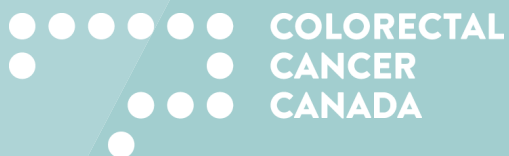


N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER

PATIENT & CAREGIVER SURVEY REPORT

PATIENT & CAREGIVER EXPERIENCES WITH EARLY-AGE ONSET
COLORECTAL CANCER IN CANADA

JANUARY 2021

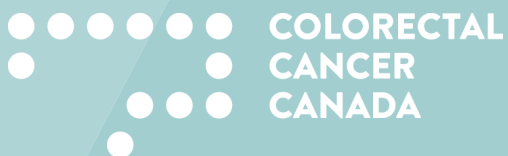


N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER

PATIENT & CAREGIVER SURVEY PROJECT REVIEW

PATIENT & CAREGIVER EXPERIENCES WITH EARLY-AGE ONSET
COLORECTAL CANCER IN CANADA

JANUARY 2021



Executive Summary

Colorectal Cancer Canada's Never Too Young program was established in 2018 and aims to increase awareness around early-age onset colorectal cancer (EAO CRC) in Canada, to support patients throughout their journey, and to sensitize the healthcare community about the unique challenges that patients face. The goal of the Never Too Young: Early-Age Onset Experiences survey was to gain additional insight into the experiences of early-age onset patients in Canada, from symptoms to diagnosis to outcomes and quality of life.

The survey gathered 68 responses from patients (24.6%), survivors (59.4%), and caregivers (15.9%) who responded on behalf of their loved ones. The respondents were located in five provinces across Canada, with nearly half (47.1%) residing in Ontario.

The overall awareness of EAO CRC prior to diagnosis was low, with 27.1% reporting that they knew CRC could happen in those under 50, and 15.7% who knew the common signs and symptoms. At the time of diagnosis, most respondents consumed fewer vegetables (2.6 servings) and fruits (2.5 servings) than the recommended combined 10 servings daily, and the majority (53.3%) were overweight or obese. The majority of respondents did not have a family history of CRC (58%).

Among respondents, the most common symptom was blood in their stool, followed by weakness/fatigue, bloating/gas, and diarrhea. After seeking medical care, 42.9% of respondents felt that they were dismissed due to their age and 78.1% saw two or more doctors before being diagnosed. The largest proportion of respondents were diagnosed at stage III (44.1%) or IV (32.4%).

About one third (35.4%) of respondents had their biomarkers tested. Additionally, a minority of respondents (25.4%) stated that clinical trials were introduced by their care team, and among those, 38.1% felt well informed about clinical trials. However, patient attitudes toward clinical trials were positive, with 75.4% who stated that they would participate and 68.8% who rated clinical trials "very important" for EAO CRC patients. It is important to note that not all participants may have been eligible for biomarker testing or clinical trials at the time of diagnosis.

Though a large proportion of respondents (59.7%) did not receive guidance on the sexual side-effects of treatment, 53.7% reported a partial or total loss of sexual function. Respondents reported low levels of financial toxicity, however, it is important to note that the sample reported relatively high levels of education compared to the average population. Overall, the majority of patients (78%) are able to enjoy life and 66.7% are satisfied with how they are coping with the disease.

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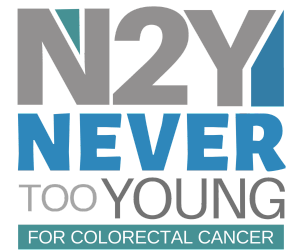
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INTRODUCTION

Colorectal cancer is the second most diagnosed cancer in Canada, with an estimated 26,900 new cases and 9,700 deaths in 2020¹. The 5-year net survival rate is estimated at about 65% in 2020 for the general population¹.

Although the rates of colorectal cancer among older adults have been declining over the past decades, the rate of early-age onset colorectal cancer (defined as those under the age of 50) is dramatically increasing². Specifically, the EAO CRC rates in women have increased an average of 4.5% per year since 2010, and in men, they have increased an average of 3.5% per year between 2006 and 2015². In Canada, regular screening practices begin at age 50, therefore this increase among those under standard testing age is alarming². Young people are often diagnosed with colorectal cancer at a later stage because they are not yet getting screened and medical teams often do not suspect cancer to develop under the age of 50.

The mission of Colorectal Cancer Canada's (CCC) Never Too Young Program (N2Y) is to raise awareness and enhance patient support around early age onset colorectal cancer (EAO CRC) in Canada in order to decrease the number of young people diagnosed with advanced-stage disease. N2Y is committed to spreading the message that young adults need to be screened earlier than age 50 if they have a family history of the disease or an associated hereditary syndrome.



N2Y envisions a future where no young person in Canada dies of colorectal cancer due to a lack of awareness, misinformation, testing delays or stigma. Young Canadians and healthcare providers will have the appropriate information to continue the fight against colorectal cancer with confidence and resilience.

It is well known that an early-age onset colorectal cancer diagnosis can cause long-lasting physical and emotional side-effects that significantly impact quality of life. Early-onset patients also face unique challenges with regards to relationships, intimacy, fertility, professional life, body image, social anxiety, among many others. This survey aims to identify challenges that Canadian patients face and gaps in care and support that may exist.

Colorectal Cancer Canada is aware of the limitations of this survey, including sample size and selection bias, however, the information gathered provides a snapshot of the challenges that Canadian EAO CRC patients face. The ultimate goal is to collaborate with stakeholders such as policymakers and medical professionals to address the overlooked and unique needs of young colorectal cancer patients, survivors and caregivers in Canada.

¹ www.cancer.ca/en/cancer-information/cancer-type/colorectal/colorectal-cancer/?region=on

² www.ncbi.nlm.nih.gov/pmc/articles/PMC6669779/

METHODOLOGY

Our online survey was developed using a Google platform to gather data on a number of factors influencing survivorship and quality of life (QoL) outcomes for early-age onset colorectal cancer patients in Canada. The survey touches on a number of factors, including the following:



Once the survey questions had been drafted internally at Colorectal Cancer Canada, the draft was sent to the Never Too Young Advisory Panel and Never Too Young Ambassadors for review. Final changes were then made, and the survey was launched on September 2, 2020. The survey remained open until October 15, 2020, for a total of 6 weeks.

The survey was available in both French and English and was primarily disseminated through Colorectal Cancer Canada's social media platforms (Facebook, Twitter, Instagram). Additionally, CCC staff, Never Too Young Ambassadors and Advisory Panel members were asked to share on their own personal platforms. It is important to note that the majority of questions asked in the caregiver section of the survey were to be responded to on behalf of the patient, reflecting on their experiences. There were, however, sections that allowed caregivers to reflect on their own experiences and challenges.

After removing duplicate responses, we gathered a total of 68 responses from patients/survivors (n=58) and caregivers (n=10). This survey was the first rendition of a bi-annual survey, and 54.4% of respondents indicated that they would be interested in participating in future surveys. Our survey introduction defined early-age onset as 50 years and under at diagnosis, however, we did not exclude the responses of those in their early fifties (50-55 years at diagnosis) as symptoms often appeared at age 49 or younger.

Descriptive statistics and comparisons with a similar survey conducted by Colorectal Cancer Alliance internationally (with a focus on the United States) were used to identify patterns in each of the sections³. This report showcases the results from CCC's Canadian survey respondents, including patients, survivors and caregivers.

³ www.ccalliance.org/about/never-too-young/survey

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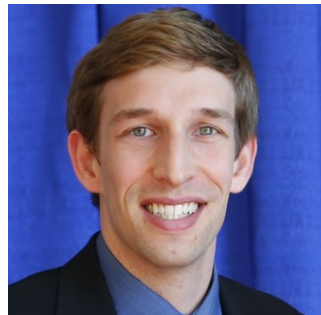
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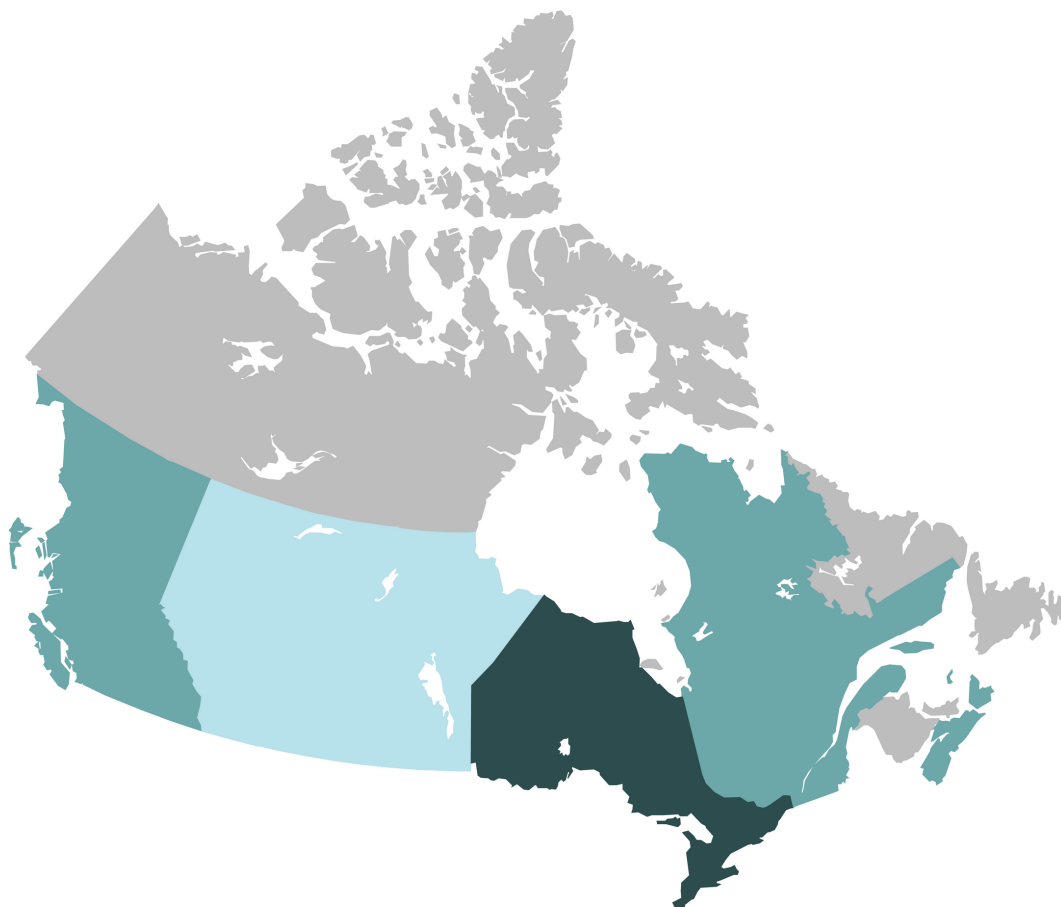
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Founder
Giant's Head Grind

PARTICIPANT DEMOGRAPHICS

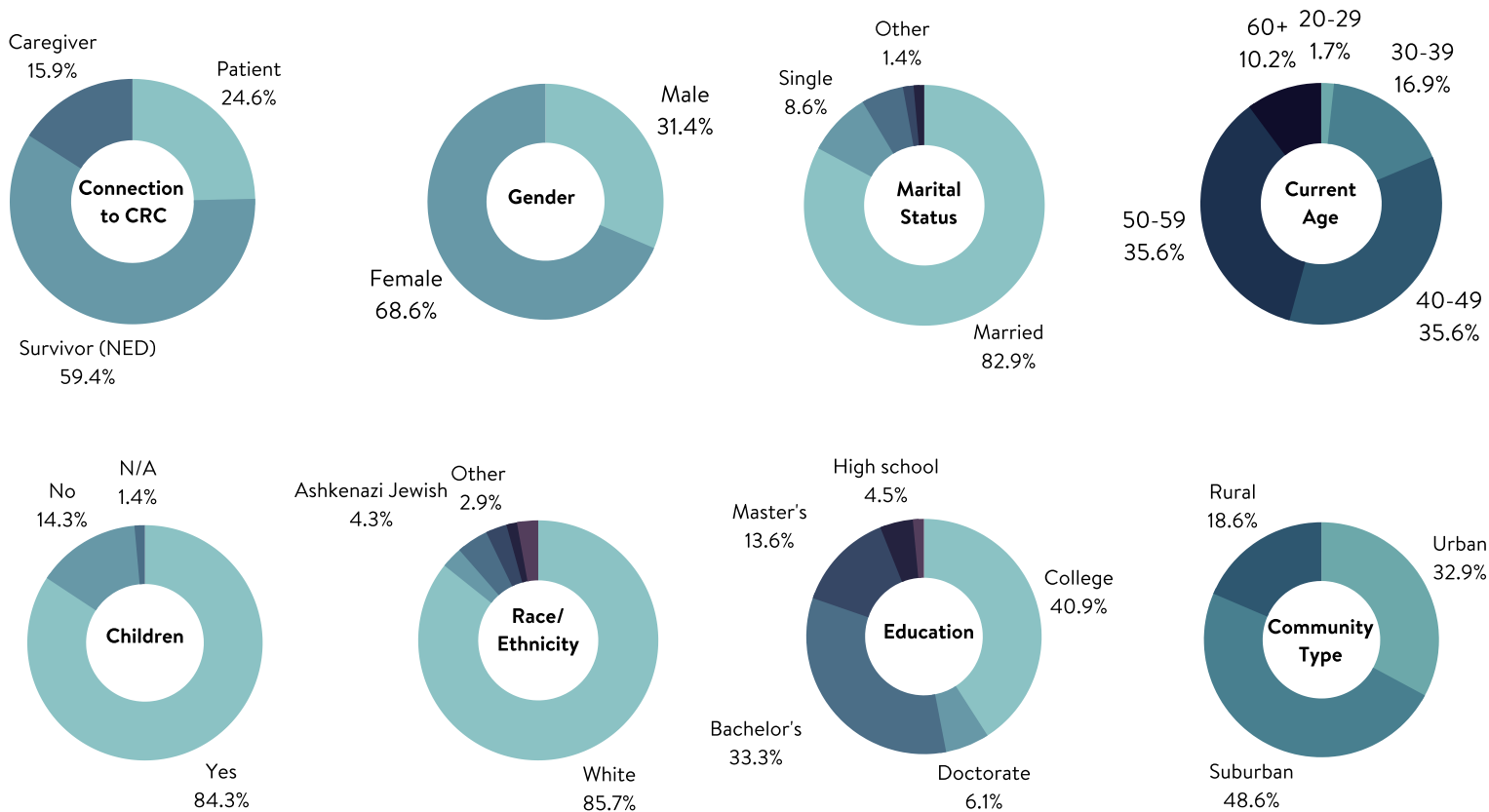
The 68 survey responders lived across seven Canadian provinces. The largest proportion reside in Ontario (47.1%), followed by Quebec (14.7%), British Columbia (11.8%), Nova Scotia (10.3%), Alberta (5.9%), Manitoba (5.9%) and Saskatchewan (4.4%).



Province of Residence

Province	Percentage
Ontario	47.1%
British Columbia	11.8%
Quebec	14.7%
Nova Scotia	10.3%
Alberta	5.9%
Manitoba	5.9%
Saskatchewan	4.4%

PARTICIPANT DEMOGRAPHICS



Of the 68 participants, 59.4% have no evidence of disease (NED, or survivors), 24.6% are patients and 15.9% are caregivers; 68.6% female and 31.4% male. Two-thirds of respondents were diagnosed with colon cancer, while one-third were diagnosed with rectal cancer. The average age at onset of symptoms was approximately 40 years old, and 26.7% of respondents were diagnosed under the age of 35.

The respondents self-identify as 85.7% white, 4.3% Ashkenazi Jewish, 2.9% Filipino, 2.9% Métis, First Nation, Inuit, 2.9% other and 1.4% South Asian. The vast majority (94%) have at least a college diploma, and 53% have a Bachelor's degree or higher. A small proportion (1.6%) of respondents had below a high school education.

PARTICIPANT DEMOGRAPHICS

The largest proportion (82.9%) of the participants are married or in common-law relationships, compared to 8.6% single. 84.3% stated that they had children compared to 14.3% who stated they did not.

In terms of community type, 48.6% reside in a suburban community, 32.9% reside in an urban area and 18.6% live in a rural setting.

It is important to note that this respondent pool does not reflect a cross-section of the overall population of Canada or those who have colorectal cancer. Based on this self-reported demographic information, respondents tend to have high levels of education and often have social support networks through their spouse and/or children.



I WAS 29

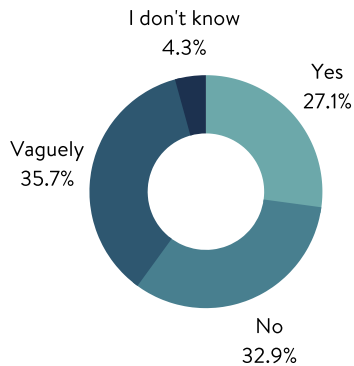
I try and advocate for CRC patients as much as I can. Being told you may live to see your kids enter kindergarten if you're lucky is a shock. I don't know where I would be today approaching my 2 year anniversary of diagnosis if I didn't seek out a second opinion.

- Meagan, 31

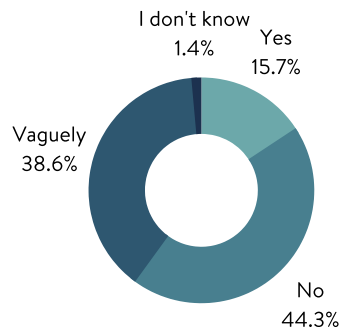
EAO CRC AWARENESS

PRE-DIAGNOSIS AWARENESS

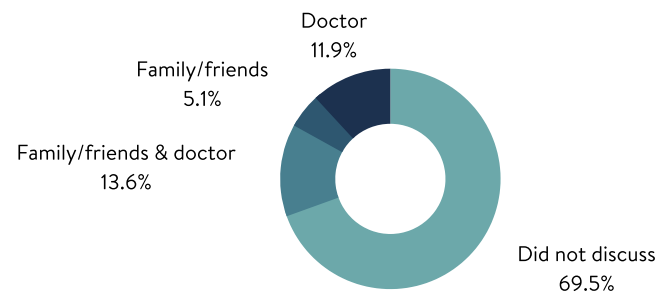
Prior to diagnosis, were you aware that CRC can happen in people under 50?



Did you know the signs and symptoms of CRC before diagnosis?



Did you discuss family health history, including CRC risk factors, with your family/friends or doctor BEFORE your diagnosis? Select with whom.



In Canada, colorectal cancer screening of those at average risk begins at the age of 50. Due to the perception of cancer as an "older person's disease" many Canadians do not know that colorectal cancer can occur in those under 50 and that the EAO CRC rates are on the rise.

Of our participants, 32.9% were not aware that CRC can happen in people under 50, and 44.3% did not know the signs and symptoms before their diagnosis. The majority of respondents (69.5%) did not discuss family history or CRC risk factors with anyone prior to their diagnosis.

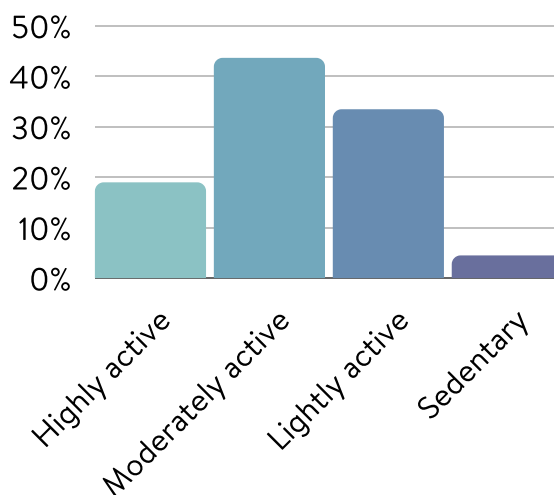
Of respondents who indicated that they have a first- or second-degree family member with the disease, 20.8% were unaware that CRC can happen in young people, significantly less than the general sample. Yet, among those with a family history, 33.3% did not know the signs and symptoms of colorectal cancer and 45.8% did not discuss their risk with their doctor, family or friends. Although those with a family history were more aware of their risk and signs to watch for, there was a concerning number of respondents who remained unaware.

HEALTH & RISK FACTORS

PHYSICAL ACTIVITY

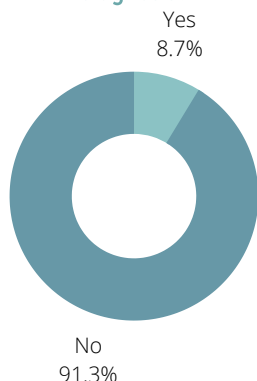
Respondents were asked to rate their weekly moderate/vigorous physical activity levels prior to diagnosis, where sedentary is less than 30 minutes, lightly active is 30-60 minutes, moderately active is 60-150 minutes and highly active is 150+ minutes.

The majority of our survey's respondents stated that they were usually moderately (43.5%) or lightly active (33.3%). Fewer respondents stated they were highly active (18.8%) or sedentary (4.3%).

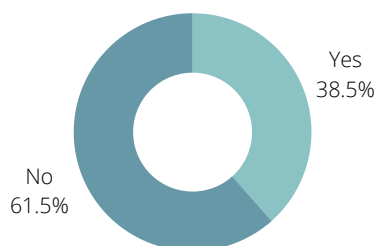


SMOKING

Were you a smoker at the time of diagnosis?



Were you ever a smoker in the past?



Smoking is a well-known risk factor for a number of health issues, including colorectal cancer.

Of our respondents, 91.3% of our participants were not smokers at the time of diagnosis, compared to 8.7% who smoked an average of 2 packs per day at the time of diagnosis.

If so, how many packs per day?



If so, for how many years?



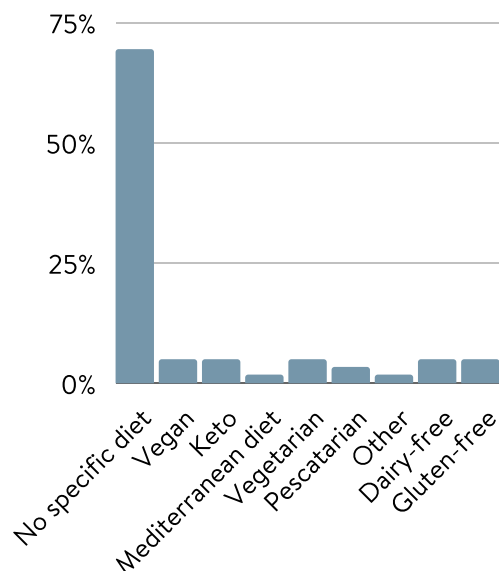
Of our respondents, 38.5% claimed they were once smokers in the past, for 11 years on average, and 61.5% of respondents never smoked in the past.

HEALTH & RISK FACTORS

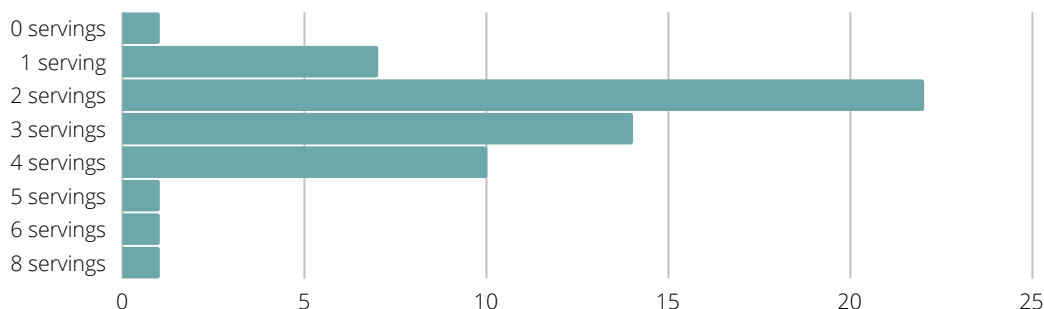
DIET & NUTRITION

Research suggests that a balanced diet including fruits and vegetables (especially cruciferous vegetables) can reduce the risk of colorectal cancer⁴. In Canada, it is recommended that the general adult population consume 7-10 servings of fruits and vegetables per day⁵. A serving was defined as a half cup of fresh, canned or frozen fruits and vegetables, a half cup of 100% fruit juice, 1 fruit or one cup of leafy green vegetables. For resources on healthy eating to prevent CRC, please see our [Foods That Fight Cancer](#) program.

Approximately 69% of participants claimed that they followed no specific diet prior to diagnosis, while other answers were equally divided amongst specific diets. The average amount of vegetable and fruit servings a day was 2.6 and 2.5 respectively, indicating that the majority of respondents were not getting the recommended servings of fruits and vegetables.

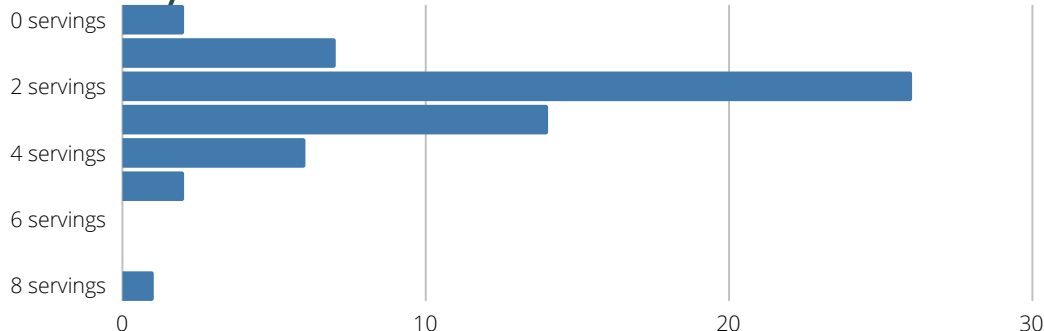


Vegetables Per Day



2.6
servings per day
on average

Fruit Per Day



2.5
servings per day
on average

⁴ www.cancer.org/cancer/colon-rectal-cancer/causes-risks-prevention/prevention.html

⁵ www.food-guide.canada.ca/en/

HEALTH & RISK FACTORS

DIET & NUTRITION

Nutritional guidelines suggest avoiding sugar-sweetened beverages and replacing them with water whenever possible⁵.

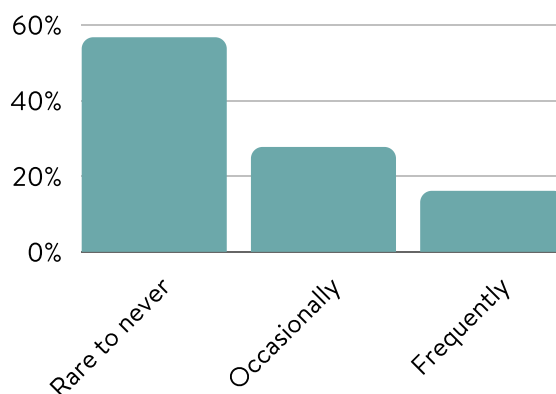
Sugar-sweetened beverages can include soda (including sugar-free and diet), iced tea, fruit juices and cocktails, sports drinks, energy drinks and more.

In terms of sugar-sweetened beverage consumption among respondents, 56.5% reported rarely or never consuming these types of beverages prior to diagnosis, as opposed to 15.9% who frequently did and 27.5% who occasionally drank sugar-sweetened beverages.

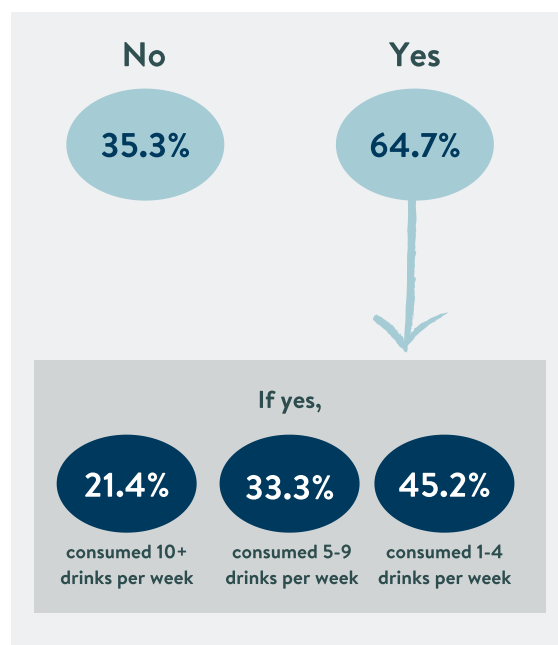
Alcohol consumption has been directly correlated to a number of chronic diseases, including colorectal cancer (among other cancers), liver disease and hypertension⁵. The Canadian Centre on Substance Use and Addiction recommends a maximum of 10 drinks per week for women (no more than 2 drinks per day) and 15 drinks per week for men (no more than 3 drinks per day).⁶

Among our respondents, 64.7% regularly consumed alcohol at the time of diagnosis, compared to 35.3% who did not. Among those who answered yes, 45.3% consumed 1 to 4 drinks per week, 33.3% consumed 5 to 9 drinks per week and 21.4% consumed 10 or more. Respondents were provided with standard guidelines for beer, wine and spirit consumption. Although self-reported, this indicates that a majority of respondents were within low-risk drinking guidelines.

Sugar-Sweetened Beverage Consumption



Did you regularly consume alcohol at the time of diagnosis?



⁵ www.food-guide.canada.ca/en/

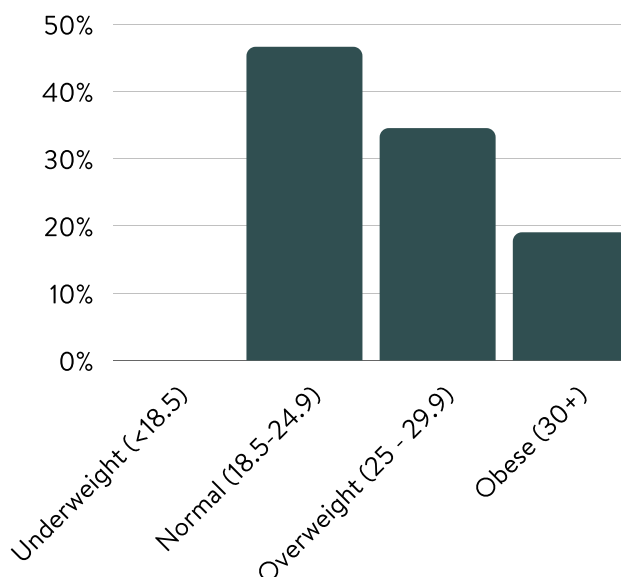
⁶ <https://www.ccsa.ca/canadas-low-risk-alcohol-drinking-guidelines-brochure>

HEALTH & RISK FACTORS

BODY MASS INDEX

The Centers for Disease Control and Prevention (CDC) Body Mass Index (BMI) formula was used to calculate respondent BMI using their height and weight: $(\text{weight (lb)} / [\text{height (in)}]^2 \times 703)^7$.

From these calculations, 46.6% of the participants reported having a normal BMI prior to diagnosis, 34.4% were considered overweight and 18.9% were considered obese. None of the participants were underweight at the time of diagnosis.



On a winter February afternoon in 2019, days after my 45th birthday, I was unexpectedly diagnosed with stage 3b colorectal cancer. In short, I went through chemotherapy and radiation and had a complete response to treatment. If I didn't keep my doctor's appointment which led to a colonoscopy, the story could have had a very different ending.

- Aneta, 46

⁷ www.cdc.gov/nccdphp/dnpao/growthcharts/training/bmiage/page5_2.html

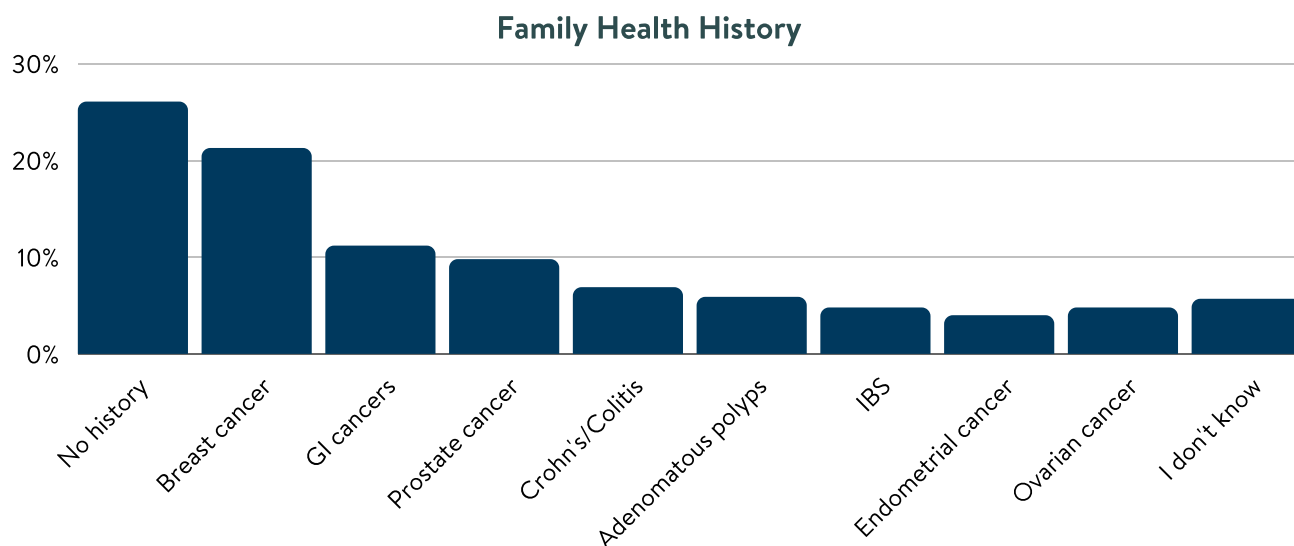
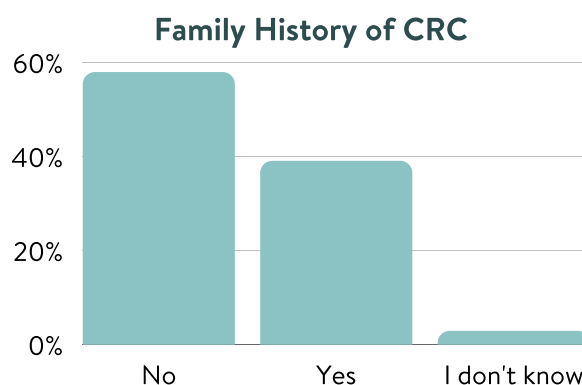
HEALTH & RISK FACTORS

FAMILY HISTORY

Having a family history of CRC and other cancers and conditions increases the probability of diagnosis.

Of our respondents, 58% indicated they did not have a family history of CRC, and 39.1% indicated they have a family history with the disease.

Among respondents, 21% reported they had a relative with a history of breast cancer, 11.5% with GI cancers and 9.4% with prostate cancer. Crohn's disease, IBS, adenomatous polyps and endometrial and ovarian cancer, were also indicated by a small percentage of our respondents as part of their family's disease history.

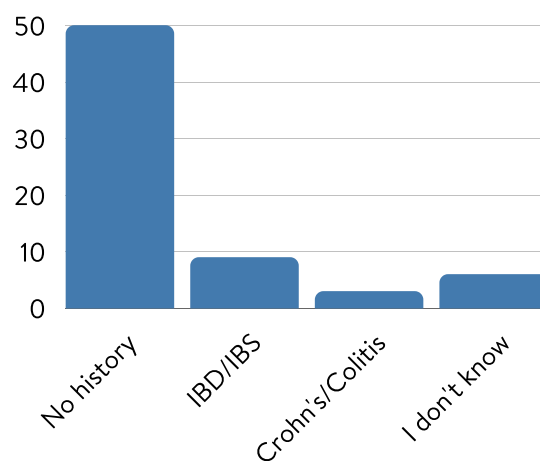


HEALTH & RISK FACTORS

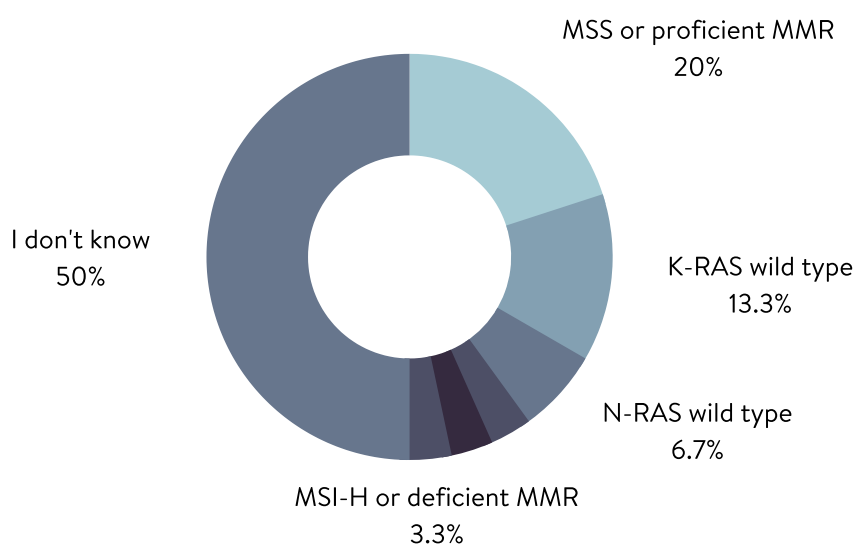
PERSONAL HISTORY

Having a personal history of some conditions such as IBD/IBS and Crohn's/Colitis can increase a person's risk for colorectal cancer.

The majority of respondents (73.5%) stated they had no personal history of disease prior to diagnosis, however, 13.2% of our participants had a history of IBD/IBS, while 4.4% had a history of Crohn's/Colitis.



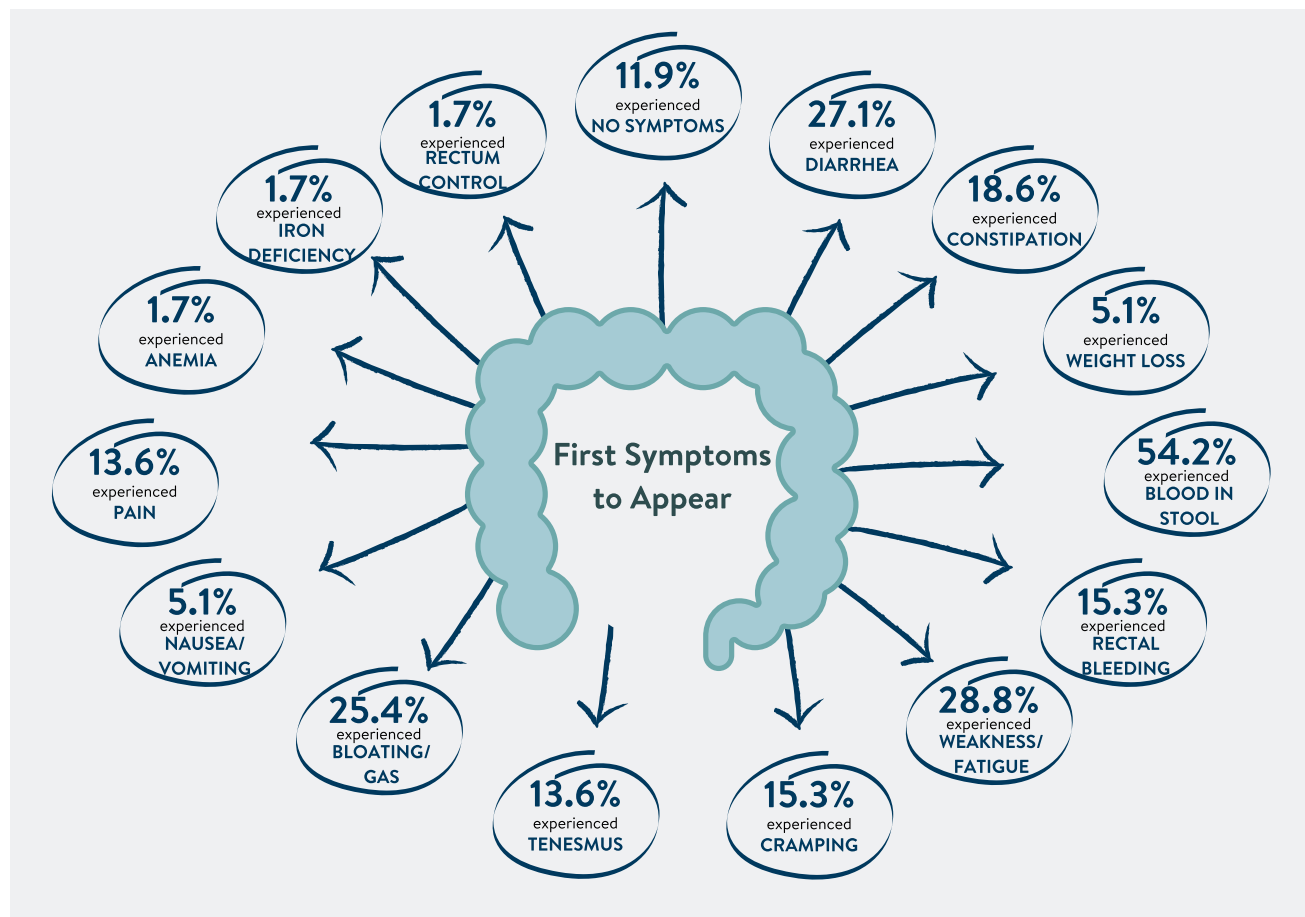
MUTATIONS



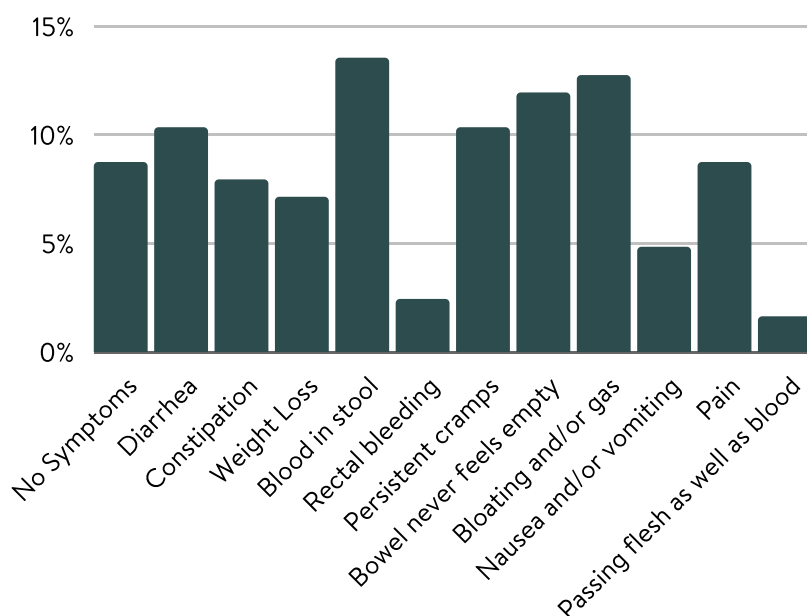
Half of our respondents indicated they did not know if they had any genetic mutations present, however 20% reported that genetic testing indicated MSS or proficient MMR type mutation. K-RAS wild type (13.3%), N-RAS wild type (6.7%) and MSI-H or deficient MMR (3.3%), PMS-2 (3.3%) and K-RAS mutant (3.3%) were types of mutations indicated by respondents through test results.

DIAGNOSIS

SYMPTOMS



Subsequent Symptoms



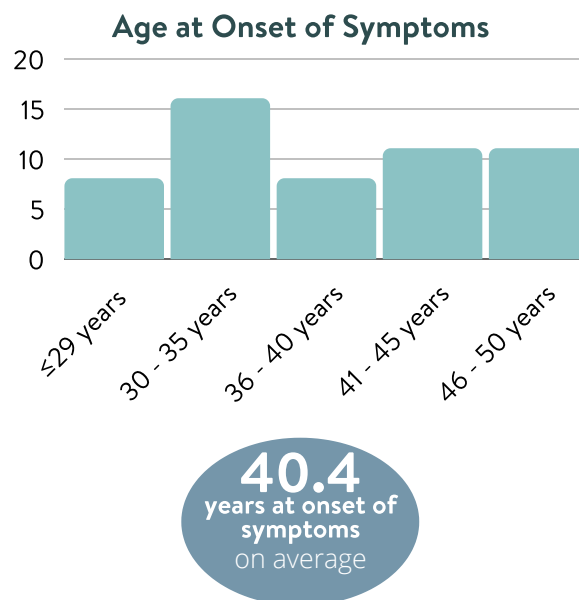
In our survey, participants were asked to indicate the first symptom(s) experienced, as well as any subsequent symptom(s) which appeared. 54.2% indicated blood in stool as a first symptom. Weakness/fatigue (28.8%) and bloating/gas (25.4%) were also common first symptoms among respondents. Blood in stool was also the most common subsequent symptom among respondents, which corresponds with findings from CC Alliance's report³.

³ www.ccalliance.org/about/never-too-young/survey

DIAGNOSIS

SYMPTOMS

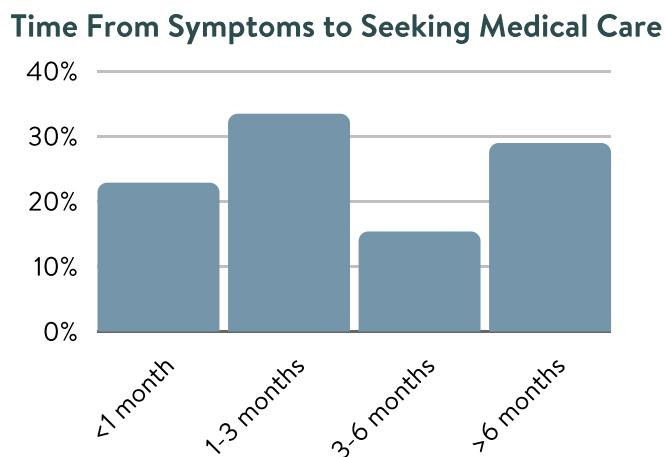
On average, the age at onset of symptoms was 40.4 years, with 25% being between 30 and 35, 12.5% less than 29 and 15.6% more than 51. It is important to note that EAO CRC is defined as those diagnosed under the age of 50, however, a small proportion of respondents shared their EAO CRC experiences after being diagnosed in their early to mid-50s (51-55) after showing symptoms under the age of 50.



PATH TO DIAGNOSIS

Early-age onset colorectal cancer patients often do not seek medical care as quickly as older patients as their symptoms may not be as alarming due to their age. Because of this, among other factors, EAO CRC patients are often diagnosed at a later stage.

The largest proportion of respondents (33.3%) sought medical care 1-3 months after the onset of symptoms, while a concerning amount of respondents waited 6 months or longer to seek care (28.8%). A smaller proportion of respondents sought care after less than 1 month (22.7%) and between 3-6 months (15.2%).



DIAGNOSIS

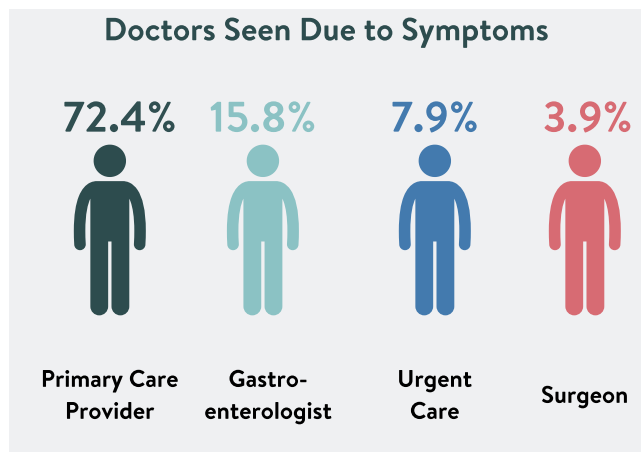
PATH TO DIAGNOSIS

The largest proportion of respondents saw their primary care provider due to their symptoms (72.4%), while 15.8% saw a gastroenterologist, and 7.9% saw urgent care providers or surgeons, respectively.

Nearly 43% of respondents felt that their CRC symptoms were dismissed by doctors due to their younger age, indicating a continued need to raise awareness and sensitize the health care community regarding EAO CRC.

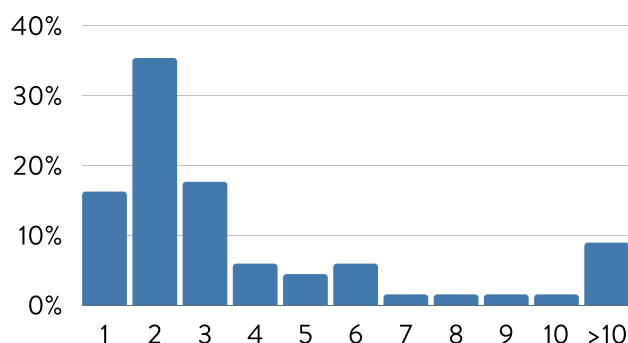
The largest proportion (35.3%) of respondents had two appointments before they were diagnosed, while 16.2% were diagnosed after one appointment and 17.6% were diagnosed after three appointments. An alarming proportion of respondents (8.8%) had more than ten appointments before they were diagnosed, indicating a long lag time from symptoms appearing, to seeking care to receiving a diagnosis.

A vast majority of respondents (78.1%) reported seeing two or more doctors prior to diagnosis, compared to 75% from the CC Alliance report results³.



42.9%
felt doctors dismissed
signs of CRC due
to age

Number of Appointments Before Diagnosis



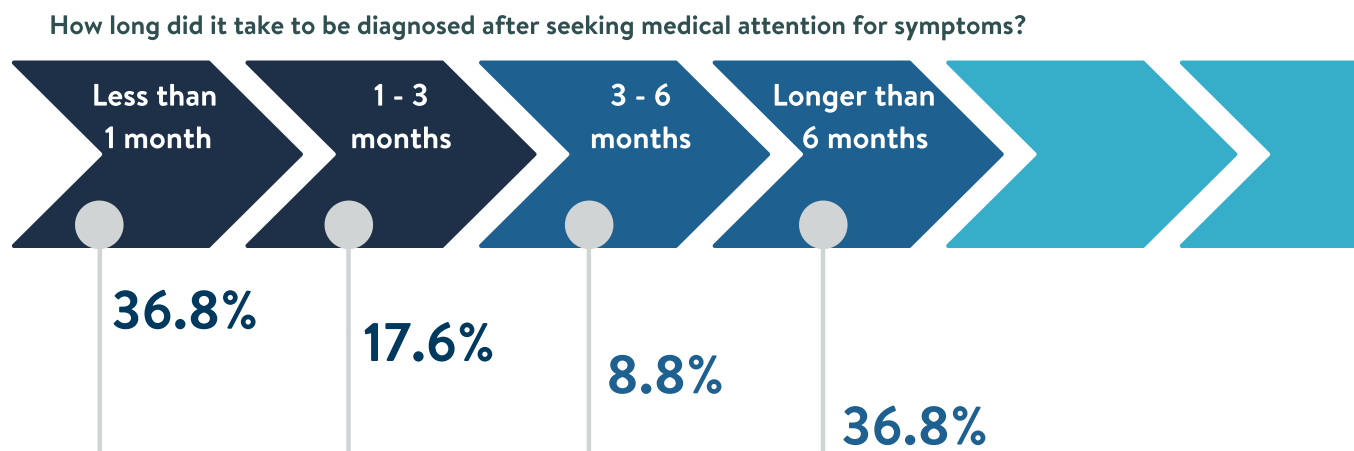
78.1% of respondents said they saw at least 2 doctors before diagnosis.



³ www.ccalliance.org/about/never-too-young/survey

DIAGNOSIS

PATH TO DIAGNOSIS

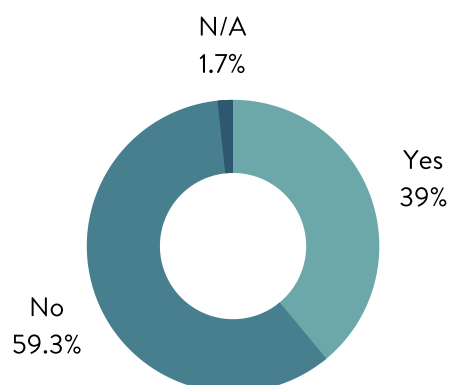


EAO CRC patients often take longer to be diagnosed after seeking medical attention compared to average age onset patients due to their younger age.

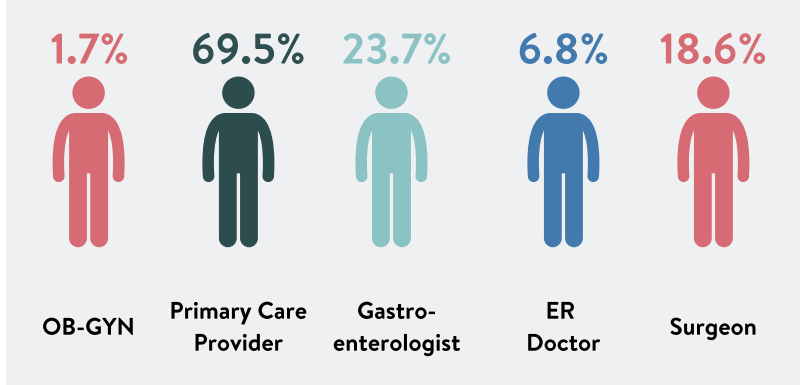
More than 50% of respondents stated that their diagnosis took less than 3 months (36.8% <1 month and 17.6% 1-3 months) after seeking medical attention. Equal proportions (36.8%) of respondents that were diagnosed in less than a month, also stated that diagnosis took longer than 6 months.

In terms of rectal exams prior to diagnosis, 59.3% stated they did not receive an exam as opposed to 39% who did. 69.5% of colonoscopies were performed by primary care providers, compared to 23.7% performed by a gastroenterologist.

Rectal Exam Prior to Diagnosis

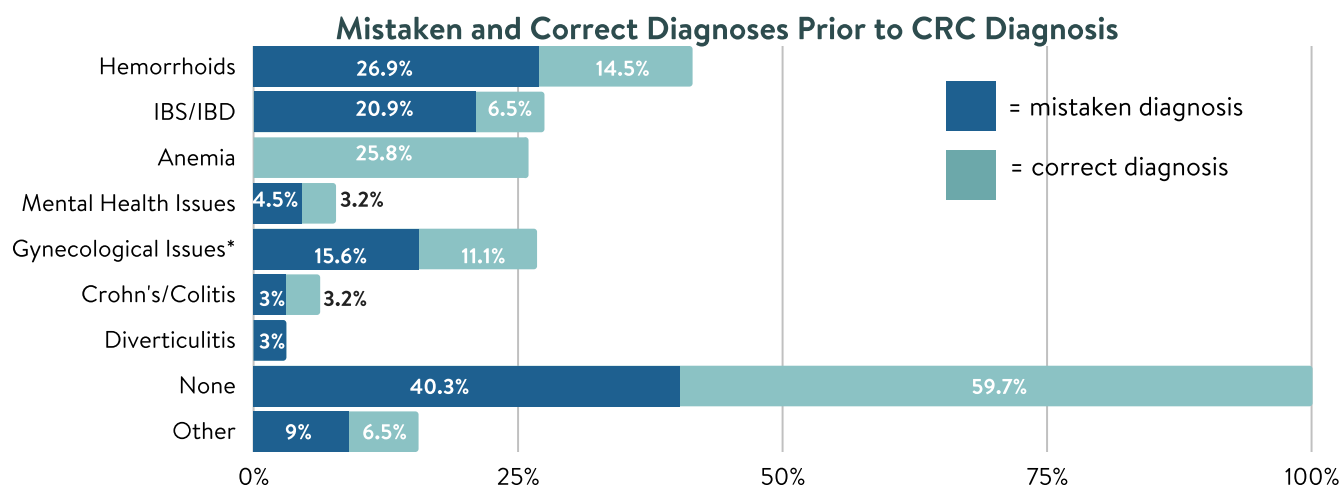


Doctor Leading To Colonoscopy



DIAGNOSIS

PATH TO DIAGNOSIS



The above graph shows a number of conditions that patients were mistakenly or correctly diagnosed with prior to their CRC diagnosis.

The most common incorrect diagnoses were hemorrhoids and IBD/IBS, while the most common correct diagnosis was anemia. Respondents also reported diagnoses of mental health issues, gynecological issues (often related to childbirth), Crohn's/Colitis and Diverticulitis.

*gynecological issues % based on population respondents who identify as female.

I WAS 30

Finally, I received a colonoscopy in November of 2011, more than 10 months after the symptoms started presenting themselves. I was very lucky. A lot of colon cancer patients do not experience noticeable symptoms until the cancer has progressed to stage IV. I was diagnosed with colon cancer on November 21st, 2011; a day that will be etched in my memory for the rest of my life.

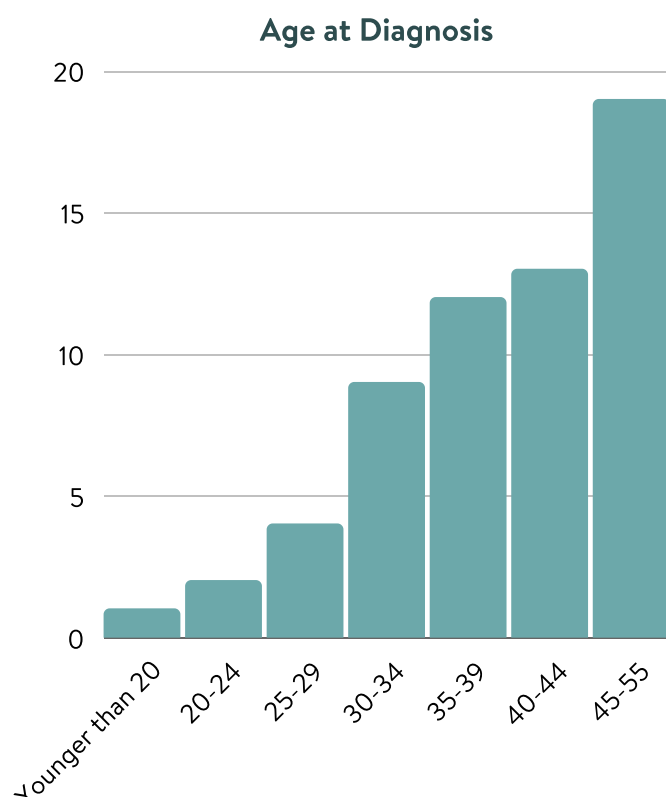
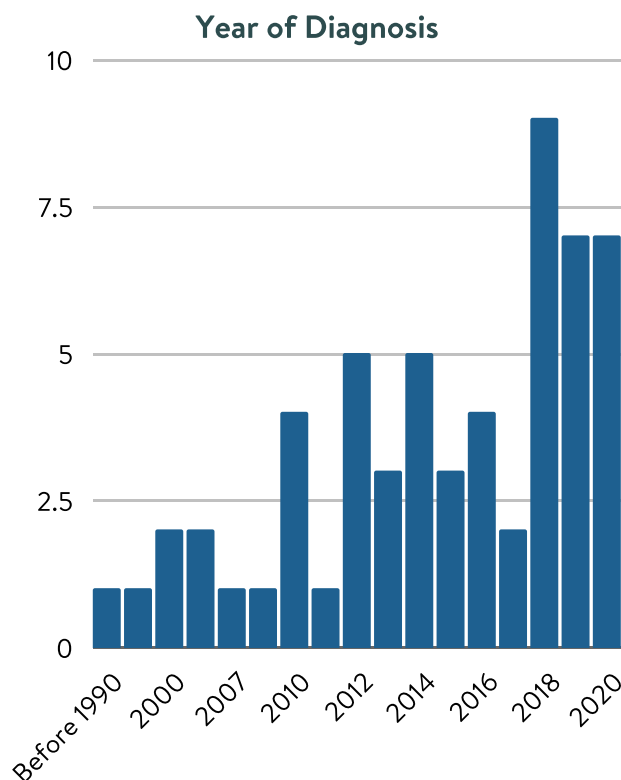
- Annette, 39

DIAGNOSIS

DETAILS OF DIAGNOSIS

Although respondents' diagnoses occurred over the course of the past 30+ years, the majority were diagnosed between 2018 and 2020.

This may be attributed to a more recent diagnosis causing patients to be more engaged and involved with organizations and initiatives at patient organizations such as CCC and increased recognition by healthcare providers of colorectal cancer as a differential diagnosis. This also indicates that the majority of patient experiences described in this report occurred in the last 5 years.



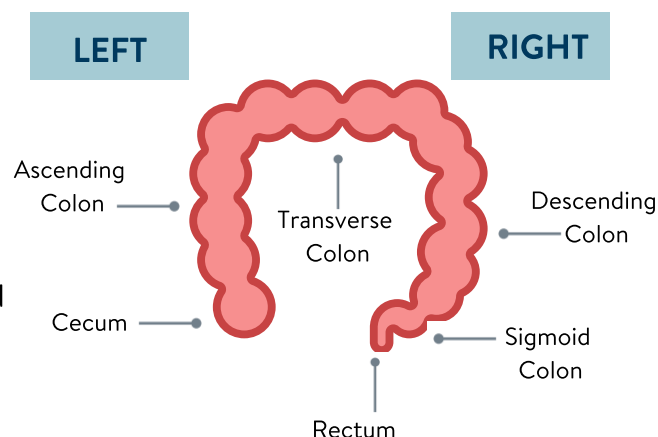
Age at diagnosis data shows a steady increase with each age category increase.

Nearly half of respondents were diagnosed above the age of 40, including 21% between the ages of 40-44 and 31.6% between the ages of 45-55, 20% between 35 and 39, 15% were between 30 and 34. Our participants also included patients diagnosed at ages 20 to 29 (9%) and one patient younger than 20.

DIAGNOSIS

DETAILS OF DIAGNOSIS

Of our respondents, two-thirds (32.4%) reported a diagnosis of colon cancer, while one-third (32.4%) reported rectal cancer. None of the respondents reported both colon and rectal cancer. 53.6% of respondents stated that the tumour was located on the left side, with 26.1% on the right side and 20.3% did not know. Additionally, 57.1% of male respondents were diagnosed with colon cancer, while 71.1% of female respondents were diagnosed with colon cancer.



As mentioned earlier in the report, EAO CRC patients are often diagnosed at a later stage compared to their older counterparts. Among respondents diagnosed with colon cancer, 77.3% were diagnosed at stage III or IV, whereas 72.7% of rectal cancer patients were diagnosed at stage III or IV. Interestingly, CC Alliance also reports 77% of respondents were diagnosed with Stage III or Stage IV metastatic disease³. Additionally, among those who were not aware of EAO CRC prior to diagnosis, 73.7% were diagnosed with stage III or stage IV (metastatic) disease.

The majority of respondents did not report metastases, however, among those who did, the liver and lymph nodes were most common, compared to liver and lung which were most common in the CC Alliance US report³.

Location of Tumour Matastases

Location	Frequency	Percentage
Liver	18	26.9%
Lung	4	6.0%
Lymph Nodes	13	19.4%
Peritoneum	4	6.0%
Other	8	11.9%
N/A	36	53.7%

STAGE I
11.8%

STAGE II
11.8%

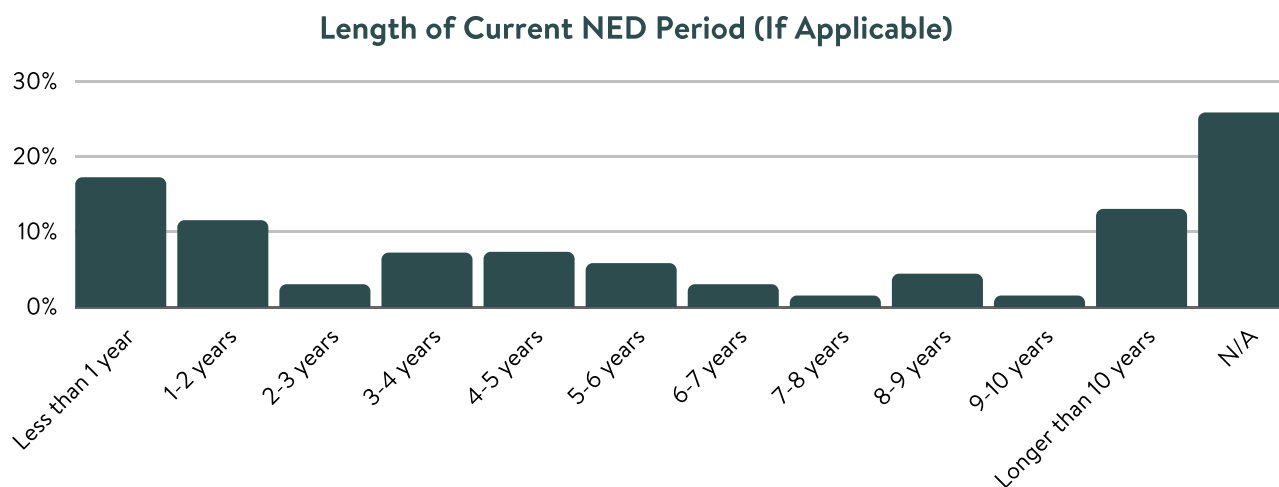
STAGE III
44.1%

STAGE IV
32.4%

³ www.ccalliance.org/about/never-too-young/survey

DIAGNOSIS

DETAILS OF DIAGNOSIS



Respondents were asked to identify how long they have had no evidence of disease (NED) status, if applicable. The largest proportion of respondents did not have NED status (25.7%), were NED for less than 1 year (17.1%) and longer than 10 years (12.9%). The remaining responses were dispersed between 1 and 10 years of NED status.

The CC Alliance also reports a large proportion of their respondents having NED status for less than 1 year, again indicating that patients with recent diagnosis and treatment may be more engaged with patient organizations and initiatives³.



Familial Adenomatous Polyposis are aggressive and unless you remove your colon, these polyps will become malignant (cancerous). At the time I was 21 years old, my brother Gabriel was 18, and Samuel, my older brother, was 27. In order to prevent cancer, we, as well as my mother, had to undergo a full colorectal surgery. Though it felt like a nightmare, fortunately, the very worst was prevented. If I hadn't spoken up at that appointment, polyps could have spread and who knows what my family's fate would be today.

- Vanessa, 32

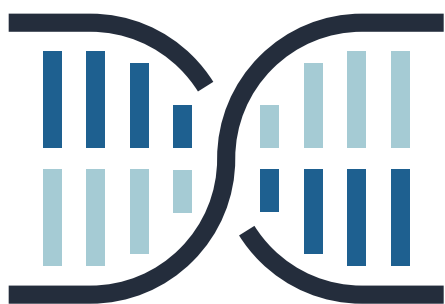
³ www.ccalliance.org/about/never-too-young/survey

GENETIC TESTING

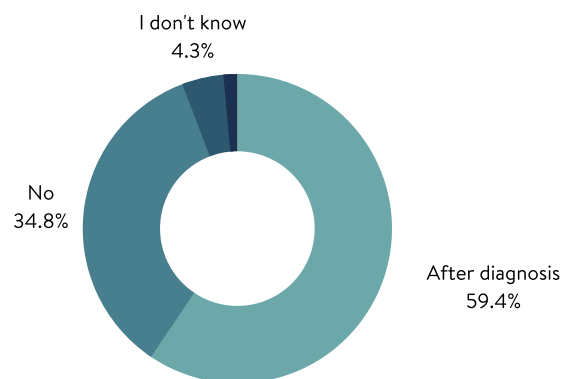
Genetic testing is an important step in recognizing patients' risk for colorectal and other cancers, and also for family members to take appropriate preventative steps.

Among 59.4% of our participants who had genetic testing before or after being diagnosed with CRC, a small proportion (16%) tested positive for one as opposed to 78% who tested negative.

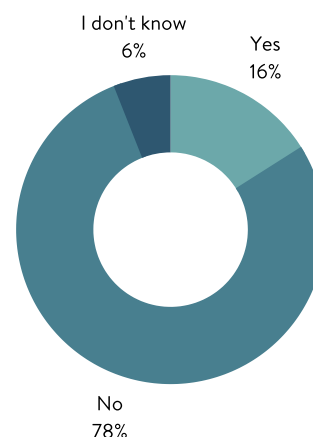
Respondents of this survey were also highly aware that their children and first-degree relatives should be screened 10 years before their own age of diagnosis. A minority (10.3%) were not informed about early family screenings.



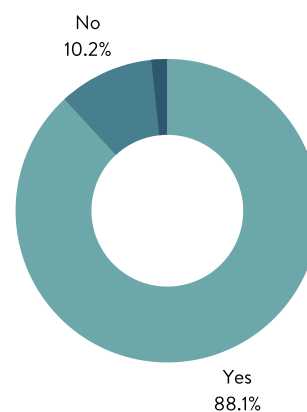
Did you have genetic testing before or after being diagnosed with CRC?



If yes, did you test positive for a genetic mutation?



Were you informed that your children and 1st degree relatives should be screened 10 years before your age of diagnosis?



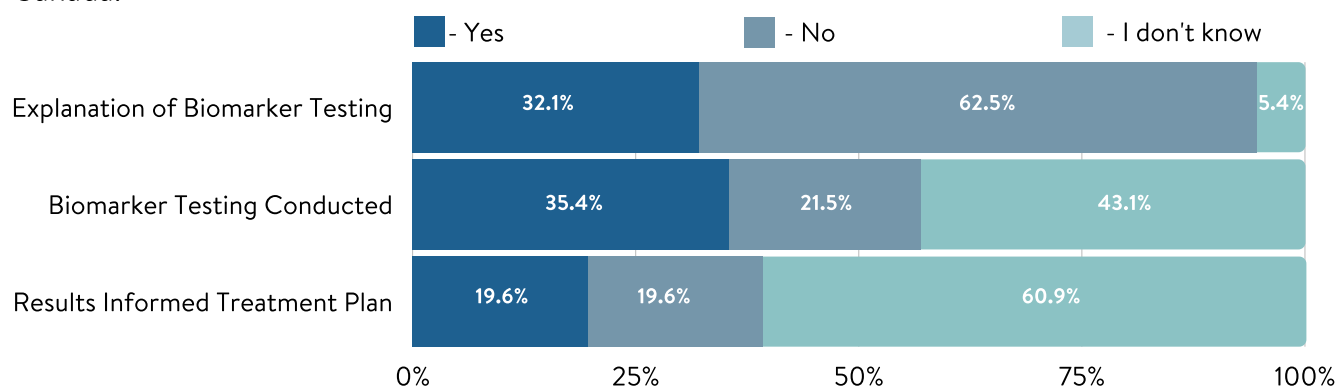
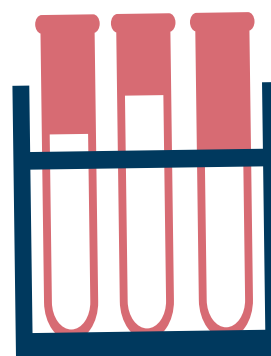
BIOMARKERS

Biomarker testing is a critical step in personalized medicine, where a patient's tumour is treated on its genetic makeup rather than the type of cancer more generally. Biomarker testing is a relatively new practice in Canada, and some provinces have adopted reflex testing (meaning that it is automatically tested for without clinician request) and in others, it must be ordered by a clinician after diagnosis. To learn more about biomarker testing, please see our [Get Personal](#) program.

Biomarkers, short for biological markers are molecules found in body tissues and fluid, including tumour tissue and blood. Biomarker testing involves the collection of a sample of a patient's tumour, either tissue biopsy or liquid biopsy (blood sample test), that will later be sent to a certified pathologist.

Less than half of respondents (32.1%) were informed about biomarker testing from their healthcare team, and a slightly higher proportion had their tumour tested for biomarkers (35.4%). Interestingly, a similar proportion (35%) of respondents from CC Alliance's US report received biomarker testing at the time of diagnosis³. A large proportion of respondents did not know if their biomarker testing results were used to inform their treatment plan (60.9%).

Of those who found out about biomarker testing from another source (outside of their healthcare team), 62.5% used internet research or online support communities, and 12.5% discovered biomarker testing through Colorectal Cancer Canada.



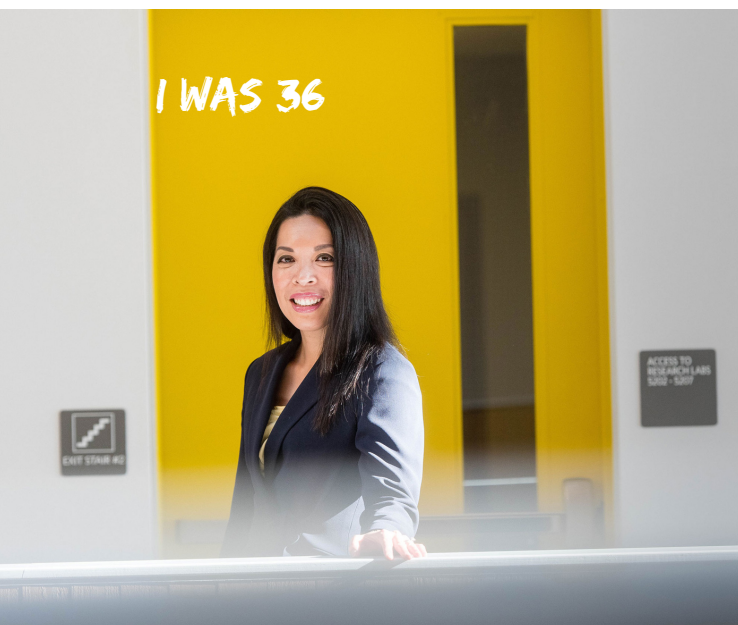
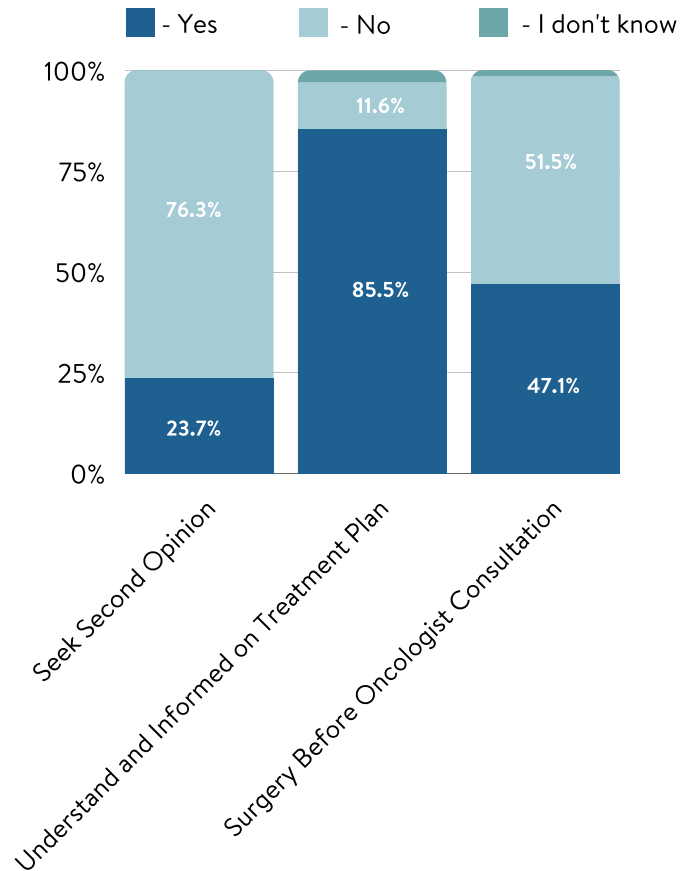
³ www.ccalliance.org/about/never-too-young/survey

TREATMENT

Seeking a second opinion and understanding and being informed regarding their treatment plan can empower patients and create a more trusting relationship with their medical team.

A small proportion of respondents (23.7%) sought a second opinion, compared to 39% of respondents in CC Alliance's survey, based in the US³.

More than 85% of respondents felt informed and understood their treatment plan, and 47.1% of respondents proceeded with surgery before an oncologist consultation.



The emotional impacts of colorectal cancer did not just hit me, they also hit my loved ones. I will never forget being hunched over the toilet, so sick after my first chemotherapy infusion, with my little girl watching. She was scared but she didn't want to leave me and instead, kept handing me towels, water...whatever could help. There is more to share about my experiences but what's more important is to share the importance of knowing one's body and taking action when things don't look "okay" down there.

- Mary, 40

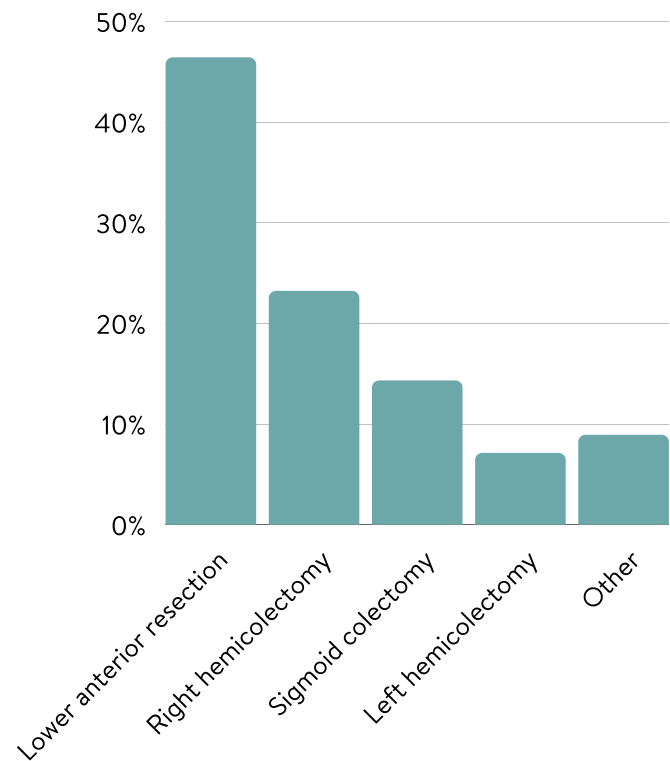
³ www.ccalliance.org/about/never-too-young/survey

TREATMENT

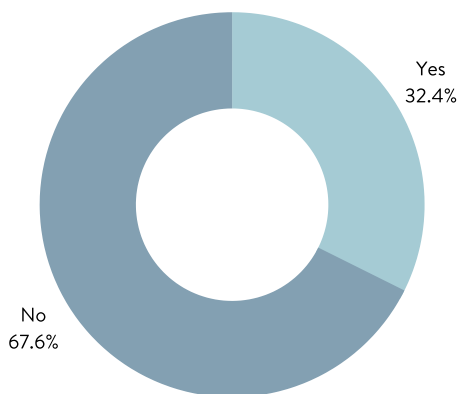
Treatment for colorectal cancer varies by patient, and there are a number of different surgery types depending on a patient's diagnosis.

The vast majority of respondents (88.1%) were candidates for surgery at the time of diagnosis. Of these patients, 46.4% had a lower anterior resection, 23.2% had a right hemicolectomy, 14.3% of our participants underwent a sigmoid colectomy, 7.1% underwent a left hemicolectomy.

In terms of radiation treatment, 67.6% did not undergo radiation treatment as opposed to 32.4% who did.



Did you have radiation treatment?



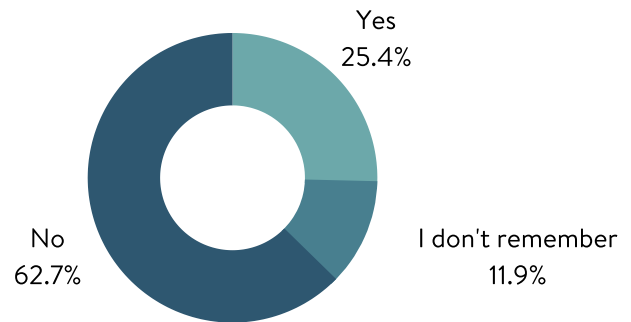
CLINICAL TRIALS

Clinical trials (CTs) are useful in determining new and effective treatment methods for CRC at all stages. Clinical trials can analyze new combination therapies, surgery and radiation techniques, new drugs, and more.

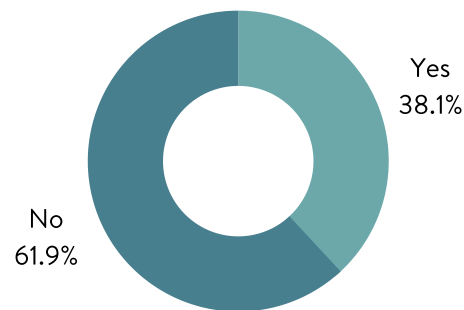
The majority of patients' doctors did not mention clinical trials at diagnosis (62.7%) with 11.9% of respondents who do not remember. Additionally, 61.9% of respondents did not feel sufficiently informed about clinical trials.

However, patient and caregiver attitudes toward clinical trials were positive, with 75.4% of respondents stating that they would consider participating and 68.8% of respondents considering clinical trials very important for EAO CRC patients.

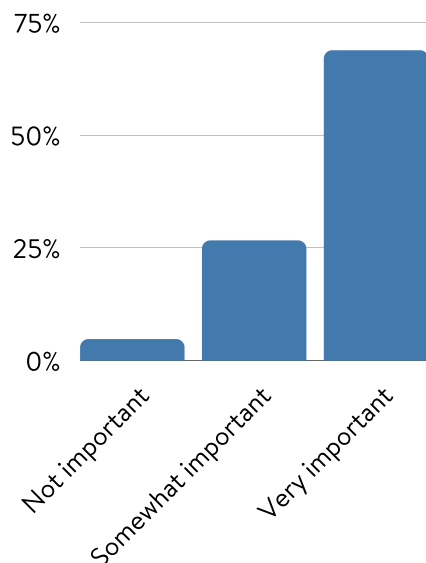
Did your loved one's doctor mention clinical trials at diagnosis?



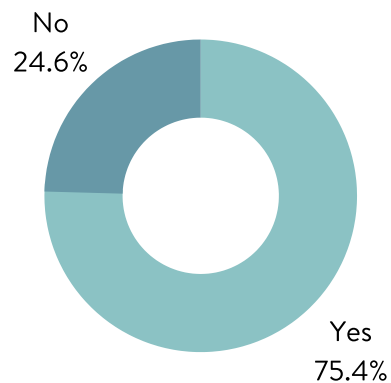
Did you (patient and/or caregiver) feel sufficiently informed about clinical trials?



Importance of Clinical Trials for EAO CRC Patients



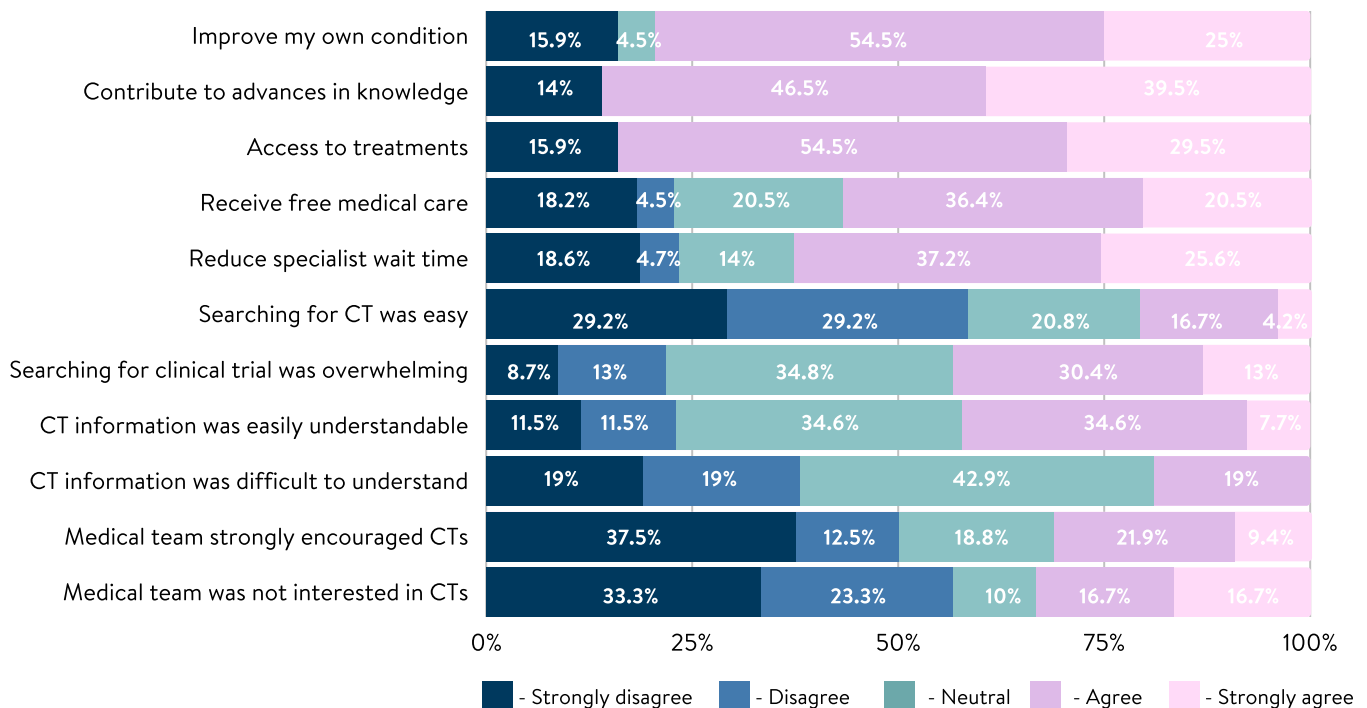
Would you consider participating in a clinical trial?



CLINICAL TRIALS

DETAILS OF DIAGNOSIS

Please rate your experiences with the following:



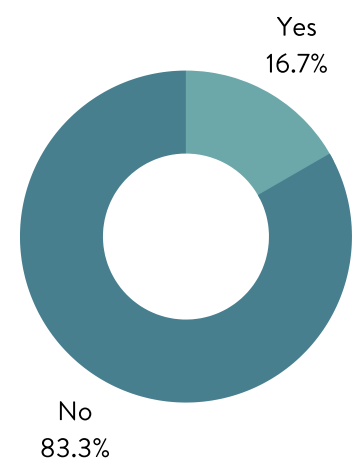
Respondents were asked to rate their experiences with a number of aspects of clinical trials.

Notably, a large proportion of respondents strongly disagreed that searching for a CT was easy and that their medical team strongly encouraged CTs.

A large proportion of respondents strongly agreed that CTs contribute to advances in knowledge, that they reduce specialist wait time and that they could improve the patient's condition. Additionally, less than half of the respondents agreed or strongly agreed that CT information was easily understandable, indicating that the information may need to be more accessible and easy to understand for patients and caregivers.

Of our respondents, 16.7% participated in a clinical trial.

Did you participate in a clinical trial?



CLINICAL TRIALS

PATIENT EXPERIENCES

“ It's a 10 year trial, so it's still ongoing. I had a slightly different chemo than standard (I did FOLFIRINOX instead of FOLFOX). It's been good. I appreciate the added scans, they provide reassurance of NED more often than standard treatment. My coordinator has been great. ”

“ It was fantastic, I had excellent care by trial team which included being monitored extra closely. The biggest benefit was receiving the study drug Avastin which my doctors thought would greatly improve my chances of survival ”

“ By the time I refused surgery, it was too late to be admitted to the local CT as I had already had CRT and remain frustrated that the CT option was never introduced.”

“ I had a very bad experience. I believe my sepsis was a result of a clinical trial in a substance to aid in the closure of my rectal resection caused by a leak at the surgical site. All my symptoms were missed. I then ended up with an emergency ileostomy. A meningitis-like illness a year later and a few obstructions along the way. I was essentially Sick for nearly three years. I think I was treated quite poorly actually and many of my symptoms pre and post-surgery were ignored until an emergency arose. ”



Cancer doesn't discriminate. That was a big surprise when I was at the hospital during my chemo and IV treatments. I was walking in thinking I was going to be in a room full of older people. I was gobsmacked by the amount of people that looked younger, around my age. From all walks of life. It was not at all what I expected. It really was people of different backgrounds, different ages, different ethnicities, and I was shocked.

- Pierre, 40

SURVIVORSHIP & OUTCOMES

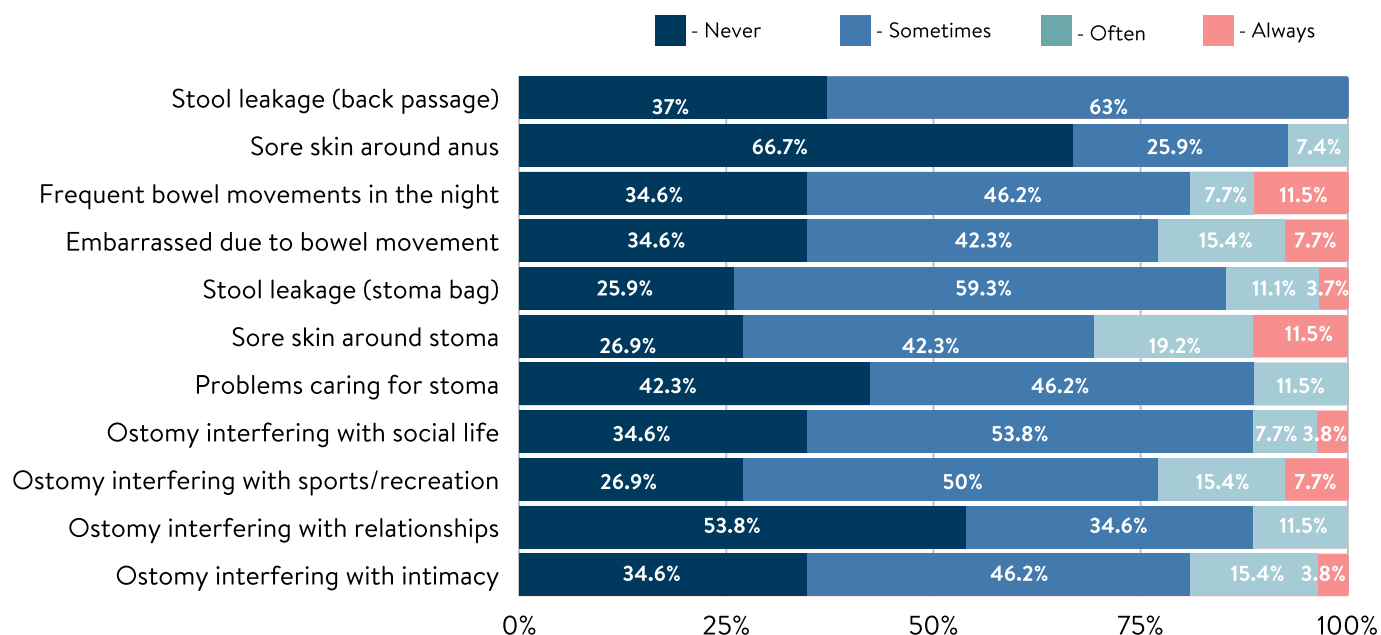
OSTOMY EXPERIENCES

Nearly half of our respondents have or had a colostomy or ileostomy (46.8%), which is slightly higher than the results (41%) from the CC Alliance's report³.

Among those who have or had an ostomy, a large proportion of respondents reported experiencing stool leakage (from their stoma bag and back passage), sore skin around the stoma, frequent bowel movements in the night and embarrassment due to bowel movements.

In terms of effects on personal life, a large proportion of respondents reported that their ostomy interferes with sports/recreation and intimacy, where a smaller proportion reported that their ostomy interferes with their relationships.

Do/did you have a colostomy or ileostomy?



³ www.ccalliance.org/about/never-too-young/survey

SURVIVORSHIP & OUTCOMES

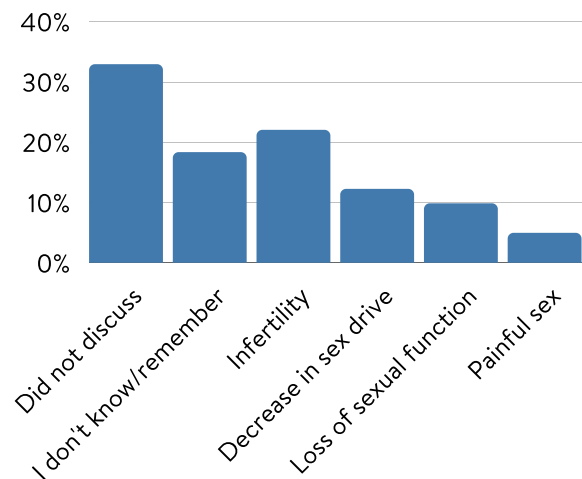
SEXUALITY AND FERTILITY

When asked about sexuality and fertility, the largest proportion (32.9%) responded that their healthcare providers did not discuss sexual side effects before the beginning of treatment. Providers who did, mainly discussed infertility (22%) with their patients and/or caregivers. A decrease in sex drive (12.2%), loss of sexual function (9.8%) and painful sex (4.9%) were less likely to be discussed.

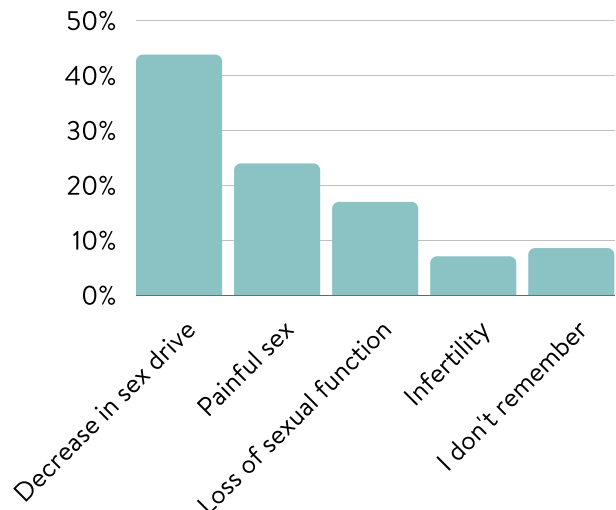
Patients reported a decrease in sex drive (43.7%) as the most common sexuality-based side effect, followed by painful sex (23.9%), loss of sexual function (16.9%), infertility (7%) and 8.5% of respondents do not remember if any of these side-effects presented after treatment.

More than half of respondents (53.7%) experienced a partial or full loss of sexual function following treatment, while 46.3% did not experience any loss of sexual function.

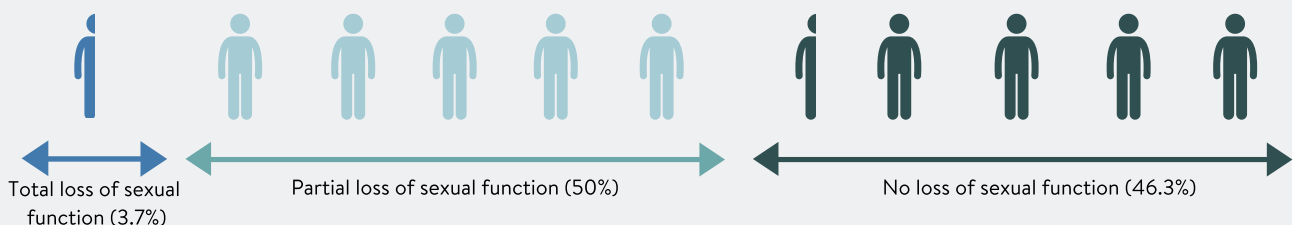
Did any of your providers discuss sexual side effects due to radiation/surgery before treatment began?



Did you experience any of the following after treatment?



50% of respondents experienced a partial loss of sexual function following treatment.



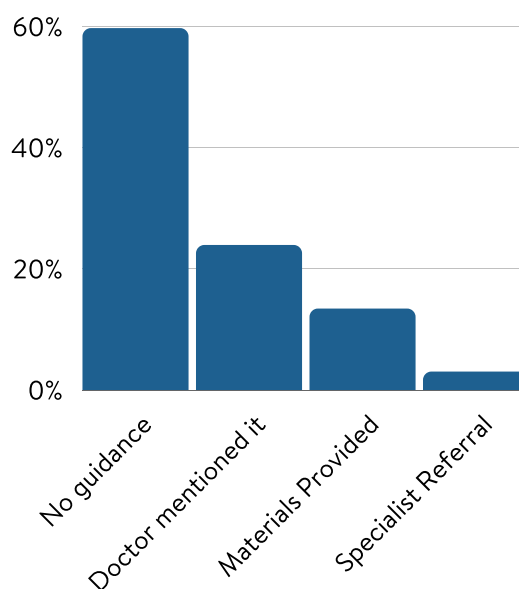
SURVIVORSHIP & OUTCOMES

SEXUALITY AND FERTILITY

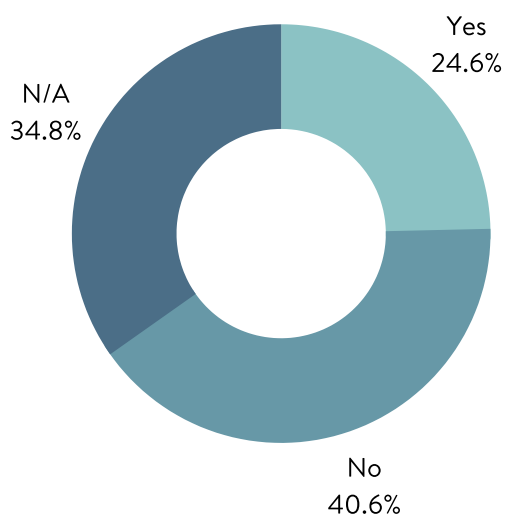
Despite the majority of respondents reporting a loss of sexual function to some degree, the majority of respondents (59.7%) did not receive any guidance on previously mentioned issues from medical staff. However, 23.9% reported that their doctor mentioned these issues, 13.4% received materials and 3% received a specialist referral.

A small proportion (24.6%) of respondents discussed fertility preservation with their medical professional and 17.9% were left infertile following treatment. However, it is important to note that a large proportion of our respondents selected N/A for questions related to fertility and fertility preservation which suggests that this may not have been an issue of concern at the time of diagnosis and/or treatment.

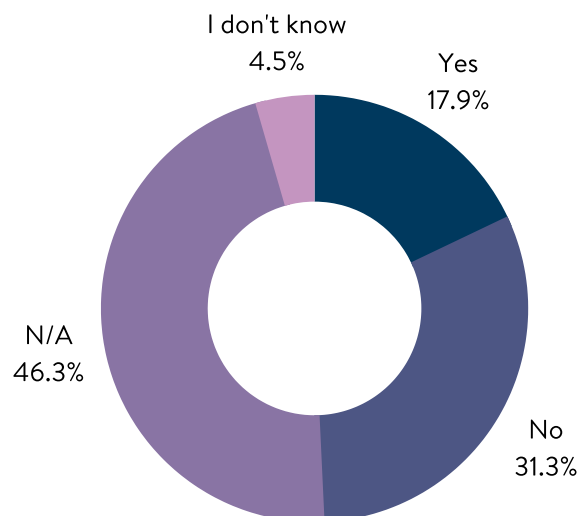
Have you received any guidance from medical staff regarding sexual health?



Did a medical professional talk to you about fertility preservation at any point?



Did treatment leave you infertile?



SURVIVORSHIP & OUTCOMES

SEXUALITY AND FERTILITY: PATIENT EXPERIENCES

“ Even though I was not sterile there was a period following chemo therapy that they believed I was. It was emotionally devastating to be 23 and not have the choice to have a baby. Luckily for me, things turned around and my body was able to fully recuperate. ”

“ Basically don't have sex anymore, more painful that it's worth. No enjoyment, no desire. ”

“ Major erectile dysfunction issues dismissed by my GP, Medical Oncologist and Surgical Oncologist ”

“ I received NO information about radiation impact on sexual functioning. I learned about vaginal dilators from a friend, not from a professional. Dilation saved what function I could have. Now, sex is impossible due to painful pelvic metastasis.. ”

“ I do not know if treatment has left me infertile. I did undergo fertility preservation prior to chemotherapy. ”

“ Harder to maintain an erection and then the worry adds to the issue, overthinking it compounds the issue. ”

“ The ileostomy made me feel sexually unattractive; however, I had a very supportive husband (we had sex only once during my 1 year treatment period)... Despite some discomfort, I continue to be sexually active with my supportive husband but it has been irregular and infrequent since diagnosis. ”

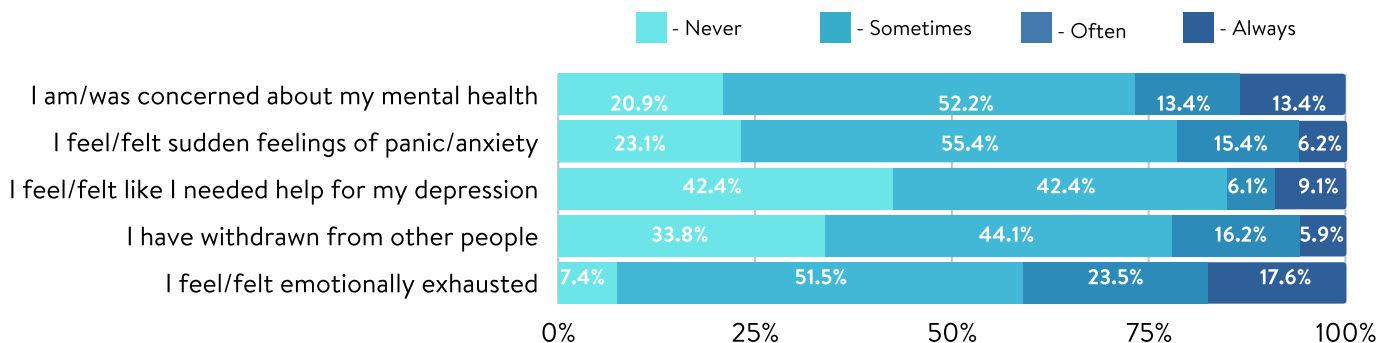
“ I have lost most of my sex drive. My bladder is prolapsed so was sent to an on/gym. He finally asked me about my sex drives. I'm on a hormonal cream. ”

SURVIVORSHIP & OUTCOMES

EMOTIONAL HEALTH

From our respondents, more than 75% of respondents noted concerns with their emotional health, which clearly illustrates the psychological impact that an EAO CRC diagnosis has on patients. Notably, a much smaller proportion (57.6%) felt that they needed help for these issues. This indicates a remaining stigma around treatment and support for these issues.

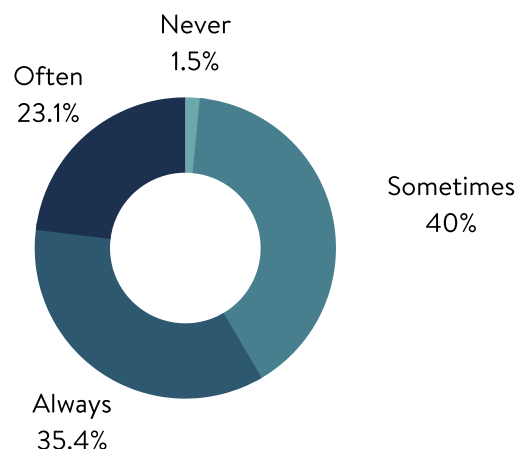
A small proportion (7.4%) of respondents have never felt emotionally exhausted, with the majority (51.5%) feeling this way sometimes, 23.5% often, and 17.6% always.



FEAR OF RECURRENCE

Fear of recurrence is a common and sometimes debilitating side-effect for many EAO CRC patients.

Of our respondents, 97.5% reported fearing recurrence to some degree, and 35.4% reported that they always feared recurrence. A large proportion of respondents (66.6%) reported that fear of recurrence interferes with daily activities to some degree. These proportions are nearly identical to CC Alliance's report, indicating that 97% of their respondents feared recurrence and 66% reported that this fear interferes with daily activities³.



³ www.ccalliance.org/about/never-too-young/survey

SURVIVORSHIP & OUTCOMES

FATIGUE

Of respondents, 22.4% - 27.5% responded "always" or "often" to fatigue impacting their quality of life and everyday activities, which is significantly lower than the responses found in the CC Alliance's US report³. The CC Alliance found that between 80% - 90% of respondents' quality of life was impacted by fatigue³.

22.4%

Answered "always" or "often" to:

How often did you have to limit social activities due to fatigue?

25.7%

Answered "always" or "often" to:

How often did your fatigue make it difficult to make decisions?

27.5%

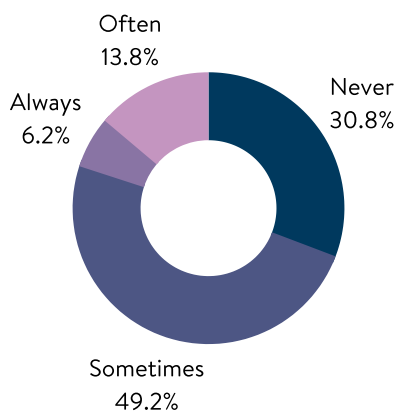
Answered "always" or "often" to:

How often were you too tired to do everyday activities?

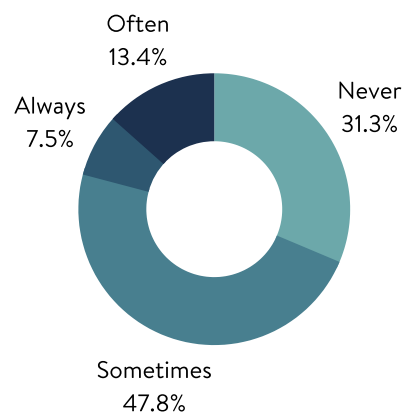
PAIN

Experiencing or fearing pain is a common and debilitating side-effect of EAO CRC. Nearly half of our participants (49.2%) stated they sometimes worried about pain, as opposed to 6.2% who always worried and 30.8% who never worried about pain. 31.3% claimed that pain never interfered with their families and everyday lives, compared to 7.5% who said that pain always caused an interference.

How much did/do you worry about pain?



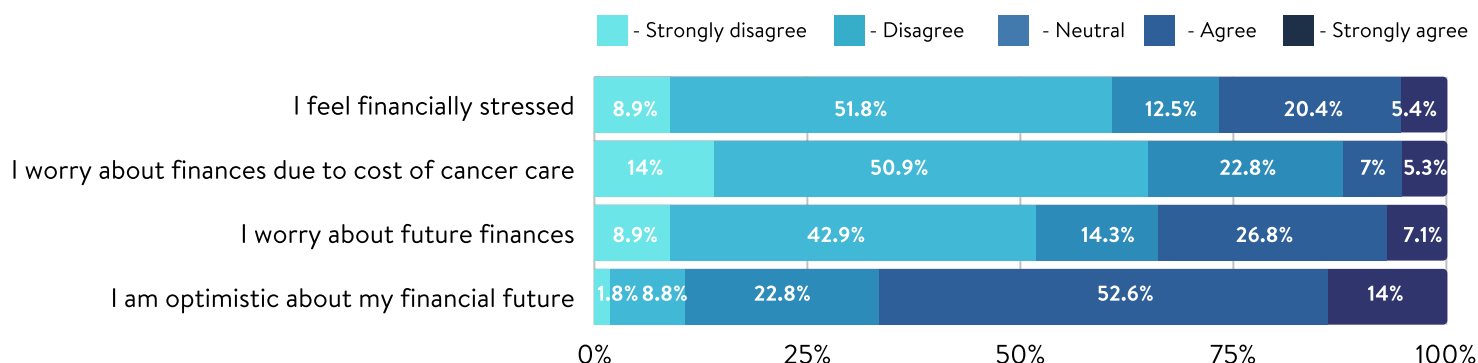
How much did/does pain interfere with your family and everyday life?



³ www.ccalliance.org/about/never-too-young/survey

SURVIVORSHIP & OUTCOMES

FINANCIAL HEALTH

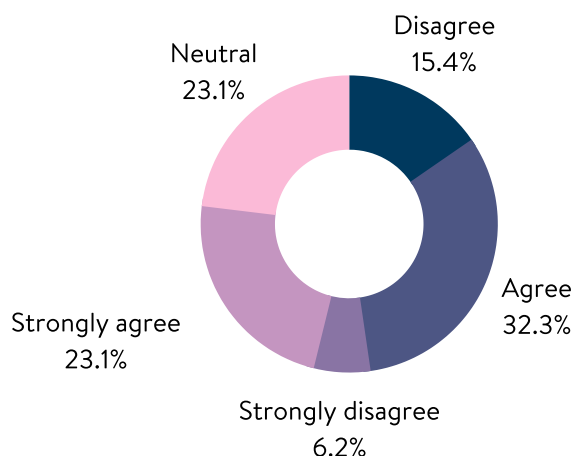


Despite Canada's universal health care system, EAO CRC patients and caregivers face many financial challenges as a result of their diagnosis. Some patients' treatment are only partially or not covered at all under their insurance coverage, many patients and caregivers are forced to leave their place of employment, and nearly all patients face costs related to hospital visits and associated travel.

The majority of respondents do not feel financially stressed and do not worry about finances due to the cost of cancer. Additionally, two-thirds of respondents feel optimistic about their financial future. However, it is important to note that the sample of respondents were highly educated compared to the general population.

Interestingly, although our respondents reported better financial health than CC Alliance's primarily US respondents, our respondents were less satisfied with their insurance coverage compared to CC Alliance's respondents³. 55.4% of our respondents agreed or strongly agreed that their insurance coverage was adequate, whereas 71.3% of CC Alliance's respondents agreed or strongly agreed³.

My insurance offered adequate coverage for treatment needs.



³ www.ccalliance.org/about/never-too-young/survey

SURVIVORSHIP & OUTCOMES

EMPLOYMENT

The vast majority of our respondents (78.3%) were employed or in school at the time of diagnosis, however, nearly all of them (76.8% of the full responder sample) had to take a leave/quit a job or school. Many EAO CRC patients are at the peak of their career when diagnosed, therefore this professional interruption may take a significant and long-lasting toll on respondents' career goals and financial stability. However, fortunately, 79.2% of responders' employers accommodated their schedule.

78.3%

of respondents were
employed at the time of diagnosis

76.8%

of respondents had to take a
leave/quit a job due to diagnosis

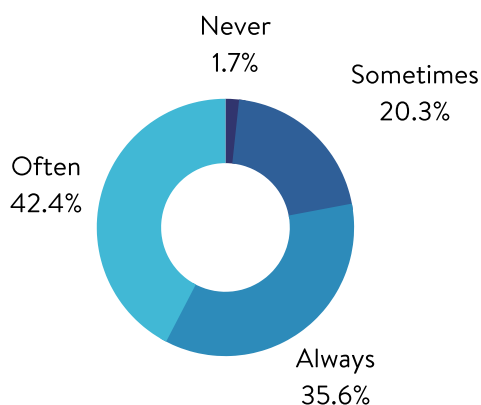
79.2%

of respondents' employers
accommodated their schedule

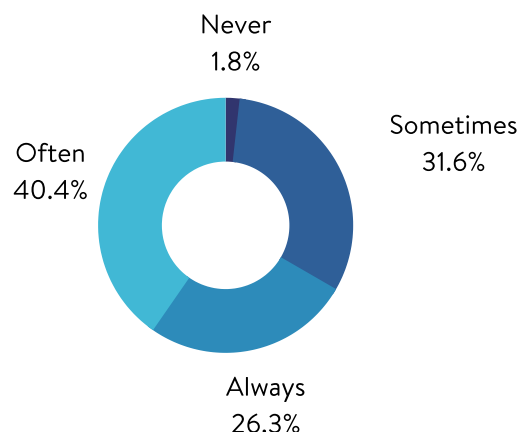
COPING

A large proportion of our respondents (78%) feel that they are often or always able to enjoy their life, while a very small proportion (1.7%) feel that they are never able to. This is slightly higher than enjoyment of life reported by CC Alliance's, which was 69.5% who reported often or always enjoying life³. Additionally, 66.7% of respondents are often or always satisfied with how they are coping with their illness, compared to 59% of respondents from CC Alliance's survey³.

I am able to enjoy life.



I feel satisfied with how I am coping with my illness.



³ www.ccalliance.org/about/never-too-young/survey

BIGGEST CHALLENGES

PATIENT PERSPECTIVES

Diagnosis

"A failing medical system. Being dismissed by family doctor, several missed opportunities including missed tumour on CT Scan 10 months before diagnosis. I had to self-advocate and self-diagnose!"

"Getting diagnosed. It took 10 years of complaining to different doctors before finally being diagnosed."

"Despite going to many doctors for a 3 year period I was dismissed and told I only had IBS. No colonoscopy was offered. I believe this was due in large part to my age."

"I could not get 4 doctors to even consider cancer in my case as I was under 50, despite having daily rectal bleeding, an immediate family history, and a positive FOBT test. It took 2 years to get endoscopy. Physician ignorance resulted in my now terminal status."

"Convincing my doctor that there really was something wrong. Afraid of being perceived as a hypochondriac."

"Lack of understanding by medical professionals about early onset & no early screening in Quebec."

"Lack of doctor assuming colon cancer was a possibility due to young age and lack of family history"

Treatment and Follow-Up

" My stoma for 9 months."

"Lack of data regarding long term chemo effects, like menopause."

"Aftercare information, ie. Now appear to be lactose intolerant, wasn't before."

"Lifelong bowel problems following treatment that prevent me from working. I beat cancer but my life will never be "normal" again."

"Follow up 2 surgeries."

"Medical professionals taking me seriously, lack of follow up—particularly mental health as it was non-existent, and nearly 3 years of illness."

BIGGEST CHALLENGES

PATIENT PERSPECTIVES

Anxiety & Recurrence

"The fact that I now have (hopefully) many years to live, but with the ongoing anxiety associated with future cancer diagnoses."

"Having to worry about cancer and its reoccurrence at such a young age."

"Worry about my children if cancer comes back."

"Biggest challenge is just making it through every day of surgery recovery fear of reoccurrence"

"Navigating my future: Career. Family. Retirement. My emotions are all over the place. Every day is a struggle...with one thing or another."

"Fear of not living to see my children grow up was paramount. Living with a colostomy was also an issue though not an insurmountable obstacle."

"Knowing I'll be leaving my kids before I feel like I should."

"The thoughts of dying and leaving two small children without their mom, and likely only a few memories of me."

"Survivor's guilt, mostly."

"The anxiety of recurrence. Would be nice to have access to liquid biopsy testing like in the US."

"Uncertain future, not much known about the long term implications for young survivors."

Lack of Support

"Lack of peer support, often cancer patients and survivors especially with colon cancer are much older."

"Having very few peers that can relate to a life altering diagnosis."

"No one to talk to about my illness"

Finding support groups; for example. needed help with Return to work..nothing available."

BIGGEST CHALLENGES

PATIENT PERSPECTIVES

Other

"As a self employed psychologist, temporarily shutting down and restarting my practice has been difficult. Worries about recurrence are up there too, but are not currently impairing."

"The sexual dysfunction is a bit annoying as was being dismissed when I asked about preserving sperm."

"Taking care of my young family."

"Not a lot of research or knowledge. Didn't understand what things like T2 N2 MX carcinoma of the rectosigmoid meant."

BIGGEST CHALLENGES: CAREGIVER PERSPECTIVES

"Lack of people who can relate."

"Waiting so long for my loved one to be diagnosed and then it being so far along that within 2 months he died. It shouldn't have happened that way. Also the expenses and drugs that are not covered."

"At time of diagnosis (stage IV with full bowel instruction) we had a one year old and I was pregnant. Caring for my husband and my children was only possible because of help from our extended family."

"Watching your child suffer and see the fear in her eyes."

"Watching my loved one go through all the painful treatments at a young age as well as the diagnosis. Truly heartbreaking for me."

"Money."

Conclusion

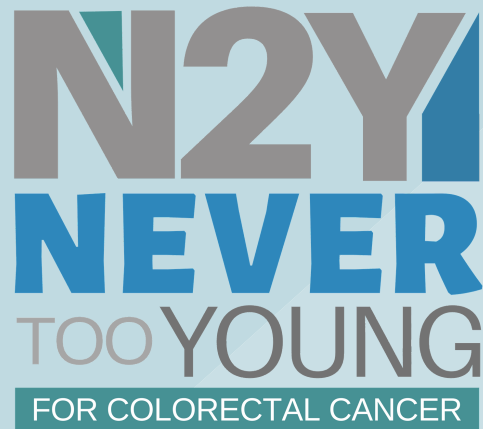
In conclusion, the Never Too Young: Early-Age Onset Experiences in Canada survey identified a number of important gaps experienced by Canadian patients. Unfortunately, the survey results suggest that EAO CRC patients continue to be diagnosed at a late stage. This could be attributed to the low perceived risk of patients under 50, combined with challenges and misinformation within the healthcare community around EAO CRC. Patients often waited months before seeking medical attention, and most patients had multiple appointments and multiple doctors prior to being diagnosed. This points to a knowledge gap both within the Canadian public and within the medical community. As part of our mission, Colorectal Cancer Canada aims to continue to decrease this knowledge gap through awareness-raising initiatives.

In addition, the survey results identified that although the majority of respondents were not introduced to clinical trials at diagnosis, the majority of them had positive attitudes around clinical trials. The majority of respondents were not introduced to biomarker testing at diagnosis and did not have the testing done. This identifies a need for improved culture and policy around clinical trials, biomarker testing and shared decision making between patients and medical teams.

The survey also identified the impact that an EAO CRC diagnosis has on mental and emotional wellness, with one of the largest concerns among patients being long-lasting and debilitating fear of recurrence. Patients cited sexual function and fertility issues and many did not receive information around these issues prior to treatment. Most patients cited concerns with their mental health, however, a fraction of these patients felt that they needed help. This suggests that a stigma remains around mental health issues, and patients may not be supported in seeking the help that they need to navigate a life-changing diagnosis.

Colorectal Cancer Canada will use the information gathered through the survey to inform our programs and advocacy initiatives, with the ultimate goal of reducing the gaps mentioned above. Specifically, the Never Too Young program will produce a Patient Toolkit resource and an EAO CRC Clinical Best-Practices model in the coming year. We would like to thank all of the patients, survivors and caregivers who participated in this survey. We would also like to thank our Expert Advisory Panel for their input and partner organizations who shared the survey with their patients. This initiative was made possible by the generosity of Ellen Walker-Matthews and Tom Matthews on behalf of their son Chris Gordon Walker who passed away at the age of 29 due to stage IV colorectal cancer.

If you have any questions regarding Never Too Young, please contact Program Manager, Elle Doherty at elled@colorectalcancercanada.com.



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Colorectal Cancer Canada (CCC) is the national Canadian not-for-profit corporation dedicated to colorectal cancer (CRC) awareness and education, support for patients and their caregivers, and advocacy on their behalf. CCC is comprised of dedicated volunteers, members, management and is governed by a national Board of Directors. A Medical Advisory Board, made up of top healthcare professionals in the field of colorectal cancer, provides counsel to CCC to ensure members are kept abreast of the latest medical advances in the diagnosis and treatment of the disease.

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