what specific information is readily available, what information is being used, and what information is being directly sought by yCRC patients and survivors. Moreover, determining how health care providers infer and aid in fulfilling the information needs of patients would provide insight into the role of health care in addressing patient information needs. Further, future research could explicitly examine the role of eHealth in supporting individuals diagnosed with yCRC. This eHealth platform would deliver reliable and appropriate yCRC information and connect patients and survivors.

4.6 Conclusion

In this thesis, insight into the epidemiological trends of yCRC and information needs of yCRC patients are presented; several concluding points are emphasized. First, in a systematic review, it was established that the risk of yCRC is increasing, particularly in North American and Oceanic countries, and is driven by rising rectal cancer rates. Second, in a descriptive cross-sectional survey, it was revealed that individuals diagnosed with yCRC have several unmet information needs regarding self-management. It was indicated that having unmet information needs was significantly associated with poor HRQoL. As a collective work, this thesis provided evidence that risk of yCRC is increasing predominantly in North American and Oceanic countries, driven by rising rectal cancers in younger adults over the past two decades. In addition, this thesis reports that the information needs of a sample comprised of mostly of highly-educated White women are substantially unmet, affecting their HRQoL. From my thesis implications, I recommend the implementation of awareness programs for the public, yCRC patients, and clinicians. It is also encouraged to change current screening guidelines for patients presenting with symptoms of rectal cancer. My findings are applicable to clinicians and other health care professionals involved in the care and education of yCRC patients.

References

- 1. Ferlay J, Ervik M, Lam F, Colombet M, Mery L, Piñeros M, et al. Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer 2018. Available from: https://gco.iarc.fr/today.
- 2. Colorectal Cancer Facts & Figures 2011-2013. American Cancer Society; 2011.
- 3. Perez-Palma J M-GJ, Dorta-Espineira M, Lorenzo-Rocha N, Bravo-Gutierrez A, Medina-Arana V. Predictive factors of years of potential life lost by colorectal cancer. Eur J Gastroenterol Hepatol. 2008; 20(8):766-72.
- 4. Mhaidat NM, Al-Wedyan TJ, Alzoubi KH, Al-Efan QM, Al-Azzam SI, Balas QA, et al. Measuring quality of life among colorectal cancer patients in Jordan. J of Palliat Care. 2014; 30(3):133-40.
- 5. Teker F, Demirag G, Erdem D, Kemal Y, Yucel I. Quality of life in colorectal cancer patients during chemotherapy in the era of monoclonal antibody therapies. Journal of BUON. 2015; 20(2):443-51.
- 6. Dunn J, Lynch B, Aitken J, Leggett B, Pakenham K, Newman B. Quality of life and colorectal cancer: A review. Aust N Z J Public Health. 2003; 27(1):41-53.
- 7. Marventano S, Forjaz M, Grosso G, Mistretta A, Giorgianni G, Platania A, et al. Health related quality of life in colorectal cancer patients: state of the art. BMC surg. 2013; 13 Suppl 2:S15.
- 8. Nagler RH, Gray SW, Romantan A, Kelly BJ, DeMichele A, Armstrong K, et al. Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. Patient Educ Couns. 2010; 81 Suppl:S54-62.
- 9. Abdelsattar ZM, Wong SL, Regenbogen SE, Jomaa DM, Hardiman KM, Hendren S. Colorectal cancer outcomes and treatment patterns in patients too young for average-risk screening. Cancer. 2016; 122(6):929-34.
- 10. Siegel RL, Jemal A, Ward EM. Increase in incidence of colorectal cancer among young men and women in the United States. Cancer Epidemiol Biomarkers Prev. 2009; 18(6):1695-8.
- 11. Nancy You Y, Xing Y, Feig BW, Chang GJ, Cormier JN. Young-onset colorectal cancer: Is it time to pay attention?. Arch Inter Med. 2012; 172(3):287-9.
- 12. Bailey CE, Hu CY, You YN, Bednarski BK, Rodriguez-Bigas MA, Skibber JM, et al. Increasing disparities in the age-related incidences of colon and rectal cancers in the United States, 1975-2010. JAMA Surg. 2015; 150(1):17-22.
- 13. Siegel RL, Fedewa SA, Anderson WF, Miller KD, Ma J, Rosenberg PS, et al. Colorectal Cancer Incidence Patterns in the United States, 1974-2013. JNCI. 2017; 109(8).
- 14. Arora NK, Johnson P, Gustafson DH, McTavish F, Hawkins RP, Pingree S. Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. Patient Educ Couns. 2002; 47(1):37-46.
- Miyashita M, Ohno S, Kataoka A, Tokunaga E, Masuda N, Shien T, et al. Unmet Information Needs and Quality of Life in Young Breast Cancer Survivors in Japan. Cancer Nurs. 2015; 38(6):E1-11.
- 16. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, et al. The unmet supportive care needs of patients with cancer. Cancer. 2000; 88(1):225-36.
- Marley AR, Nan H. Epidemiology of colorectal cancer. Int J Mol Epidemiol Genet. 2016; 7(3):105-14.
- 18. Huxley RR, Ansary-Moghaddam A, Clifton P, Czernichow S, Parr CL, Woodward M. The impact of dietary and lifestyle risk factors on risk of colorectal cancer: A quantitative overview of the epidemiological evidence. Int J Cancer. 2009; 125(1):171-80.
- 19. Ahnen DJ, Wade SW, Jones WF, Sifri R, Silveiras JM, Greenamyer J, et al. The increasing incidence of young-onset colorectal cancer: A call to action. Mayo Clin Proc. 2014; 89(2):216-24.

- 20. Peeters KC, van de Velde CJ, Leer JW, Martijn H, Junggeburt JM, Kranenbarg EK, et al. Late side effects of short-course preoperative radiotherapy combined with total mesorectal excision for rectal cancer: increased bowel dysfunction in irradiated patients-a Dutch colorectal cancer group study. J Clin Oncol. 2005; 23(25):6199-206.
- 21. Zheng Z JA, Guy G, Han X, Banegas M, Li C, Ekwueme DU, Yabroff KR. Medical expenditures and productivity loss among colorectal, breast, and prostate cancer survivors in the US. Asian Pac J Cancer Prev. 2015; 15(Supp15).
- 22. Cotrim H PG. Impact of colorectal cancer on patient and family: implications for care. Eur J Oncol Nurs. 2008; 12(3):217-26.
- 23. Carli F, Charlebois P, Stein B, Feldman L, Zavorsky G, Kim DJ, et al. Randomized clinical trial of prehabilitation in colorectal surgery. BJS. 2010; 97(8):1187-97.
- 24. Mayo NE, Feldman L, Scott S, Zavorsky G, Kim DJ, Charlebois P, et al. Impact of preoperative change in physical function on postoperative recovery: argument supporting prehabilitation for colorectal surgery. Surg. 2011; 150(3):505-14.
- 25. Dunn J, Ng SK, Breitbart W, Aitken J, Youl P, Baade PD, et al. Health-related quality of life and life satisfaction in colorectal cancer survivors: trajectories of adjustment. Health Qual Life Outcomes. 2013; 11:46.
- 26. Hawkes AL, Pakenham KI, Chambers SK, Patrao TA, Courneya KS. Effects of a multiple health behavior change intervention for colorectal cancer survivors on psychosocial outcomes and quality of life: a randomized controlled trial. Ann Behav Med. 2014; 48(3):359-70.
- 27. Care CTFoPH. Recommendations on screening for colorectal cancer in primary care. CMAJ. 2016; 188(5):340-8.
- 28. Ebell MH, Thai TN, Royalty KJ. Cancer screening recommendations: An international comparison of high income countries. PHR. 2018; 39(1).
- 29. Edwards BK, Ward E, Kohler BA, Eheman C, Zauber AG, Anderson RN, et al. Annual report to the nation on the status of cancer, 1975-2006, featuring colorectal cancer trends and impact of interventions (risk factors, screening, and treatment) to reduce future rates. Cancer. 2010; 116(3):544-73.
- 30. Cress RD, Morris C, Ellison GL, Goodman MT. Secular changes in colorectal cancer incidence by subsite, stage at diagnosis, and race/ethnicity, 1992-2001. Cancer. 2006; 107(5 Suppl):1142-52.
- 31. Merrill RM, Anderson AE. Risk-adjusted colon and rectal cancer incidence rates in the United States. Dis Colon Rectum. 2011; 54(10):1301-6.
- 32. Patel P, De P. Trends in colorectal cancer incidence and related lifestyle risk factors in 15-49year-olds in Canada, 1969-2010. Cancer Epidemiol. 2016; 42:90-100.
- 33. Siegel R, Desantis C, Jemal A. Colorectal cancer statistics, 2014. CA Cancer J Clin. 2014; 64(2):104-17.
- 34. Troeung L, Sodhi-Berry N, Martini A, Malacova E, Ee H, O'Leary P, et al. Increasing Incidence of Colorectal Cancer in Adolescents and Young Adults Aged 15-39 Years in Western Australia 1982-2007: Examination of Colonoscopy History. Frontiers in Public Health. 2017; 5:179.
- 35. Bailey CE, Hu CY, You YN, Bednarski BK, Rodriguez-Bigas MA, Skibber JM, et al. Increasing disparities in the age-related incidences of colon and rectal cancers in the United States, 1975-2010. Erratum appears in JAMA Surg. 2015 Mar 1;150(3):277; PMID: 25785512. JAMA surgery. 2015; 150(1):17-22.
- 36. Boyce S, Nassar N, Lee CY, Suen MK, Al Zahrani S, Gladman MA. Young-onset colorectal cancer in New South Wales: a population-based study. Erratum appears in Med J Aust. 2016 Dec 12;205(11):508; PMID: 27927159. Med J Aust. 2016; 205(10):465-70.
- 37. Marrett LD, Frood J, Nishri D, Ugnat AM, Cancer in Young Adults in Canada Working G. Cancer incidence in young adults in Canada: preliminary results of a cancer surveillance project. Chron Dis Canada. 2002; 23(2):58-64.

- 38. Park HS, Lloyd S, Decker RH, Wilson LD, Yu JB. Overview of the Surveillance, Epidemiology, and End Results Database: Evolution, Data Variables, and Quality Assurance. Curr Prob Cancer. 2012; 36(4):183-90.
- 39. Hogan TP, Palmer CL. Information preferences and practices among people living with HIV/AIDS: Results from a nationwide survey. J Med Libr Assoc. 2005; 93(4):431-9.
- 40. Case D. Looking for Information: A Survey of Research on Information Seeking, Needs, and Behavior. Boyce BR, editor. London: Elsevier; 2007.
- 41. Nicholas D. Assessing Information Needs: tools, techniques and concepts for the Internet age. Webb S, editor: Aslib; 2005.
- 42. Belkin NJ, A.Vickery. Interaction in information systems.: British Library; 1989. Chapter 2 p.
- 43. Brashers D, Goldsmith D, Hsieh E. Information Seeking and Avoiding in Health Contexts. Human Communic Res. 2006; 28(2):258–71.
- 44. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). Patient Educ Couns. 2005; 57(3):250-61.
- 45. Hogbin B, Fallowfield L. Getting it taped: the 'bad news' consultation with cancer patients. Br J Hosp Med. 1989;41(4):330-3.
- 46. Lorig KR, Sobel DS, Stewart AL, Brown BW, Jr., Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care. 1999; 37(1):5-14.
- 47. van Mossel C, Leitz L, Scott S, Daudt H, Dennis D, Watson H, et al. Information needs across the colorectal cancer care continuum: scoping the literature. Eur J Cancer Care. 2011; 21(3):296-320.
- 48. Street Jr RL. Information-giving in medical consultations: The influence of patients' communicative styles and personal characteristics. Soc Sci Med. 1991; 32(5):541-8.
- 49. Zebrack B. Information and service needs for young adult cancer survivors. Support Care Cancer. 2009; 17(4):349-57.
- 50. Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. Med Pediatr Oncol. 2008; 38(1):1-10.
- 51. Bolte S, Zebrack B. Sexual issues in special populations: adolescents and young adults. Semin Oncol Nurs. 2002; 24(2):115-9.
- 52. Dunn J, Steginga SK. Young women's experience of breast cancer: defining young and identifying concerns. Psychooncology. 2000; 9(2):137-46.
- 53. Evan EE, Kaufman M, Cook AB, Zeltzer LK. Sexual health and self-esteem in adolescents and young adults with cancer. Cancer. 2006; 107(7 Suppl):1672-9.
- 54. Evan EE, Zeltzer LK. Psychosocial dimensions of cancer in adolescents and young adults. Cancer. 2006; 107(7 Suppl):1663-71.
- 55. MacLure K, Paudyal V, Stewart D. Reviewing the literature, how systematic is systematic?. Int J Clin Pharm. 2016; 38(3):685-94.
- 56. Aran V, Victorino AP, Thuler LC, Ferreira CG. Colorectal Cancer: Epidemiology, Disease Mechanisms and Interventions to Reduce Onset and Mortality. Clin Colorectal Cancer. 2016; 15(3):195-203.
- 57. Perez-Palma J, Marchena-Gomez J, Dorta-Espineira M, Lorenzo-Rocha N, Bravo-Gutierrez A, Medina-Arana V. Predictive factors of years of potential life lost by colorectal cancer. Eur J Gastroenterol Hepatol. 2008; 20(8):766-72.
- 58. Zheng Z, Jemal A, Guy G, Han X, Banegas M, Li C, et al. Medical expenditures and productivity loss among colorectal, breast, and prostate cancer survivors in the US. J Clin Oncol. 2015; 108(5).
- 59. Cotrim H, Pereira G. Impact of colorectal cancer on patient and family: implications for care. Eur J Oncol Nurs. 2008; 12(3):217-26.

- 60. Bao PP, Zheng Y, Wu CX, Huang ZZ, Gao YT, Jin F, et al. Cancer incidence in urban Shanghai, 1973-2010: an updated trend and age-period-cohort effects. BMC Cancer. 2016; 16:284.
- 61. Siegel RL, Miller KD, Fedewa SA, Ahnen DJ, Meester RGS, Barzi A, et al. Colorectal cancer statistics, 2017. CA Cancer J Clin. 2017; 67(3):177-93.
- 62. Major D, Bryant H, Delaney M, Fekete S, Gentile L, Harrison M, et al. Colorectal cancer screening in Canada: results from the first round of screening for five provincial programs. Curr Oncol. 2013; 20(5):252-7.
- 63. Saengow U, Chongsuwiwatvong V, Geater A, Birch S. Preferences and acceptance of colorectal cancer screening in Thailand. Asian Pac J Cancer Prev. 2015; 16(6):2269-76.
- 64. Wolf AMD, Fontham ETH, Church TR, Flowers CR, Guerra CE, LaMonte SJ, et al. Colorectal cancer screening for average-risk adults: 2018 guideline update from the American Cancer Society. CA Cancer J Clin. 2018.
- 65. Stahlman S, Oetting A. Age period cohort analysis of CRC service members aged 20-59 years U.S. Armed Forces 1997. MSMR. 2017; 24(7): 12-19.
- 66. Zhou Q, Li K, Lin GZ, Shen JC, Dong H, Gu YT, et al. Incidence trends and age distribution of colorectal cancer by subsite in Guangzhou, 2000-2011. Chin J Cancer. 2015; 34(8):358-64.
- 67. Munn Z, Moola S, Riitano D, Lisy K. The development of a critical appraisal tool for use in systematic reviews addressing questions of prevalence. Int J Health Policy Manag. 2014 ;3(3):123-8.
- 68. Downes MJ, Brennan ML, Williams HC, Dean RS. Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). BMJ Open. 2016; 6(12):e011458.
- 69. Zaridze DG, Filipchenko VV. Incidence of colo-rectal cancer in Moscow. Int J Cancer. 1990; 45(3):583-5.
- 70. Chow WH, Devesa SS, Blot WJ. Colon cancer incidence: recent trends in the United States. Cancer Causes Control. 1991; 2(6):419-25.
- 71. Polednak AP. Trends in cancer incidence in Connecticut, 1935-1991. Cancer. 1994; 74(10):2863-72.
- 72. Zhang B, Xie SH, Yu IT. Differential incidence trends of colon and rectal cancers in Hong Kong: an age-period-cohort analysis. Cancer Communications. 2018; 38(1):42.
- 73. Ullah MF, Fleming CA, Mealy K. Changing trends in age and stage of colorectal cancer presentation in Ireland From the nineties to noughties and beyond. Surgeon Journal of the Royal Colleges of Surgeons of Edinburgh & Ireland. 2018; 16(6):350-4.
- 74. Jacobs D, Zhu R, Luo J, Grisotti G, Heller DR, Kurbatov V, et al. Defining Early-Onset Colon and Rectal Cancers. Frontiers in Oncology. 2018; 8:504.
- 75. Garcia S, Pruitt SL, Singal AG, Murphy CC. Colorectal cancer incidence among Hispanics and non-Hispanic Whites in the United States. Cancer Causes Control. 2018; 29(11):1039-46.
- 76. Ellis L, Abrahao R, McKinley M, Yang J, Somsouk M, Marchand LL, et al. Colorectal Cancer Incidence Trends by Age, Stage, and Racial/Ethnic Group in California, 1990-2014. Cancer Epidemiol Biomarkers Prev. 2018; 27(9):1011-8.
- 77. Crosbie AB, Roche LM, Johnson LM, Pawlish KS, Paddock LE, Stroup AM. Trends in colorectal cancer incidence among younger adults-Disparities by age, sex, race, ethnicity, and subsite. Cancer Med. 2018; 7(8):4077-86.
- 78. Ansa BE, Coughlin SS, Alema-Mensah E, Smith SA. Evaluation of Colorectal Cancer Incidence Trends in the United States (2000-2014). J Clin Med. 2018; 7(2):30.
- 79. Haggar FA, Preen DB, Pereira G, Holman CD, Einarsdottir K. Cancer incidence and mortality trends in Australian adolescents and young adults, 1982-2007. BMC Cancer. 2012; 12:151.
- 80. Meyer JE, Narang T, Schnoll-Sussman FH, Pochapin MB, Christos PJ, Sherr DL. Increasing incidence of rectal cancer in patients aged younger than 40 years: an analysis of the surveillance, epidemiology, and end results database. Cancer. 2010; 116(18):4354-9.

- Hamdi Cherif M, Serraino D, Mahnane A, Laouamri S, Zaidi Z, Boukharouba H, et al. Time trends of cancer incidence in Setif, Algeria, 1986-2010: an observational study. BMC Cancer. 2014; 14:637.
- 82. Larsen IK, Bray F. Trends in colorectal cancer incidence in Norway 1962-2006: an interpretation of the temporal patterns by anatomic subsite. Int J Cancer. 2010; 126(3):721-32.
- 83. Gandhi J, Davidson C, Hall C, Pearson J, Eglinton T, Wakeman C, et al. Population-based study demonstrating an increase in colorectal cancer in young patients. BJS. 2017;104(8):1063-8.
- 84. Giddings BH, Kwong SL, Parikh-Patel A, Bates JH, Snipes KP. Going against the tide: Increasing incidence of colorectal cancer among Koreans, Filipinos, and South Asians in California, 1988-2007. Cancer Causes Control. 2012;23(5):691-702.
- Wu QJ, Vogtmann E, Zhang W, Xie L, Yang WS, Tan YT, et al. Cancer incidence among adolescents and young adults in urban Shanghai, 1973-2005. PLoS ONE [Electronic Resource]. 2012;7(8):e42607.
- 86. Wang DY, Thrift AP, Zarrin-Khameh N, Wichmann A, Armstrong GN, Thompson PA, et al. Rising Incidence of Colorectal Cancer Among Young Hispanics in Texas. Journal of Clinical Gastroenterology. 2017;51(1):34-42.
- 87. Austin H, Henley SJ, King J, Richardson LC, Eheman C. Changes in colorectal cancer incidence rates in young and older adults in the United States: what does it tell us about screening. Cancer Causes Control. 2014;25(2):191-201.
- 88. Nakagawa H, Ito H, Hosono S, Oze I, Mikami H, Hattori M, et al. Changes in trends in colorectal cancer incidence rate by anatomic site between 1978 and 2004 in Japan. Eur J Cancer Prev. 2017 ;26(4):269-76.
- 89. Siegel RL, Miller KD, Jemal A. Colorectal Cancer Mortality Rates in Adults Aged 20 to 54 Years in the United States, 1970-2014. JAMA. 2017;318(6):572-4.
- 90. Nooyi SC, Murthy NS, Shivananjaiah S, Sreekantaiah P, Mathew A. Trends in rectal cancer incidence--Indian scenario. Asian Pac J Cancer Prev. 2011;12(8):2001-6.
- 91. Rahman R, Schmaltz C, Jackson CS, Simoes EJ, Jackson-Thompson J, Ibdah JA. Increased risk for colorectal cancer under age 50 in racial and ethnic minorities living in the United States. Cancer Med. 2015;4(12):1863-70.
- 92. Sarakarn P, Suwanrungruang K, Vatanasapt P, Wiangnon S, Promthet S, Jenwitheesuk K, et al. Joinpoint Analysis Trends in the Incidence of Colorectal Cancer in Khon Kaen, Thailand (1989 2012). Asian Pac J Cancer Prev. 2017;18(4):1039-43.
- Sheneman DW, Finch JL, Messersmith WA, Leong S, Goodman KA, Davis SL, et al. The impact of young adult colorectal cancer: Incidence and trends in Colorado. Colorectal Cancer. 2017;6(2):49-56.
- 94. Singh KE, Taylor TH, Pan CG, Stamos MJ, Zell JA. Colorectal Cancer Incidence Among Young Adults in California. J Adolesc Young Adult Oncol. 2014;3(4):176-84.
- 95. Koblinski J, Jandova J, Nfonsam V. Disparities in incidence of early- and late-onset colorectal cancer between Hispanics and Whites: A 10-year SEER database study. Am J Surg. 2017:31.
- 96. Ellison LF, Wilkins K. Canadian trends in cancer prevalence. Health Reports Statistics Canada. 2012;23(1):Catalogue no. 82-003-XPE.
- 97. Aran V, Victorino AP, Thuler LC, Ferreira CG. Colorectal Cancer: Epidemiology, Disease Mechanisms and Interventions to Reduce Onset and Mortality. Clin Colorectal Cancer. 2016;15(3):195-203.
- 98. Ahnen DJ, Wade SW, Jones WF, Sifri R, Mendoza Silveiras J, Greenamyer J, et al. The increasing incidence of young-onset colorectal cancer: a call to action. Mayo Clin Proc. 2014;89(2):216-24.
- 99. Campos FG. Colorectal cancer in young adults: A Difficult challenge. World J Gastroenterol. 2017;23(28):5041-4.

- 100. O'Connell JB, Maggard MA, Livingston EH, Yo CK. Colorectal cancer in the young. Am J Surg. 2004;187(3):343-8.
- Bleyer A. Caution! Consider cancer: common symptoms and signs for early detection of cancer in young adults. Semin Oncol. 2009 ;36(3):207-12.
- 102. Ose D, Winkler EC, Berger S, Baudendistel I, Kamradt M, Eckrich F, et al. Complexity of care and strategies of self-management in patients with colorectal cancer. Patient Prefer Adherence. 2017;11:731-42.
- 103. Fricker. Sampling Methods for Web and E-mail Surveys. Hughes, editor. London: SAGE; 2012.
- 104. Qualtrics: UBC Survey Tool University of British Columbia: UBC; 2019 [Available from: https://it.ubc.ca/services/teaching-learning-tools/survey-tool.
- 105. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, et al. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: TheCaSUN (Cancer Survivors' Unmet Needs measure). Psychooncology. 2007;16(9):796-804.
- 106. Qualtrics. Survey Translate 2019 [Available from: https://www.qualtrics.com/support/survey-platform/survey-module/survey-tools/translate-survey/.
- 107. #Never2Young Leading change for younger bowel cancer patients. Bowel Cancer UK; 2015.
- 108. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res. 2011;20(10):1727-36.
- 109. Williams A. EuroQol A new facility for the measurement of health-related quality of life. Health Policy. 1990;16(3):199-208.
- 110. Brooks R, De Charro F. EuroQol: The current state of play. Health Policy. 1996;37(1):53-72.
- 111. Koch-Weser S, Bradshaw YS, Gualtieri L, Gallagher SS. The Internet as a health information source: findings from the 2007 Health Information National Trends Survey and implications for health communication. J Health Commun. 2010;15 Suppl 3:279-93.
- 112. Xie F, Pullenayegum E, Gaebel K, Bansback N, Bryan S, Ohinmaa A, et al. A Time Trade-offderived Value Set of the EQ-5D-5L for Canada. Medical Care. 2016;54(1):98-105.
- 113. Vu JV, Matusko N, Hendren S, Regenbogen SE, Hardiman KM. Patient-Reported Unmet Needs in Colorectal Cancer Survivors After Treatment for Curative Intent. Dis Colon Rectum. 2019.
- 114. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of selfmanagement in chronic illness. J Nurs Scholarsh. 2012;44(2):136-44.
- 115. Lee SY, Hawkins R. Why do patients seek an alternative channel? The effects of unmet needs on patients' health-related Internet use. J Health Commun. 2010;15(2):152-66.
- 116. Freimuth VS. The chronically uninformed: Closing the knowledge gap in health. Communication and health: Systems and applications. Communication textbook series. Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc; 1990. p. 171-86.
- 117. Street RL. Communication in medical consultations: A review essay. Q J Speech. 1990;76(3):315-32.
- 118. Young Onset Colorectal Cancer Survey Report. Washington, DC: Colorectal Cancer Alliance; 2017.
- 119. Regitz-Zagrosek V. Therapeutic implications of the gender-specific aspects of cardiovascular disease. Nat Rev Drug Discov. 2006;5(5):425-39.
- 120. Regitz-Zagrosek V, Petrov G, Lehmkuhl E, Smits JM, Babitsch B, Brunhuber C, et al. Heart transplantation in women with dilated cardiomyopathy. Transplant. 2010;89(2):236-44.
- 121. Regitz-Zagrosek V. Sex and gender differences in health. Science & Society Series on Sex and Science. EMBO Reports. 2012;13(7):596-603.
- 122. Van Cutsem E, Cervantes A, Adam R, Sobrero A, Van Krieken JH, Aderka D, et al. ESMO consensus guidelines for the management of patients with metastatic colorectal cancer. Ann of Oncol. 2016;27(8):1386-422.

- 123. Zimmerman B, Woolf S, Haley A. Understanding the Relationship Between Education and Health: A Review of the Evidence and an Examination of Community Perspectives Agency for Healthcare Research and Quality; 2015. Available from: http://www.ahrq.gov/professionals/education/curriculum-tools/populationhealth/zimmerman.html.
- 124. Burg JAR, Allred SL, Sapp IJH. The potential for bias due to attrition in the National Exposure Registry: An examination of reasons for nonresponse, nonrespondent characteristics, and the response rate. Toxicol Ind Health. 1997;13(1):1-13.
- 125. Cameron Wild T, Cunningham J, Adlaf E. Nonresponse in a follow-up to a representative telephone survey of adult drinkers. J Stud Alcohol Drugs. 2001;62(2):257-61.
- 126. Dunn KM, Jordan K, Lacey RJ, Shapley M, Jinks C. Patterns of consent in epidemiologic research: evidence from over 25,000 responders. Am J Epidemiol. 2004;159(11):1087-94.
- 127. Eagan TML, Eide GE, Gulsvik A, Bakke PS. Nonresponse in a community cohort study -Predictors and consequences for exposure-disease associations. J Clin Epidemiol. 2002;55(8):775-81.
- 128. Galea S, Tracy M. Participation Rates in Epidemiologic Studies. Ann Epidemiol. 2007;17(9):643-53.
- 129. Hille ET, Elbertse L, Gravenhorst JB, Brand R, Verloove-Vanhorick SP. Nonresponse bias in a follow-up study of 19-year-old adolescents born as preterm infants. Pediatr. 2005;116(5):e662-6.
- 130. #Never2Young Leading change for younger bowel cancer patients. 2015.
- 131. Levin KA. Study design III: Cross-sectional studies. Evid Based Dent. 2006;7(1):24-5.
- 132. Quan H, Fong A, De Coster C, Wang J, Musto R, Noseworthy TW, et al. Variation in health services utilization among ethnic populations. CMAJ. 2006;174(6):787-91.
- 133. Richter LK. International Tourism and its Global Public Health Consequences. 2003;41(4):340-7.
- 134. Putsch R, Joyce M. Dealing with Patients from Other Cultures. 3rd edition ed. Walker H, Hall W, Hurst J, editors. Boston: Butterworths1990.
- 135. Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patientcentered care. Health Affairs. 2010;29(7):1310-8.
- 136. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care B. What are the results and how do they help me care for my patients? Evidence-Based Medicine Working Group. JAMA.284(4):478-82.

Appendix

#	Searches	Results
1	exp Colorectal Neoplasms/	222458
2	colon tumor/ or rectum tumor/ or colorectal tumor/	134997
3	("adenomatous polyposis coli" or "adenomatous polyposis colus" or "familial polyposis syndrome*" or "familial adenomatous polyposis coli" or "adenomatous polyposis of the colon" or "familial adenomatous polypos*" or "familial polyposis coli" or "familial adenomatous polyposis of the colon" or "familial multiple polypos*" or "familial polyposis of the colon" or "herary polyposis coli" or "herary polyposis colus" or "familial multiple polypos*" or "familial multiple polyposis syndrome*" or "familial polyposis syndrome*" or "myh associated polypos*" or "polyposis coli" or "polyposis colus" or "familial polyposis colus" or "familial intestinal polypos*" or "adenomatous intestinal polypos*").ti,ab.	17139
4	("Gardner syndrome*" or "Gardner's syndrome*" or "Gardners syndrome*").ti,ab.	2264
5	("Lynch cancer family syndrome 2" or "Lynch cancer family syndrome II" or "Lynch syndrome*").ti,ab.	6712
6	((colorectal or colon or sigmoid or rectal or rectum or anus or anal or perianal or circumanal or rectosigmoid) adj4 (neoplasm* or carcinoma* or cancer* or tumor* or tumour*)).ti,ab.	449975
7	CRC.ti,ab.	62271
8	or/1-7 [CRC]	544262
9	("young onset" or "early onset" or AYA or "young age" or "younger age" or "early age").ti,ab.	201499

10	(adolescen* or youth* or teen* or "young adult*" or "under 50" or "under the age of 50" or "younger than 50" or "49 and younger" or "15-49 year" or "under 40" or "under the age of 40" or "younger than 40" or "under 30" or "under the age of 30" or "younger than 30" or "under 20" or "under the age of 20" or "younger than 20" or "young patient*" or "younger patient*").ti,ab.	962686
11	9 or 10 [UNDER 50]	1138392
12	yCRC.ti,ab.	9
13	(8 and 11) or 12 [YOUNG ONSET CRC (focussed)]	10360
14	Incidence/ or cancer incidence/ or incidence*.ti,ab.	1861525
15	Prevalence/ or prevalence*.ti,ab.	1503427
16	Epidemiology/ or Epidemiology.fs. or "cancer epidemiology"/ or epidemiolog*.ti,ab.	3177339
17	or/14-16 [INCID/PREVAL/EPIDEM]	5195949
18	13 and 17 [YOUNG ONSET CRC (focussed) + INCID/PREVAL/EPIDEM]	4093
19	(English or French or German or Spanish).lg.	5626966 6
20	18 and 19 [YOUNG ONSET CRC (focussed) + INCID/PREVAL/EPIDEM with limits]	3926
21	(Animals/ or Animal Experimentation/ or "Models, Animal"/ or (animal* or nonhuman* or non human* or rat or rats or mouse or mice or rabbit or rabbit or pig or pigs or porcine or dog or dogs or hamster or hamsters or fish or chicken or chickens or sheep or cat or cats or raccoon or raccoons or rodent* or horse or horses or racehorse or racehorses or beagle*).ti,ab.) not (Humans/ or (human* or participant* or patient or patients or child* or seniors or adult or adults).ti,ab.)	8467912
22	(editorial or comment or letter or newspaper article).pt.	3301205
----	---	---------------------------
23	(conference or conference abstract or congresses).pt.	3688549
24	20 not (21 or 22 or 23) Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> EBM Reviews - Cochrane Database of Systematic Reviews <2005 to January 10, 2018> Embase <1974 to 2018 January 16>	3077 1718 0 1359
25	remove duplicates from 24 Embase <1974 to 2018 January 16> Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> EBM Reviews - Cochrane Database of Systematic Reviews <2005 to January 10, 2018>	1813 325 1488 0
26	Adolescent/ or Young Adult/	393686
27	Age Factors/	851900
28	8 and (26 or 27) [CRC AND (YOUNG OR AGE FACTORS)]	27142
29	28 and 17 [CRC AND (YOUNG OR AGE FACTORS) + INCID/PREVAL/EPIDEM]	9934
30	29 and 19 [CRC AND (YOUNG OR AGE FACTORS) + INCID/PREVAL/EPIDEM with limits] Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Embase <1974 to 2018 January 16>	9342 6178 3164
31	30 not (21 or 22 or 23) Embase <1974 to 2018 January 16> Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>	8945 2854 6091
32	from 31 keep 1-6000	6000

33	from 31 keep 6001-8945	2945
34	remove duplicates from 32	4664
35	remove duplicates from 33	2945
36	34 or 35 Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Embase <1974 to 2018 January 16>	7609 5543 2066
37	24 or 31 [(yCRC OR GENERAL CRC) + INCID/PREVAL/EPIDEM with limits] Embase <1974 to 2018 January 16> Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>	10796 3812 6984
38	37 not 24 [GENERAL CRC NOT FOCUSSED yCRC] Embase <1974 to 2018 January 16> Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>	7719 2453 5266
39	from 38 keep 1-6000	6000
40	from 38 keep 6001-7719	1719
41	remove duplicates from 39	4587
42	remove duplicates from 40	1719
43	41 or 42 Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non- Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Embase <1974 to 2018 January 16>	6306 4678 1628

Item	Yes (=1)	No (=0)	Unclear (=0)	NA (=0)
Introduction (1 item)				
1. Were the aims/objectives of the study clear?*				
Methods (14 items)				
2. Was the study design appropriate for the stated aim(s)?*				
3. Is the sample size adequate? [§]				
4. Were the study subjects and setting described in detail? [§]				
5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?*				
6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?*				
7. Were objective, standard criteria used for the measurement of the condition?§				
8. Was the condition measured reliably? [§]				
9. Were the risk factor and outcome variables measured appropriate to the aims of the study? [*]				
10. Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialed, piloted or published previously?*				
11. Was the data analysis conducted with sufficient coverage of the identified sample? [§]				
12. Was there appropriate statistical analysis? [§]				
13. Is it clear what was used to determined statistical significance and/or precision estimates? (eg, p values, CIs)?*				
14. Were the methods (including statistical methods) sufficiently described to enable them to be repeated? [*]				
15. Are all important confounding factors/subgroups/differences identified and accounted for? $\ensuremath{\$}$				
Results (3 items)				

16. Were the basic data adequately described?*

17. Were the results internally consistent?*

18. Are the estimates of prevalence or incidence given with confidence intervals and in detail by subgroup, if appropriate?*

Discussion (2 items)

19. Were the authors' discussions and conclusions justified by the results?*

20. Were the limitations of the study discussed?^{*}

Total score

[§]Item from the Joanna Briggs Institute Prevalence Critical Appraisal Tool; *Item from the AXIS tool

Reported incidence rates (per 100,000) for yCRC overall and according to sex

Study	Date Range	Overall	Women	Men
Studies reportin	g overall			
Meyer 2010	1973- 2005	CC: 1.11 RC: 0.42	-	-
Boyce 2016	2001 to 2008	CRC: 11.8	-	-
Siegel 2017	2004- 2013	CRC: 7.2	-	-
Ansa, 2018	2000- 2014	CRC <40y: 2.3 (2.3, 2.4) CRC 40-49y: 22.5 (22.1, 22.8)	-	-
Garcia, 2018	2001- 2014	CRC: 12.2	-	-
Ullah, 2018	1994- 2012	CRC 20-29y: 0.0291 CRC 30-39y: 0.0634 CRC 40-49y: 0.2066	-	-
Studies reporting	according t	to sex		
Zaridze, 1990	1971 to 1987	-	CC <29 y: 0.2 CC 30-39y: 2.8 CC 40-49 y: 9.5 RC <29 y: 0.1 RC 30-39y: 0.8 RC 40-49 y: 8.0	CC <29 y: 0.2 CC 30-39y: 1.9 CC 40-49 y: 8.2 RC <29 y: 0.1 RC 30-39y: 1.3 RC 40-49 y: 7.5
Chow 1991	1976- 1987	-	CC White: 4.2 CC Black: 6.3	CC White: 4.7 CC Black: 7.2
Polednak, 1994	1965- 1991	-	CRC: 4.2	CRC: 3.4
Giddings, 2012	1998- 2007	-	CRC Chinese: 4.3 CRC Japanese: 4.4 CRC Filipino: 4.5 CRC Korean: 5.3 CRC South Asian: 3.8 CRC Vietnamese: 6.0	CRC Chinese: 4.3 CRC Japanese: 6.0 CRC Filipino: 5.1 CRC Korean: 9.7 CRC South Asian: 4.2 CRC Vietnamese: 6.8

among included studies

Wu 2012	1973 to 2005	-	CRC: 5.5	CRC: 6.2
Gandhi 2017	1975 to 2012	-	proximal CC: 1.9 distal CC: 2.1 RC: 2.3	proximal CC: 1.3 distal CC: 1.8 RC: 2.9
Ellis, 2018	, 2018 2010- 2014 -		CRC Chinese: 3.3 (2.5, 4.3) CRC Japanese: 4.7 (2.9, 7.3) CRC Filipino: 2.8 (2.1, 3.8) CRC Korean: 2.7 (1.6, 4.4) CRC South Asian: 2.6 (1.5, 4.1) CRC Vietnamese: 3.6 (2.3, 5.2) CRC SEast Asian: 1.7 (0.6, 3.9) CRC White: 4.0 (3.6, 4.3) CRC Black: 3.9 (3.1, 4.8) CRC Hispanic: 3.0 (2.7, 3.3)	CRC Chinese: 3.2 (2.4, 4.4) CRC Japanese: 5.0 (2.8, 8.2) CRC Filipino: 3.6 (2.7, 4.8) CRC Korean: 4.7 (3.0, 7.0) CRC South Asian: 2.4 (1.4, 3.7) CRC Vietnamese: 4.0 (2.7, 5.8) CRC SEast Asian: 3.7 (1.7, 6.9) CRC White: 3.8 (3.5, 4.1) CRC Black: 4.0 (3.2, 4.8) CRC Hispanic: 2.8 (2.5, 3.0)
Studies reporting	overall and	according to sex		
Cress, 2006	1992- 2001	CRC: 5.5*	CRC: 5.1	CRC: 5.9
Wang 2017	1995- 2010	CRC 20-39y: 3.7 CRC 40-49y: 20.0	CRC 20-39: 3.7 CRC 40-49y: 17.1	CRC 20-39: 3.8 CRC 40-49y: 22.9
Troeung 2017	1982 to 2007	CRC: 4.8	CRC: 4.7	CRC: 4.8
Crosbie, 2018	1992- 2014	CRC: 9.6 (9.5, 9.8)	CRC: 8.9 (8.7, 9.1)	CRC: 10.3 (10.1, 10.5)

Where incidence rates were reported for more than one time period, I tabulated those for the most recent; p-values corresponding to incidence rates tabulated as reported;

*- obtained from authors after contacting them; Abbreviations: CRC – colorectal cancer; RC – rectal cancer; CC – colon cancer;

CONNECT survey

Qualtrics Survey Software



Invitation to participate in a research study on colorectal cancer

We invite you to participate in a study to better understand the information needs of **colorectal cancer** (colon cancer, rectal cancer, or cancer at both sites) patients and survivors. This involves completing an online survey asking questions about information needed over the course of the disease, during treatment, and into survivorship. This survey will also assess the potential role of a future eHealth resource (eHealth is the use of information and communication technologies for health) tailored for colorectal cancer patients and survivors. Results will be used to inform doctors, other medical health professionals, and researchers about how to best support the information needs of colorectal cancer patients and survivors. The survey should take approximately 20 minutes to complete.

Your rights

6/3/2019

Your participation in this study is voluntary. You may choose to withdraw at any time and you do not have to provide any reasons for your decision.

Protecting your confidentiality

The survey is hosted on Qualtrics, a Canadian survey platform, which fully complies with the British Columbia Freedom of Information and Protection of Privacy Act. Your confidentiality will be respected. No information that discloses your identity will be collected in the survey. Survey responses will be stored on a secure server at the University of British Columbia.

Honorarium

There is no remuneration or compensation for completing this survey. However, you may opt to be entered in a raffle for a draw for 1 of 2 iPads.

Potential risks

There are no known risks associated with this study as it only involves the completion of one survey. **Contact for information about the study**

If you have questions or need more information about this study, you may contact Khalid Saad El Din.

Contact for concerns about the rights of research subjects

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC

https://ubc.cal.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

Qualtrics Survey Software

Office of Research Ethics.

Consent

If you understand what is involved and wish to participate in this study, please click **Yes** below then click **Next** to proceed to the survey. By completing the survey, you are consenting to participate in this study.

If you do not wish to participate, please close your browser.

O Yes

Country

In which country do you currently reside?

Å.

In which state do you currently reside?

\$

In which province do you currently reside?

*

Section 1. About you and your experiences with colorectal cancer

For the purpose of this study, colorectal cancer will refer to colon cancer, rectal cancer or colon and rectal cancer.

1. What is your gender?

O Male

- O Female
- O Other
- O Prefer not to answer

2. What age are you now?

O Under 19

O 20-29

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

- O 30-39
- O 40-49
- O 50-59
- O 60-69
- O 70-79
- O 80 and over
- O Prefer not to answer

3. What type of cancer where you diagnosed with?

- O Colon
- O Rectal
- O Both sites
- O Prefer not to answer

4. How old were you when you were first diagnosed with colorectal cancer?

Qualtrics Survey Software

- O Under 19
- O 20-29
- O 30-39
- O 40-49
- O 50-59
- O 60-69
- O 70-79
- O 80 and over
- O Prefer not to answer

5. What stage of colorectal cancer were you diagnosed with?

- O Stage 0
- O Stage I
- O Stage II
- O Stage III
- O Stage IV
- O Do not know
- O Prefer not to answer

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6. We want to know about your information needs about colorectal cancer. For each specific need listed below, please indicate the degree to which it has been met.

	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) Information about the location of the cancer	0	0	0	0	0	0
b) Information about cancer stage	0	0	0	0	0	0
c) Information on surviving the cancer	0	0	0	0	0	0
d) Information on what caused this cancer or why you got cancer	Ο	0	Ο	0	0	0
e) Risk of cancer for family members	0	0	0	0	0	0
f) Information about current research and clinical trials of treatment for colorectal cancer	0	0	0	0	Ο	0
g) Information about specialized tests (eg., genetic testing, biomarker testing)	0	0	0	0	Ο	0
h) Other information needs about colorectal cancer that have not been met (please describe)	Ο	0	0	0	0	0

Section 2. About your experiences with treatment for colorectal cancer

7. What treatment are you receiving, or did you receive for colorectal cancer?

- O Radiation only
- O Surgery only
- **O** Chemotherapy only
- O Radiation and chemotherapy
- **O** Radiation and surgery

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

4/20

6/3/2019

6/3/2019	Qualtrics Survey Software
O Chemotherapy and surgery	
O All (radiation, surgery, and chemotherapy)	
O None	
O Other please describe]
O Prefer not to answer	

Questions about your information needs about <u>radiation</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) What to expect with radiation	0	0	0	0	0	0
b) What are the side effects with radiation	0	0	0	0	0	0
c) How to deal with the side effects of radiation	0	0	0	0	0	0
d) How does radiation work?	0	0	0	0	0	0
e) Other information needs (please describe)	0	0	0	0	0	0

Questions about your information needs about <u>surgery</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been met. How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) What to expect with surgery	0	0	0	0	0	0
b) What are the side effects with surgery	0	0	0	0	0	0

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6/3/2019	Qualtrics Survey Software					
	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
c) How to deal with the side effects of surgery	0	0	0	0	0	0
d) What types of surgery are available	0	0	0	0	0	0
e) Other information needs (please describe)	0	0	0	0	0	0

Questions about your information needs about <u>chemotherapy</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
	0	0	0	0	0	0
a) What to expect with chemotherapy	0	0	0	0	0	0
b) What are the side effects with chemotherapy	0	0	0	0	0	0
c) How to deal with the side effects of chemotherapy	0	0	0	0	0	0
d) How does chemotherapy work	0	0	0	0	0	0
e) What types of chemotherapy are available	0	0	0	0	0	0
f) Other information needs (please describe)	0	0	0	0	0	0

Questions about your information needs about <u>radiation and chemotherapy</u>: For each specific need listed below, please indicate the degree to which it has been

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

met.

6/3/2019

	This information need has not been met. How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) What to expect with radiation	0	0	0	0	0	0
b) What are the side effects with radiation	0	0	0	0	0	0
c) How to deal with the side effects of radiation	0	0	0	0	0	0
d) How does radiation work?	0	0	0	0	0	0
e) What to expect with chemotherapy	0	0	0	0	0	0
f) What are the side effects with chemotherapy	0	0	0	0	0	0
g) How to deal with the side effects of chemotherapy	0	0	0	0	0	0
h) How does chemotherapy work	0	0	0	0	0	0
 i) What types of chemotherapy are available 	Ο	Ο	0	0	Ο	0
j) Other information needs (please describe)	0	Ο	0	Ο	Ο	0

Questions about your information needs about <u>radiation and surgery</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been met. How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure	
a) What to expect with radiation	0	Ο	Ο	Ο	0	0	

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6/3/2019	Qualtrics Survey Software						
	This information need has not been met. How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure	
b) What are the side effects with radiation	0	0	0	0	0	0	
c) How to deal with the side effects of radiation	0	0	0	0	0	0	
d) How does radiation work?	0	0	0	0	0	0	
e) What to expect with surgery	0	0	0	0	0	0	
f) What are the side effects with surgery	0	0	0	0	0	0	
g) How to deal with the side effects of surgery	0	0	0	0	0	0	
h) What types of surgery are available	0	0	0	0	0	0	
i) Other information needs (please describe)	0	0	0	0	0	0	

Questions about your information needs about <u>surgery and chemotherapy</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been met. How strong is your information need? WEAK	This information need has <u>not been</u> <u>met</u> . How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) What to expect with surgery	0	0	0	0	0	0
b) What are the side effects with surgery	0	0	0	0	0	0
c) How to deal with the side effects of surgery	0	0	0	0	0	0
d) What types of surgery are available	0	0	0	0	0	0

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6/3/2019	Qualtrics Survey Software					
	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
e) What to expect with chemotherapy	0	0	0	0	0	0
f) What are the side effects with chemotherapy	0	0	0	0	0	0
g) How to deal with the side effects of chemotherapy	Ο	0	0	0	0	0
h) How does chemotherapy work	0	0	0	0	0	0
i) What types of chemotherapy are available	Ο	0	0	0	0	0
j) Other information needs (please describe)	0	0	Ο	Ο	0	0

Questions about your information needs about <u>radiation, surgery and</u> <u>chemotherapy</u>: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been met. How strong is your information need? WEAK	This information need has <u>not been</u> <u>met</u> . How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) What to expect with radiation	0	0	0	0	0	0
b) What are the side effects with radiation	0	0	0	0	0	0
c) How to deal with the side effects of radiation	0	0	0	0	0	0
d) How does radiation work?	0	0	0	0	0	0
e) What to expect with surgery	0	0	0	0	0	0

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

Qualtrics Survey Software This This This information information information need has need has need has This <u>not been</u> <u>not been</u> <u>not been</u> information met. How met. How met. How need is not strong is strong is applicable strong is This your your your

	your information need? WEAK	your information need? MODERATE	your information need? STRONG	This information need <u>has</u> <u>been</u> met	because it is not a need for you	Not sure
f) What are the side effects with surgery	0	0	0	0	0	0
g) How to deal with the side effects of surgery	0	0	0	0	0	0
h) What types of surgery are available	0	0	0	0	0	0
i) What to expect with chemotherapy	0	0	0	0	0	0
j) What are the side effects with chemotherapy	0	0	0	0	0	0
 k) How to deal with the side effects of chemotherapy 	0	0	Ο	Ο	Ο	0
l) How does chemotherapy work	0	0	0	0	0	0
m) What types of chemotherapy are available	0	0	Ο	Ο	0	0
n) Other information needs (please describe)	0	0	0	0	0	Ο

8. Please indicate if you are:

- O Currently undergoing treatment for colorectal cancer
- O Have completed treatment for colorectal cancer and are actively being followed-up
- ${\ensuremath{\mathsf{O}}}$ More than 5 years from your last treatment for colorectal cancer
- O Do not know

Questions about your information needs while <u>undergoing treatment</u> for colorectal cancer: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has <u>not been</u> <u>met</u> . How strong is your information need? MODERATE	This information need has <u>not been</u> <u>met</u> . How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
a) Alternative or complementary treatments	0	0	0	0	0	0
b) Clinical trials for new treatments	0	0	0	0	0	0
c) What are the chances of the cancer coming back after treatment	0	0	0	0	0	0
d) Exercise and physical activity during treatment	0	0	0	0	0	0
e) Nutrition and diet during treatment	0	0	0	0	0	0
f) Bowel activity during treatment	0	0	0	0	0	0
g) Other patients' experiences about treatment	0	0	0	0	0	0
h) Other information needs (please describe)	0	0	0	0	0	0

Qualtrics Survey Software

Questions about your information needs while <u>being actively followed up</u> after treatment for colorectal cancer: For each specific need listed below, please indicate the degree to which it has been met.

	This information need has not been <u>met</u> . How strong is your information need?	This information need has <u>not been</u> <u>met</u> . How strong is your information need?	This information need has not been <u>met</u> . How strong is your information need?	This information need <u>has</u>	This information need is <u>not</u> <u>applicable</u> because it is not a need for	
	WEAK	MODERATE	STRONG	<u>been</u> met	you	Not sure
a) Dealing with a stoma	0	0	0	0	0	0
 b) Exercise and physical activity after treatment 	0	0	0	Ο	0	0
c) Nutrition and diet after treatment	0	0	0	0	0	0

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6/3/2019		Qualtri				
	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has not been met. How strong is your information need? MODERATE	This information need has not been met. How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
d) Bowel activity after treatment	0	0	0	0	0	0
e) Other patients' experiences after treatment	Ο	0	0	0	0	0
f) Other information needs (please describe)	0	Ο	0	Ο	0	0

Section 3. Information you need about other related issues with colorectal cance

9. Living with colorectal cancer is not easy. We want to know about your information needs on how colorectal cancer has affected aspects of your life. For each specific need listed below, please indicate the degree to which it has been met.

	This information need has <u>not been</u> <u>met</u> . How strong is your information need? WEAK	This information need has <u>not been</u> <u>met</u> . How strong is your information need? MODERATE	This information need has <u>not been</u> <u>met</u> . How strong is your information need? STRONG	This information need <u>has</u> <u>been</u> met	This information need is <u>not</u> <u>applicable</u> because it is not a need for you	Not sure
Sexual activity	0	0	0	0	0	0
Fertility	0	0	0	0	0	0
Work and cancer	0	0	0	0	0	0
Parenting with cancer	0	0	0	0	0	0
Mental health and cancer	0	0	0	0	0	0
Bowel activity after cancer	0	0	0	0	0	0
Long-term side effects of treatment	0	0	0	0	0	0
Other information needs (please describe)	0	0	0	0	0	0

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

6/3/2019

Section 4. How you find information about colorectal cancer

	Not at all	A little	Some	A lot	Not sure
Cancer organizations	0	0	0	0	0
Doctors or other medical health professionals	Ο	0	0	0	Ο
Family members or friends	0	0	0	0	0
Government health agencies	0	0	0	0	0
Internet	0	0	0	0	0
Newspapers or magazines	0	Ο	0	0	0
Radio	0	0	0	0	0
Religious organizations and leaders	0	0	0	0	0
Television	0	0	0	0	0
Other (please describe)	0	Ο	0	0	0

10. In general, how much do you trust information about health or medical topics from each of the following?

11. When you need specific information about your colorectal cancer (for example, treatment or side effects), where would you go first? Mark only <u>one</u>.



- **O** Family members or friends
- **O** Government health agencies
- O Internet
- O Magazines
- O Newspapers
- O Other (please describe)
- O Do not know

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

	Never	Sometimes	Usually	Always	Not sure
Books	0	0	0	0	0
Brochures, pamphlets, etc.	0	0	0	0	0
Cancer organizations	0	0	0	0	0
Doctors or other medical health professionals	0	0	0	0	0
Family members or friends	0	0	0	0	0
Government health agencies	0	0	0	0	0
Internet	0	0	0	0	0
Magazines	0	0	0	0	0
Newspapers	0	0	0	0	0
Other (please describe)	0	0	0	0	0

12. With respect to colorectal cancer, how often do you look for information from <u>each</u> of the following?

13. At the most recent time you looked for information about colorectal cancer, where did you go first?

O Books

6/3/2019

- **O** Brochures, pamphlets, etc.
- O Cancer organizations
- **O** Doctors or other medical health professionals
- O Family members or friends
- **O** Government health agencies
- O Internet
- O Magazines
- O Newspapers
- O Other (please describe)
- O Do not know

14. Based on your most recent search for information for colorectal cancer, state the amount of effort you needed to get the information you needed:

O No effort (easy to find)

O A little effort (somewhat easy to find)

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

Qualtrics Survey Software

- O A moderate amount of effort (not easy to find)
- O A lot of effort (information still not found)
- O Prefer not to answer

15. Overall, how confident are you that you could get advice or information about colorectal cancer if you needed it?

- O Completely confident
- O Very confident
- O Somewhat confident
- O A little confident
- O Not confident at all
- O Prefer not to answer

Section 5. Using the Internet to find information

16. In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following...

	Yes	No	Not sure
Looked for medical information	0	Ο	0
Looked for a doctor or other medical health professional	Ο	0	Ο
Made appointments with a doctor or other medical health professional	Ο	Ο	0
Tracked health care charges and costs	0	0	0
Filled out forms or paperwork related to your health care	Ο	Ο	Ο
Looked up results from a medical test	0	0	0

17. Please indicate if you have <u>any</u> of the following.

🔲 Tablet computer like an iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire

- Smartphone, such as an iPhone, Android, Blackberry, or Windows Phone
- Basic cell phone only
- Do not have any of the listed

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

Qualtrics Survey Software

Prefer not to answer

18. On your tablet or smartphone, do you have any "apps" related to health and wellness?

- O Yes
- O No
- O Do not know

19. Do you currently have any apps related to cancer?

- O Yes
- O No
- O Do not know

20. Would you find the following features important or valuable in providing information relating to your cancer? Please mark one option for each.

	Yes	No	Not sure
Reliable information on colorectal cancer	Ο	0	0
Sharing your cancer journey (blogs, tips, advice)	Ο	Ο	Ο
Cancer diary (timeline)	0	0	0
Appointment or treatment tracker	0	0	0
Sharing pictures or videos	Ο	0	0
Other (please describe)	0	0	0

Section 6. Overall Health

Under each heading, please tick the ONE box that best describes your health $\underline{\text{TODAY}}$

21. In general, would you say your health is

- O Excellent
- O Very good

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

- O Good
- O Fair
- O Terrible

22. Mobility

- O I have no problems in walking about
- **O** I have slight problems in walking about
- **O** I have moderate problems in walking about
- O I have severe problems in walking about
- O I am unable to walk about

23. Self-care

- **O** I have no problems washing or dressing myself
- **O** I have slight problems washing or dressing myself
- O I have moderate problems washing or dressing myself
- **O** I have severe problems washing or dressing myself
- O I am unable to wash or dress myself

24. Usual Activities (e.g. work, study, housework, family or leisure activities)

Qualtrics Survey Software

- O I have no problems doing my usual activities
- **O** I have slight problems doing my usual activities
- O I have moderate problems doing my usual activities
- O I have severe problems doing my usual activities
- **O** I am unable to do my usual activities

25. Pain/Discomfort

- O I have no pain or discomfort
- O I have slight pain or discomfort
- O I have moderate pain or discomfort
- O I have severe pain or discomfort
- O I have extreme pain or discomfort

26. Anxiety/Depression

O I am not anxious or depressed

https://ubc.cal.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

Qualtrics Survey Software

- O I am slightly anxious or depressed
- O I am moderately anxious or depressed
- O I am severely anxious or depressed
- O I am extremely anxious or depressed

27. We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Please click and drag the slider

	0	10	20	30	40	50	60	70	80	90	100
--	---	----	----	----	----	----	----	----	----	----	-----

Section 7. Additional information about you to help us understand findings of th

28. What race/ethnicity do you identify as? <u>One or more</u> categories may be selected.

Ц	White (i.e., German, Irish, English, Italian, Polish, etc.)
	Hispanic, Latin, or Spanish of origin (i.e., Mexican, Cuban, Salvadoran, Columbian, etc.)
	Black or African American (i.e., Nigerian, Jamaican, Somalian, etc.)
	Asian
	Native/Indigenous/Aboriginal
	Middle Eastern or North African (i.e., Lebanese, Syrian, Saudi, Iranian, etc.)
	Other race, ethnicity, or origin
	Prefer not to answer

29. What is your marital status?

- O Married
- O Common-law or Co-habiting
- O Divorced
- O Widowed
- O Separated
- O Single, never been married
- O Prefer not to answer

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

30. What is the highest grade or level of education you have completed?

- **O** No schooling completed
- O Elementary, primary or grade school
- O Secondary or high school
- O Postsecondary (university, college, vocational, technical school)
- O Prefer not to answer

31. Which of the following best describes the area you live in?

O Urban

6/3/2019

- O Rural
- O Suburban
- O Prefer not to answer
- O Do not know

Powered by Qualtrics

https://ubc.ca1.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview

	Information	Information	Information		Information	
	need not	need not met	need not met	Information	need not	
Information topic	met (weak)	(moderate)	(strong)	need met	applicable	Not sure
Cancer location	3.83%	9.56%	9.84%	74.32%	1.37%	0.55%
Cancer stage	6.56%	8.74%	10.11%	70.22%	1.64%	1.91%
Surviving the cancer	12.30%	21.04%	15.03%	44.26%	2.19%	1.91%
Cause of cancer	22.13%	21.58%	31.97%	16.39%	1.91%	2.73%
Risk of cancer to family	12.30%	17.76%	18.03%	46.72%	0.27%	1.64%
Clinical trials	18.03%	21.31%	24.59%	16.94%	10.93%	4.92%
Specialized cancer tests (i.e., genetic						
biomarker tests)	14.48%	21.86%	21.58%	34.43%	1.91%	2.73%
Alternative/complementary treatments	25.21%	24.37%	27.73%	13.45%	3.36%	2.52%
Clinical trials for new treatments	19.33%	17.65%	36.97%	15.13%	4.20%	0.84%
Cancer recurrence	11.76%	16.81%	27.73%	24.37%	11.76%	3.36%
Exercise/ physical activity	17.65%	20.17%	21.01%	32.77%	3.36%	1.68%
Nutrition/diet	12.61%	26.05%	27.73%	26.89%	2.52%	1.68%
Bowel activity	12.61%	22.69%	17.65%	39.50%	4.20%	0%
Other patients' experiences	22.69%	24.37%	13.45%	30.25%	5.04%	0.84%
Dealing with stoma	1.34%	11.16%	5.36%	26.34%	43.30%	7.59%
Exercise/ physical activity	7.38%	12.02%	9.29%	27.60%	1.09%	0.82%
Nutrition/diet	12.05%	19.64%	15.18%	45.09%	1.79%	1.34%
Bowel activity	16.52%	16.52%	22.32%	36.61%	1.79%	0.89%
Other patients' experiences	19.64%	19.64%	21.43%	23.21%	3.57%	7.14%
Sexuality	17.21	15.85%	22.40%	27.60%	3.83%	1.91%
Fertility	13.11%	6.83%	9.56%	29.78%	28.14%	1.09%
Work and cancer	15.03%	18.85%	16.67%	28.96%	7.92%	1.37%
Parenting with cancer	15.30%	10.38%	15.57%	19.95%	24.86%	2.73%
Mental health and cancer	17.76%	15.30%	25.68%	24.86%	3.83%	1.37%
Bowel activity after cancer	14.21%	17.76%	23.22%	28.69%	4.10%	1.37%

The proportion of information items being unmet or met by yCRC respondents analyzed