

# Never Too Young Survey Report 2020

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Findings from an online survey  
of young-onset colorectal cancer  
patients and survivors.

# Executive Summary

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Young-onset is a term that refers to the segment of patients diagnosed with colorectal cancer under the age of 50. Research from 2014 highlighted grim predictions for the young-onset population: an increase in colon cancer diagnoses, with the largest increase in the 20-34-year age group of 37.8% by 2020 and 90.0% by 2030. The increase for rectal cancer is also highest in the 20-34-year age group of 49.7% by 2020 and 124.2% by 2030.

With a mission to support this community, the Colorectal Cancer Alliance launched an annual Never Too Young Survey to better understand critical unmet needs of the young-onset population. In 2019, the Alliance's fourth survey was developed, disseminated, and analyzed. This report highlights the critical findings from this Never Too Young Survey of 884 patient and survivor respondents who were in treatment or had finished treatment (results from the 204 caregiver respondents will be separately analysed and shared). The median age of patient and survivor respondents was 42.

The survey addressed myriad topics from pre-diagnosis through survivorship, including demographics, community, lifestyle prior to diagnosis, symptoms and diagnosis, knowledge of biomarkers and clinical trials, and quality of life.

Most respondents (79%) are women, and 90% of respondents are white or Caucasian. The majority (75%) have at least a college degree, with 40% having professional or graduate degrees. Most responses (87%) are from the United States, with representation from seven other countries. Sixty percent of respondents live in a suburb, 19% in an urban area, and 21% a rural community.

Most (77%) indicated that they were in excellent or good health prior to diagnosis and 21% reported that they were in good health. African American respondents were four times more likely than Whites to report that they were in poor health prior to diagnosis, and poor health was not reported by Native Americans and Asian/Pacific Islanders. Eighty-five percent of respondents reported that they were active or very active prior to diagnosis, with 15% reporting a sedentary lifestyle. Men consumed fewer fruits and vegetables than women, and people in rural communities consumed less than those in urban or suburban areas. Based on BMI calculations using self-reported diet, exercise, and overall health parameter, most respondents were overweight (30%) and obese (30%) prior to diagnosis, while 33% were normal weight, and 7% were underweight.

Most respondents (81%) reported that they had at least three symptoms of colorectal cancer prior to diagnosis, and the majority (62%) waited more than three months to go to the doctor. When they did seek help, they saw multiple doctors and had multiple appointments before being correctly diagnosed with colorectal cancer. More than 75% of respondents saw at least two different doctors prior to a correct diagnosis, and 11% of those patients visited 10+ doctors. For those who only saw one doctor, many required multiple visits before they were referred for a colonoscopy and ultimately diagnosed. Forty percent of respondents felt that their symptoms were dismissed by doctors; this finding was even more significant in the 19-39-year age range. Hemorrhoids were the most frequent diagnosis prior to a correct diagnosis.

Of the 884 respondents, 77% were diagnosed with stage III, indicating lymph node involvement, or stage IV metastatic disease. The survey found that a larger percentage of colon cancer patients and survivors were diagnosed at stage IV, and most rectal cancers were diagnosed at stage III. Only 39% of respondents sought a second opinion before starting treatment.

Thirty-five percent of respondents had genetic testing at diagnosis and 38% had testing during treatment. This difference may be attributed to the year when these patients were diagnosed, as treatment guidelines and standards of care have changed in recent years. At diagnosis only 27% of oncologists discussed clinical trials. An overwhelming number of stage III (70%) and stage IV (61%) patients did not have any discussion of clinical trials before starting treatment.

Survey results demonstrate the psychological impact of a colorectal cancer diagnosis in the young-onset community. Nearly 75% of survey participants shared concern about their mental health and 64% responded that they have needed help for depression. Ninety-five percent of respondents said that emotional exhaustion impacted their lives at least some of the time, and more than 50% said it impacted their lives always or often.

Along with mental exhaustion, young-onset colorectal cancer patients also suffer with fear of recurrence, fatigue, pain, sexual health and intimacy, infertility, and financial and employment challenges. Most respondents (97%) have a fear of recurrence and suffer from fatigue that impairs their ability to make decisions (80%), limits social activity (88%), and interferes with their ability to carry out everyday activities (90%). Further, 75% indicated that they worry about pain, and 71% stated that their pain interferes with their family and day-to-day life.

Forty-one percent had ostomy surgery, among which 71% were temporary and 29% were permanent. People with ostomies reported a poorer quality of life particularly regarding sexual health and intimacy. The survey found that 50% of medical providers failed to inform

the respondents of the possibility of sexual dysfunction. This is especially concerning since 65% of respondents reported some sexual dysfunction that impacts their overall and mental health. Twenty-five percent indicated that they would have chosen a different treatment if they had known that they would experience sexual dysfunction.

Another concerning finding is that only 31% of respondents were told about the option of fertility preservation even though 37% of women and 16% of men were infertile or sterile because of treatment. Among survey respondents, 12% of women had an egg retrieval procedure, and 36% of men had their sperm preserved prior to the start of treatment. Of the women surveyed, more than half (53%) revealed that treatment triggered early menopause.

Seventy-five percent of respondents were employed full-time when they were diagnosed, and only half were still employed at the time of the survey. More than half of the respondents indicated they feel financially stressed and worry about the loss of their family's financial stability, as well as the financial problems they will face in the future because of their illness and treatments.

The survey did have several limitations, including that survey respondents did not serve as a holistic representation of those who have or have had colorectal cancer. Survey respondents skewed highly informed and engaged in colorectal cancer. Despite these limitations in the population, several important gaps were identified. Young-onset colorectal cancer patients are diagnosed at a late stage after many visits to medical providers, and missed diagnoses indicate a knowledge gap not only in the population but also with the medical community. The young-onset group presents unique problems with fertility and sexual dysfunction. More shared decision making is needed around clinical trial and biomarker education, as well as options around lifestyle and wellness during survivorship.

The Colorectal Cancer Alliance is dedicated to working with all stakeholders, including policymakers, to address the unmet needs in this unique and often overlooked population of colorectal cancer patients and survivors to improve their outcomes.

## Introduction

Colorectal cancer is the third-most commonly diagnosed cancer and the second-leading cause of cancer death in men and women combined in the United States. The American Cancer Society estimates that 147,950 people will be diagnosed with colorectal cancer in 2020, with 104,610 people diagnosed with colon cancer and 43,340 people diagnosed with rectal cancer. Additionally, 53,200 individuals will die of colorectal cancer in 2020. Estimates show that 17,930 (12%) people under the age of 50 will be diagnosed with colorectal cancer and approximately 3,640 (8%) will die from the disease.<sup>1</sup>

Young-onset colorectal cancer refers to individuals diagnosed under the age of 50. Colorectal cancer incidence has increased in adults 20-39 years since the mid-1980s and in adults aged 40-54 years since the mid-1990s. The steepest increase has been in the younger age groups. In recent years, the incidence has increased by 2.2% annually in individuals younger than 50 years, and 1% in individuals 50-64, in contrast to a 3.3% decrease in adults 65 years and older. Mortality rates have decreased in recent decades in individuals diagnosed over the age of 50, although the decline has slowed down. In contrast, mortality rates in individuals diagnosed under the age of 50 have increased by 1.3% per year. While the risk of developing colorectal cancer is increasing in individuals under the age of 50, only 15-25% can be attributed to familial or hereditary conditions. It is not clear why the remaining 75-85% of individuals under the age of 50 develop colorectal cancer. There are multiple lifestyle hypotheses currently under investigation, including diet, physical activity, smoking, and alcohol consumption, as well as the role of the microbiome and environmental exposures before and after birth.

The Colorectal Cancer Alliance launched a trailblazing young-onset colorectal cancer survey in 2016 to better understand challenges and unmet needs in the under-50 population. This survey included caregivers for the first time in 2018, a section that was greatly expanded this year. As previously reported by Alliance research and is evidenced elsewhere, young-onset colorectal cancer patients are increasingly diagnosed with advanced disease requiring aggressive treatment in comparison to those diagnosed after the age of 50, the current recommended screening age. There are limited studies that address the impact of young-onset colorectal cancer outcomes on patients' and survivors' quality of life (QoL) and their unique unmet needs.<sup>2,3</sup>

The Alliance aims to use these aggregated, self-reported results to inform the young-onset colorectal cancer community, as well as healthcare providers, about trends and gaps in the care of young-onset colorectal cancer patients, survivors, and caregivers.

It is well known that patients receiving aggressive treatments for advanced colorectal cancer may experience profound, life-long physical and emotional side effects impacting their quality of life. These physical and emotional side effects can be particularly devastating for young-onset colorectal

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<sup>1</sup> <https://www.cancer.org/cancer/colon-rectal-cancer/about/key-statistics.html>

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6803402/>

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4983017/>

cancer patients who may have just entered the workforce, have new relationships, or are in the process of starting a family. Some of the physical side effects may include loss of bowel function, nerve damage, a permanent ostomy, pain, fatigue, sexual dysfunction, and infertility. Emotional side effects including stress, fear, changes in self-esteem, body image, social anxiety, and depression and fear of recurrence can also be difficult for the survivor and also have a deep impact on caregivers.

Additionally, many young-onset colorectal cancer patients, survivors, and their families face financial hardship as a result of the disease. This can be attributed to multiple factors related to navigating cancer, including serving as a primary caregiver to dependent children or aging parents, or loss of employment and/or health insurance. Even those with health insurance can experience financial hardship due to out-of-pocket costs or use of fertility preservation.

The results outlined below begin with a summary of findings from the respondent population, including key demographic breakdowns of education level, gender, racial/ethnic backgrounds, and communities type. The report addresses the path to diagnosis, including the length of time to obtain a correct diagnosis, and includes lifestyle information prior to diagnosis including diet, employment, smoking, and alcohol consumption. Critically, the report discusses emotional health, including sexual health, and depression.

Although the Alliance is aware of the limitations of the survey, including sample size, selection bias, and homogeneity, the information reported has significant value in identifying areas for improvement in the diagnosis, treatment, and survivorship for this unique and increasing group of young-onset colorectal cancer patients and survivors.

The ultimate goal is to collaborate with all stakeholders, including policymakers, to identify solutions and address the unmet needs of this often overlooked population and improve their outcomes.

## Methodology

Our online survey was designed based on several established and validated instruments including AYA-HOPE, EORTC-QOL-30, EORTC-CR-29, EORTC-SHC-22, PROMIS-29, FACT-C, and COH-47 pertaining to several domains of survivorship including physical, emotional, and financial needs. Health literacy questions pertaining to biomarkers, genetics, and awareness of and participation in clinical trials are also included.



Lifestyle



Diagnosis



Treatments



Clinical Trials



Outcomes



Financial  
Toxicity



Symptoms



Family History



Biomarkers



Fertility



Mental Health

Once the questions had been collectively drafted and iterated upon, the final survey instrument and study plan were reviewed and approved by the Aspire Inc. Institutional Review Board.

The survey was launched in the summer of 2019 and disseminated through multiple Colorectal Cancer Alliance social media platforms, as well as through channels offered by numerous colorectal cancer advocacy partners with extended reach to the patient and caregiver community.

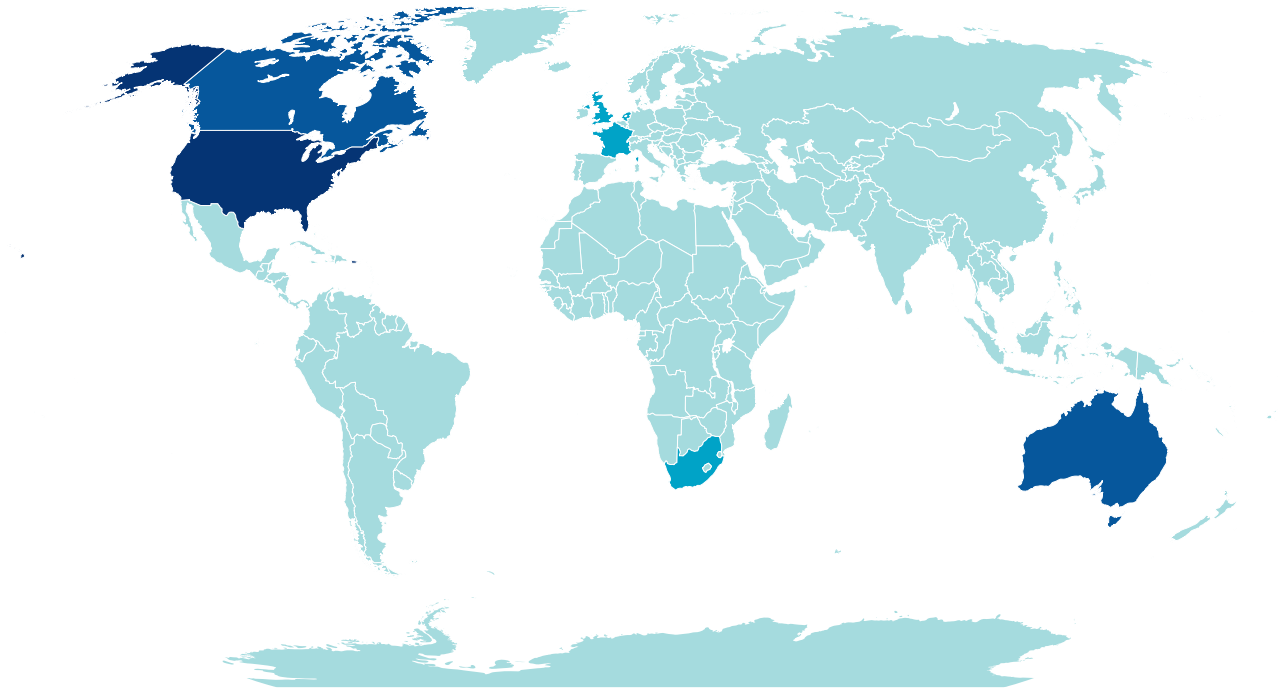
Over a period of eight weeks, 885 patients and survivors and 204 caregivers completed the questionnaire that included up to 140 questions (exact number dependent on response logic). For the majority of patient/survivor respondents (83%), this was the first time they participated in the Alliance's Never Too Young Survey. Approximately 13% of respondents indicated that they had participated in a previous year, 2.5% participated for the third time, and five individuals participated for the fourth time.

Descriptive statistics were used to characterize the patterns of unmet needs in each of the domains. Comparisons are drawn on the reported unmet needs among patients and survivors based on the type of cancer, gender, education, residential community (rural, suburban, or urban), stage at diagnosis, and other variables.

This report showcases findings among patient and survivor respondents. The Alliance will be releasing a second report to further explore caregiver characteristics and themes.

## Survey Question Topics

Of the 885 respondents, 86% reside in the United States. Responses were also received from Australia (5%), Canada (4%), the United Kingdom (1.3%), New Zealand and South Africa (0.5% each), as well as several other countries. Within the US, most responses were received from patients and survivors in California (10%), Texas (7%), Pennsylvania and Florida (5% each), Ohio and Illinois (4% each).

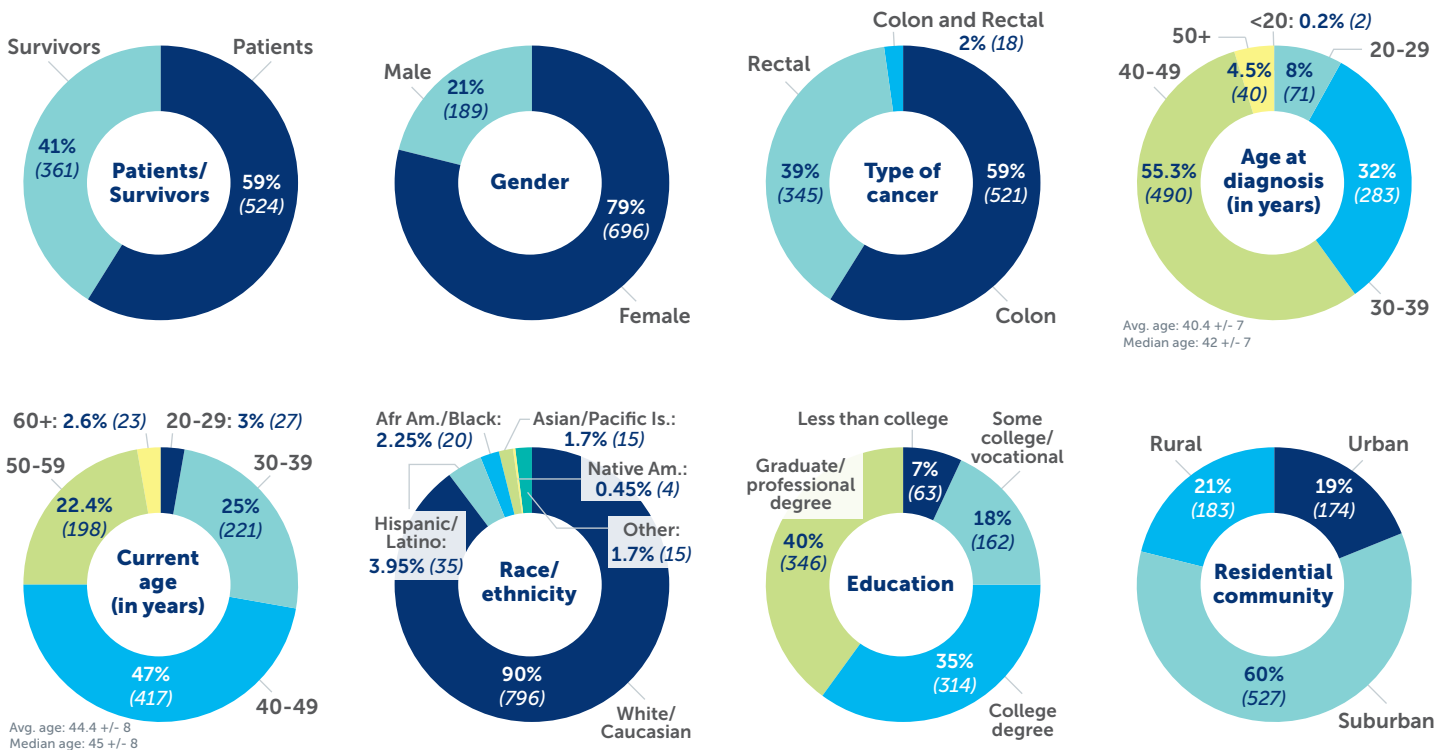


### Country of Origin

Response	Frequency	Percentage
United States	766	86.651%
Australia	46	5.204%
Canada	38	4.299%
United Kingdom	12	1.357%
France	3	0.339%
South Africa	3	0.339%
Netherlands	2	0.226%



### Participant Demographics (n=885)



Of the 885 participants, 41% are survivors and 59% current patients; 79% female and 21% male. Fifty-nine percent of respondents indicated that they were diagnosed with colon cancer, 39% with rectal cancer, and 2% with colon and rectal cancer. The average age at diagnosis was 42 years with 28% being diagnosed under the age of 40 years.

The respondents self-identify as 90% White or Caucasian, 4% Hispanic/Latino, and 2% African American/Black. The remainder are Asian/Pacific Islanders, Native Americans, and other races. The majority (75%) have at least a college degree, with 40% having professional or graduate degrees. Approximately 7% have no college experience, and 18% have some college or vocational experience.

In terms of community setting, 19% reside in an urban area, 21% live in a rural environment, and the majority (60%) reside in the suburbs.

Note that one identified limitation of this survey is that this respondent pool does not represent an exact cross-section of the overall population or those who have or have had colorectal cancer. Future studies will seek out additional channels aimed at reaching a more diverse sample.

# Findings

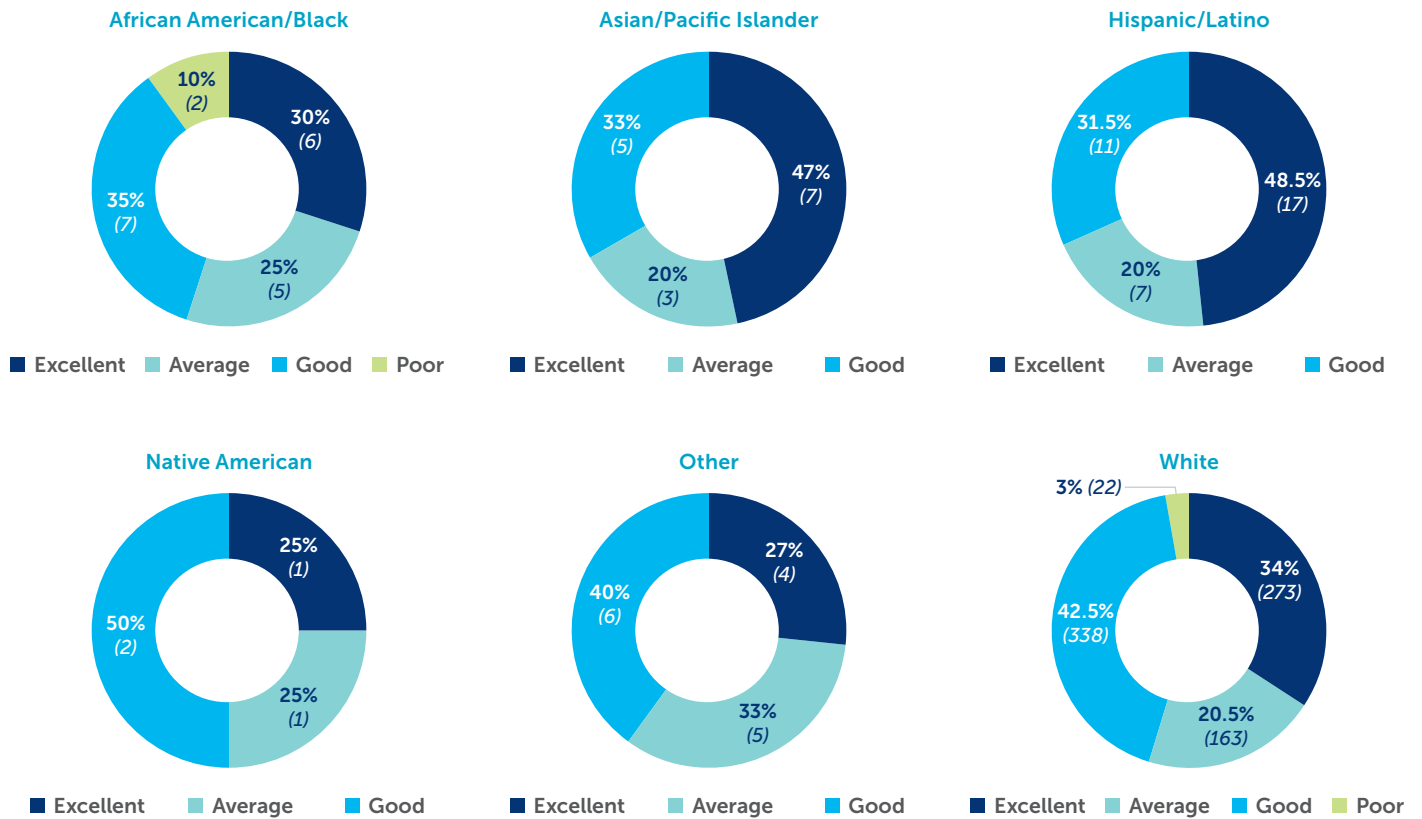
## LIFESTYLE AND HABITS PRIOR TO DIAGNOSIS

Patients and survivors were asked to assess their overall health prior to their diagnosis. Most of the respondents indicated that they were living a healthy lifestyle, with 42% reporting that their health was good and 35% reporting excellent health. About 21% reported that their health was average, and 3% suggested their health was poor.

The reporting of overall health differed between ethnic groups. African American respondents were four times more likely to report poor health compared to White respondents. Poor health was not noted in any other ethnic groups. A higher proportion of Asian/Pacific Islanders and Hispanic/Latinos reported they were in excellent health.



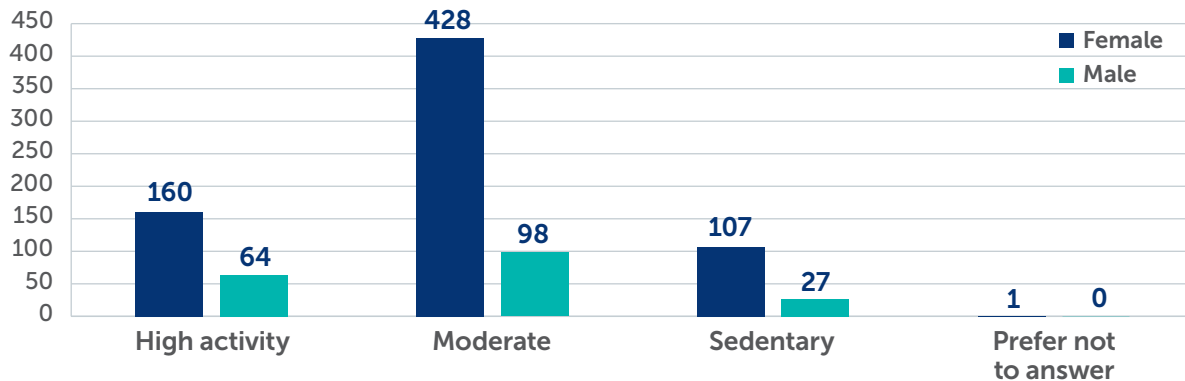
### Overall Health Before Diagnosis



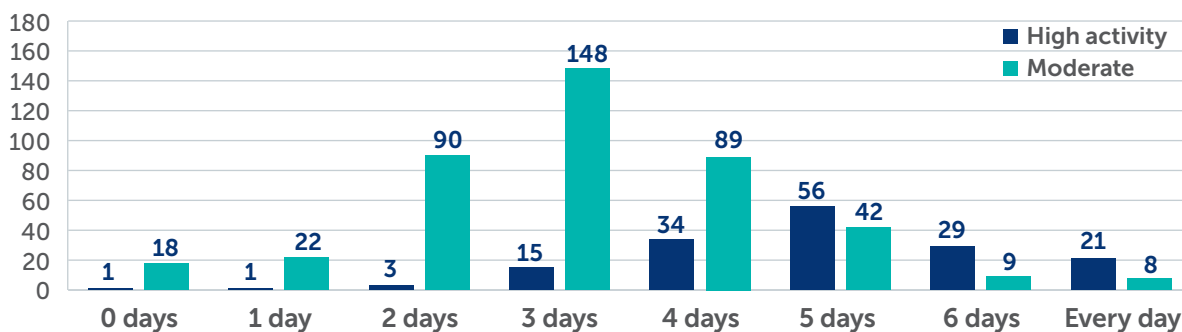
## PHYSICAL ACTIVITY

Respondents were asked to characterize their physical activity prior to their diagnosis. According to the US Department of Agriculture (USDA) and the Department of Health and Human Services (HHS), adults should engage in 150 minutes of moderate-intensity activity and two days of strength training each week.<sup>4</sup> Of survey participants, 85% believed they led an active or very active lifestyle, while 15% replied that they were sedentary. Twenty-three percent of women and 34% of men reported being highly active, 62% of women and 52% of men reported that they were moderately active, and 15% of women and 14% of men reported that they were sedentary.

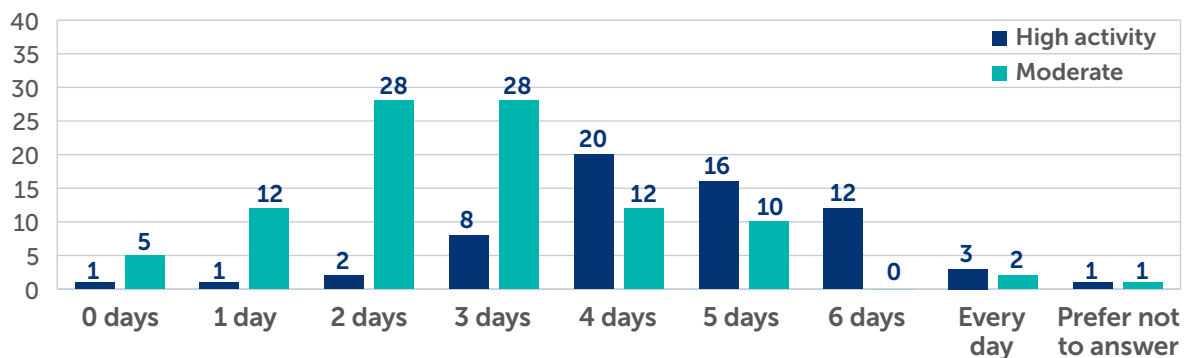
Physical Activity Prior to Diagnosis — by Gender



Females — How many days of the week do you exercise?



Males — How many days of the week do you exercise?



<sup>4</sup> <https://health.gov/our-work/food-nutrition/2015-2020-dietary-guidelines/guidelines/appendix-1/>

## DIET: FOOD AND BEVERAGES

It is well documented that diet can impact overall health and the risk of numerous diseases, including colorectal cancer. Recent literature has suggested that diets that are high in fruits, vegetables, and fiber may lower the risk of colorectal cancer. A diet high in red meat or processed food, including those with nitrates, increases the risk of colorectal cancer. Refined grains and added sugars may also increase the risk of developing colorectal cancer. Currently, it is not clear which factors are the most important.<sup>5</sup>

The most recent Dietary Guidelines for Americans recommends consuming a variety of vegetables, fruits, grains, fat-free or low-fat dairy products, and lean proteins. It is also recommended to limit the amount of saturated and trans fats, added sugars, and sodium.<sup>6</sup> The most recent guidelines are based on MyPlate<sup>7</sup> which suggests half of the plate should have fruits and vegetables; the other half of the plate should have a small portion of protein plus grains, at least half of which are whole grains.

Vegetables (per day)			Fruits (per day)		
Don't eat	27	3.1%	Don't eat	62	7.0%
At least one serving	348	39.3%	At least one serving	420	47.5%
Two servings	213	24.1%	Two servings	218	24.6%
Three servings	163	18.4%	Three servings	124	14.0%
Four servings	75	8.5%	Four servings	36	4.1%
Five servings	28	3.2%	Five servings	14	1.6%
Six or more servings	31	3.1%	Six or more servings	11	1.2%

The majority of those surveyed (87%) did not follow a specific diet, such as vegetarian or Mediterranean, prior to their diagnosis.

Of the respondents living in a rural area, 12 (7%) did not consume any vegetables, while 69 (38%) consumed 2-3 servings per day. Of those in the suburbs, 12 (2%) did not eat vegetables, and 228 (43%) consumed 2-3 servings per day. Of the urban respondents, three (1%) did not eat any vegetables, and 79 (45%) consumed 2-3 servings per day.

<sup>5</sup> <https://www.cancer.org/cancer/colon-rectal-cancer/causes-risks-prevention/prevention.html>

<sup>6</sup> [https://www.dietaryguidelines.gov/sites/default/files/2019-05/2015-2020\\_Dietary\\_Guidelines.pdf](https://www.dietaryguidelines.gov/sites/default/files/2019-05/2015-2020_Dietary_Guidelines.pdf)

<sup>7</sup> [https://choosemyplate-prod.azureedge.net/sites/default/files/tentips/mini\\_poster\\_0.pdf](https://choosemyplate-prod.azureedge.net/sites/default/files/tentips/mini_poster_0.pdf)

Similar themes emerged for fruit consumption: 9% of rural respondents did not eat fruit and 30% consumed 2-3 servings per day. In the suburbs, 6% did not consume fruit and 40% consumed 2-3 servings per day. Of the urban respondents, 6% did not consume any fruit and 44% had 2-3 servings per day.

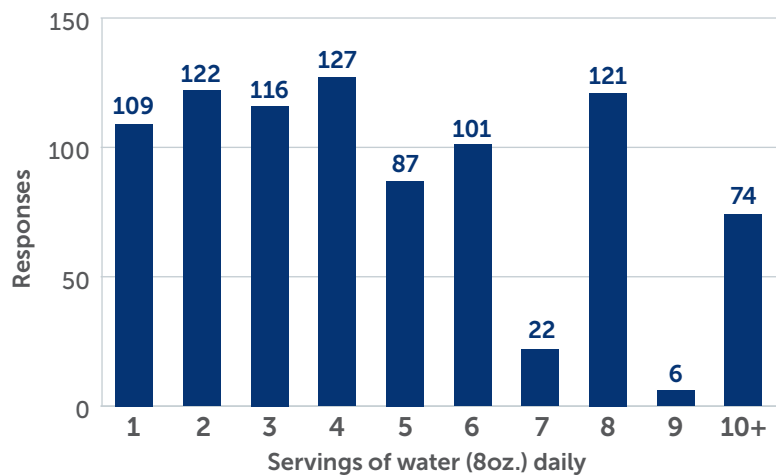
Regardless of the community in which they live, women consumed more vegetables than men, with 3% of women not eating vegetables compared to 6% of men, and 45% of women consumed 2-3 servings a day compared to 35% of men. Women also consumed more fruit than men, with 5% of women not consuming fruit compared to 8% of men and 42% of women consuming 2-3 servings per day compared to only 27% of men.

## WATER AND SODA CONSUMPTION

Current daily recommendations for water intake are 11.5 8 oz. glasses (92 ounces) for women and 15.5 8 oz. glasses (124 ounces) for men, although guidelines recognize that the previous recommendation of eight 8 oz. glasses of water may be a more attainable goal.<sup>8</sup> This survey was based on the previous recommendation of eight 8 oz. glasses of water each day. Of the respondents, only 23% meet or exceed 64 oz. of water each day.

General guidelines limit soda intake,<sup>9</sup> including sugar-free, as studies show a possible link to weight gain. This survey showed that 70% of respondents drink regular or diet soda at least once a week, and 12% consume 10 or more sodas per week.

Daily Water Intake



### Soda intake prior to diagnosis

<b>29.4%</b>	<b>No, I don't drink soda</b>
<b>12.4%</b>	<b>Yes, diet soda at least once a day</b>
<b>14.7%</b>	<b>Yes, regular soda at least once a day</b>
<b>7.91%</b>	<b>Yes, diet soda at least once a week</b>
<b>10.6%</b>	<b>Yes, regular soda at least once a week</b>
<b>24.9%</b>	<b>Yes, occasional regular or diet soda</b>

<sup>8</sup> <https://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/water/art-20044256>

<sup>9</sup> [https://www.cdc.gov/nccdphp/dnpa/nutrition/pdf/r2p\\_sweetend\\_beverages.pdf](https://www.cdc.gov/nccdphp/dnpa/nutrition/pdf/r2p_sweetend_beverages.pdf)

## BODY MASS INDEX (BMI)

Body Mass Index (BMI) of survey respondents was calculated based on self-reported height and weight prior to diagnosis using the following Centers for Disease Control and Prevention (CDC) formula: (weight (lb) / [height (in)]<sup>2</sup> x 703).<sup>10</sup>

From those calculations, it was determined that the majority of respondents were clinically overweight (30%) or obese (30%) prior to diagnosis, 33% of survey participants had a BMI that was within the normal range, and 7% were underweight.

Interestingly, this also revealed that, among survey participants, a higher proportion of male respondents are considered overweight and/or obese compared to females.

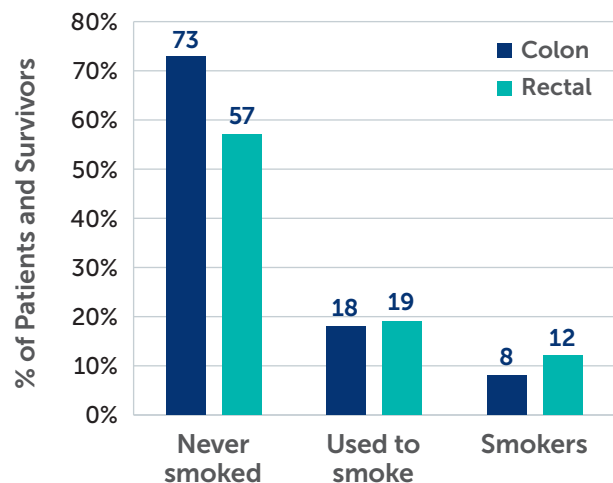
More participants who report residing in rural areas are clinically obese compared with participants residing in suburban and urban areas.

The relationship between calculated Body Mass Index at diagnosis and reported stage at diagnosis was not statistically significant. Therefore, among these respondents, being overweight or obese was not strongly associated with cancer stage at diagnosis.

## SMOKING

Previous studies have shown that smoking increases the risk of developing colorectal cancer in all ages.<sup>11</sup> In a 2010 study, it was found that people who smoked, even in the past, were more likely to develop colorectal cancer than those who never smoked.<sup>12</sup> Little is known about the association between smoking and a higher risk of being diagnosed with young-onset colorectal cancer. Among survey respondents, 70% reported they never smoked cigarettes prior to their diagnosis, although 9% indicated they were exposed to second-hand smoke. About 18% of participants suggested they had smoked in the past but were not smoking at the time of diagnosis. Only 10% of survey participants identified themselves as smokers at the time of diagnosis. More than half of those smokers shared that they smoked at least two packs

### Smoking and Diagnosis



<sup>10</sup> [https://www.cdc.gov/nccdphp/dnpao/growthcharts/training/bmiage/page5\\_2.html](https://www.cdc.gov/nccdphp/dnpao/growthcharts/training/bmiage/page5_2.html)

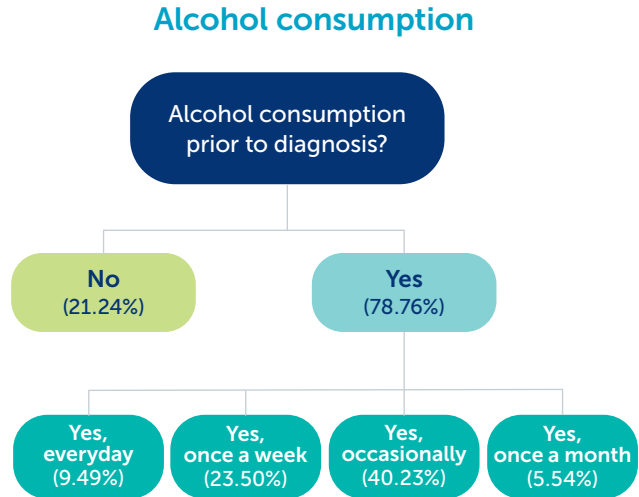
<sup>11</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2915616/>

<sup>12</sup> J Natl Cancer Inst. 2010 Jul 21; 102(14): 1012–1022

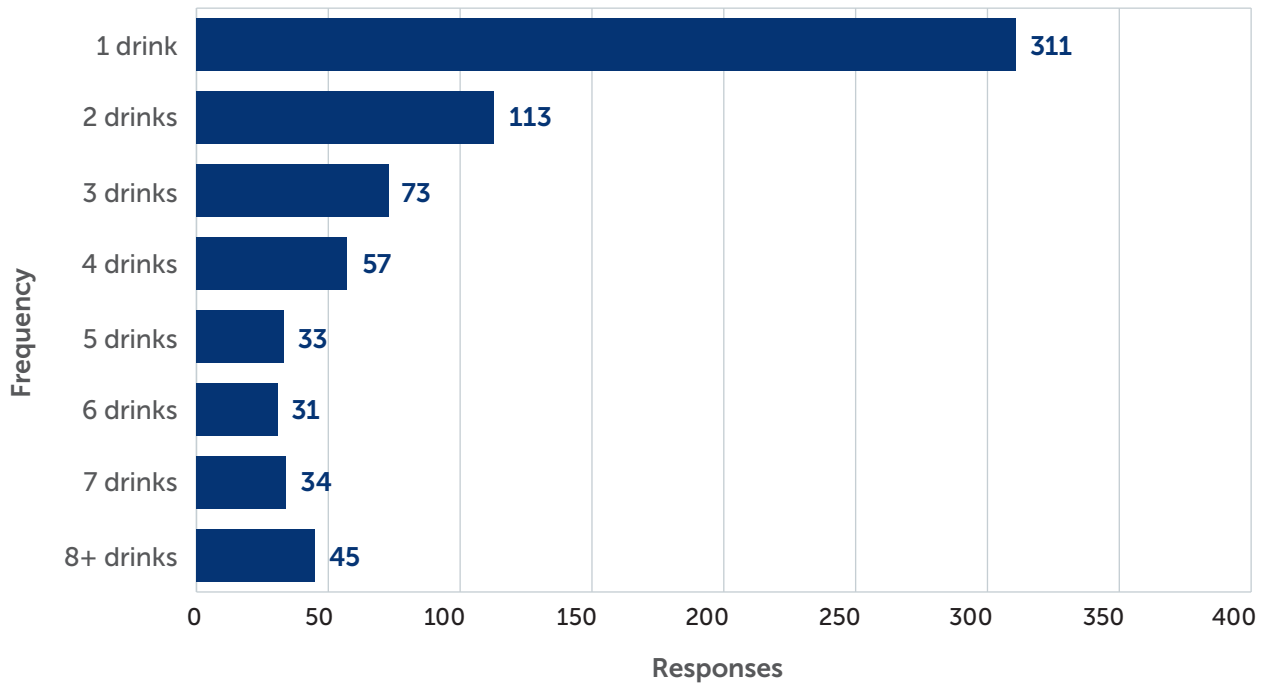
of cigarettes per week. Participant responses showed a higher percentage of non-smokers among people who were diagnosed with colon cancer (73%) than rectal cancer (57%). However, no link was found between smoking and age at diagnosis, stage of diagnosis, or tumor recurrence.

## ALCOHOL CONSUMPTION

Among survey respondents, men disclosed drinking more often than women. Findings showed that 23% of women (161) did not report consumption of alcohol compared to 14% of men (27). Eight percent (55) of women and 15% (20) of men indicated that they drink every day. Those who reside in a rural area are more likely not to drink than those in the suburbs or in an urban community.



### Alcoholic Beverage Consumption Per Week



## Family History

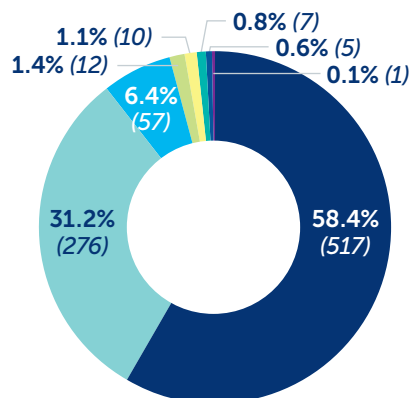
A family history of colorectal cancer increases the risk of being diagnosed with the disease. Nearly 28% of survey respondents indicated they have a family history of colorectal cancer.<sup>13</sup> This finding is consistent with previous surveys and the scientific literature.

Fifty-two percent of respondents are aware that their family history increased their risk for colorectal cancer, as well as gastric, endometrial, and ovarian cancers. Patients and survivors who do not have a family history were less aware (20%) of the increased risk to their family members based on their diagnosis.



Interestingly, respondents who are aware of their family history of colorectal cancer were diagnosed at earlier stages than those who did not know or did not have a family history.

### Mutations Discovered



- No mutation identified
- Don't know/didn't answer
- Lynch/Hereditary non-polyposis colorectal cancer (HNPCC)
- BRCA1/2
- MUTYH-associated polyposis (MAP)
- p53/Li-Fraumeni
- Familial adenomatous polyposis (FAP)
- Serrated polyposis syndrome (SPS)

Of the respondents, 9% reported that they had a first-degree relative with a history of Crohn's disease, inflammatory bowel disease, ovarian, and/or gastrointestinal cancer. Many of these patients also reported a second-degree relative with colorectal cancer, most often a grandparent.

At the time of diagnosis, 35% of patients and survivors were offered genetic testing. A few patients and survivors (2%) had genetic testing prior to diagnosis, and 38% had genetic testing done after diagnosis and during treatment.

It is important to note that genetic testing was not considered necessary until around 2010. Therefore, it is not surprising that 21% of patients and survivors were never offered genetic testing, and 7% did not remember if they had testing or preferred not to answer.

Knowing family history and encouraging open dialogue among family members is the first step to increase awareness, prevention, and early detection of colorectal cancer. Although 28% of patients and survivors were aware of their family history with colorectal cancer, many did not initiate open discussion on the risk for additional family members.

<sup>13</sup> <https://acsjournals.onlinelibrary.wiley.com/doi/10.1002/cncr.32851>



Gender or the community in which respondents live did not appear to influence patients' and survivors' awareness of the increased risk associated with family history. Patients and survivors with a graduate or professional degree are slightly more aware than college graduates and high-school graduates of the risk with a family history (28% vs 24% respectively).

The parental status of each participant was assessed to understand medical conversation about familial risk. Approximately three-quarters of the study population have children, with the average number of children being two. Patients were asked if their medical provider informed them that their children should be screened for colorectal cancer 10 years before the age of their parent's diagnosis. Of the 660 patients and survivors with children, 83% said they were informed, but 12% (77 patients) did not receive this information. Participants were also asked if they would have their family members undergo genetic testing. Participants with children were 1.5 times more likely to say they would have their family members tested, while those without children were 1.6 times more likely to leave this decision up to their family members.

The majority of the patients and survivors felt fearful or extremely fearful (76%) that their mutation would be passed down to their children, and participants with children were 1.5 times more likely to have their family members tested for genetic mutations than those without children.

## The Path from Symptoms to Diagnosis

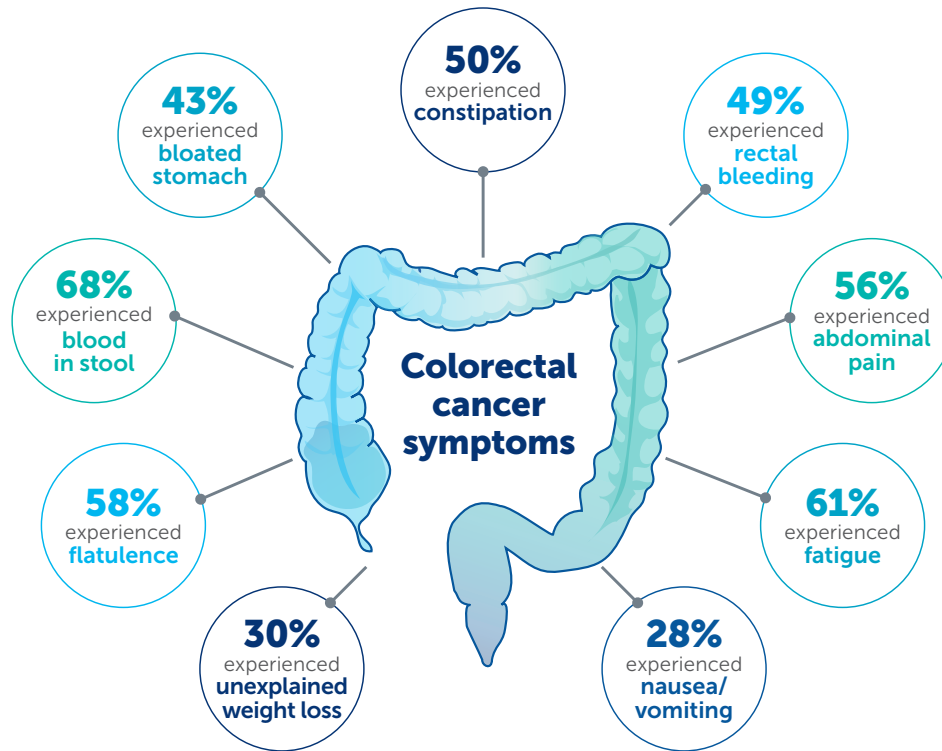
Screening for colorectal cancer was previously recommended to begin at the age of 50 for people at average risk, which means those without a family history. In 2018, the American Cancer Society suggested reducing the screening age from 50 to 45 years old for those at average risk. This has yet to gain widespread adoption by the United States Preventive Services Task Force (USPSTF) and the Center of Medicare and Medicaid Services (CMS), both of which most insurance companies follow for reimbursement and payment. Currently, people under 50 usually do not get screened unless they have a personal or family history. Therefore, it is important that people recognize the symptoms of colorectal cancer and seek medical advice as soon as possible if they are experiencing any of them.



<b>14%</b>	<b>aware of the signs and symptoms associated with colorectal cancer before they were diagnosed</b>
<b>49%</b>	<b>no knowledge of signs and symptoms of colorectal cancer before their diagnosis</b>
<b>37%</b>	<b>somewhat familiar with signs and symptoms of colorectal cancer before their diagnosis</b>

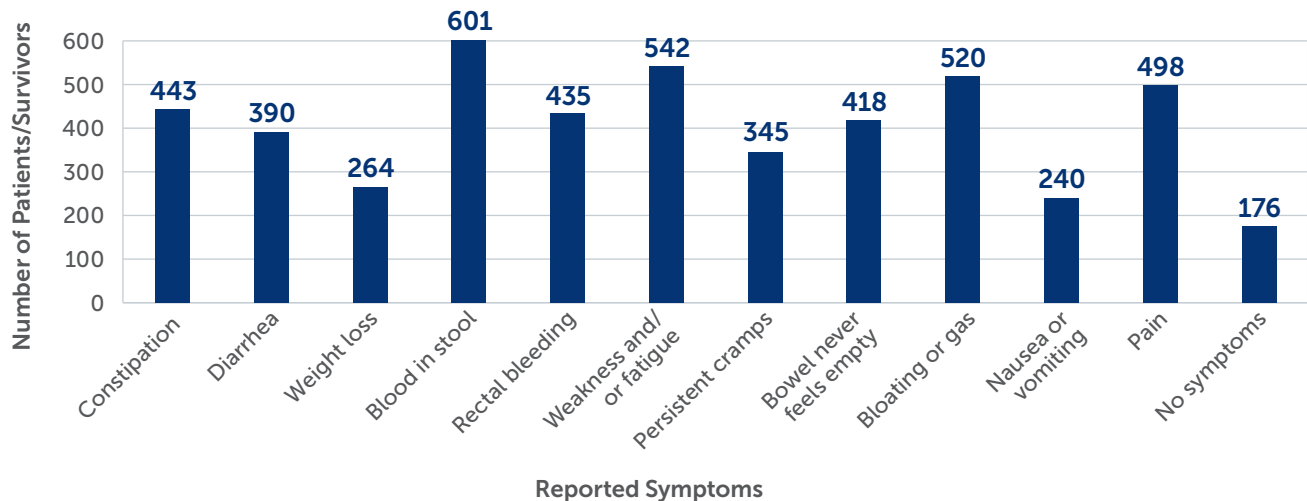
Patients reported that blood in the stool was the first symptom they noticed. It was also the most commonly experienced symptom (68% of patients). Other noted symptoms included constipation, diarrhea, weakness and fatigue, bloating and gas, and rectal bleeding and associated pain. Less frequent symptoms included bowel never feeling empty, persistent cramps, and weight loss.

### Colorectal Cancer Symptoms

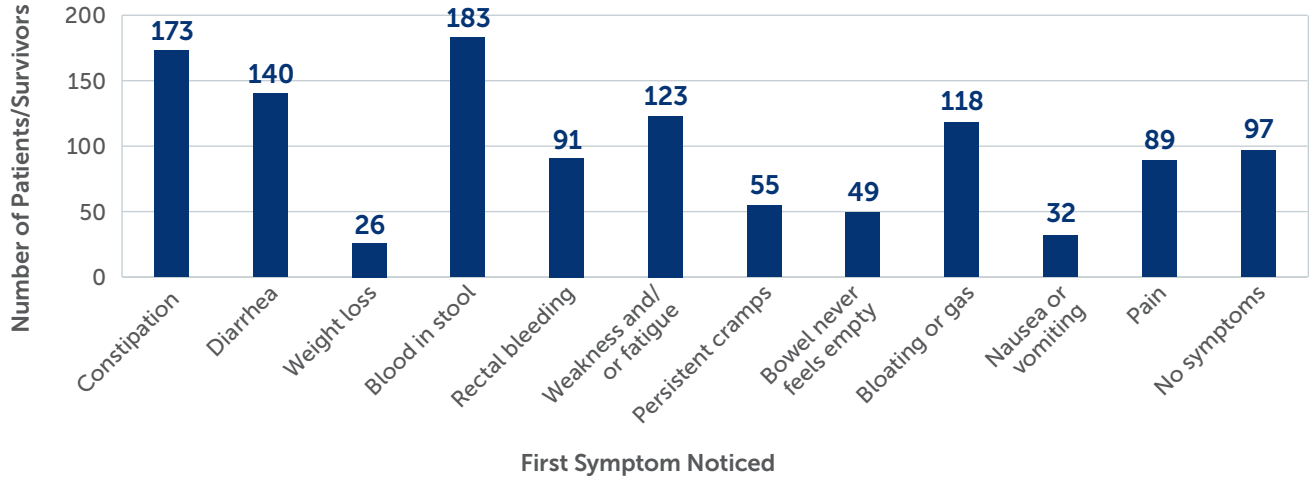


The majority of patients and survivors reported they experienced multiple symptoms, with 81% of them experiencing at least three different symptoms prior to diagnosis.

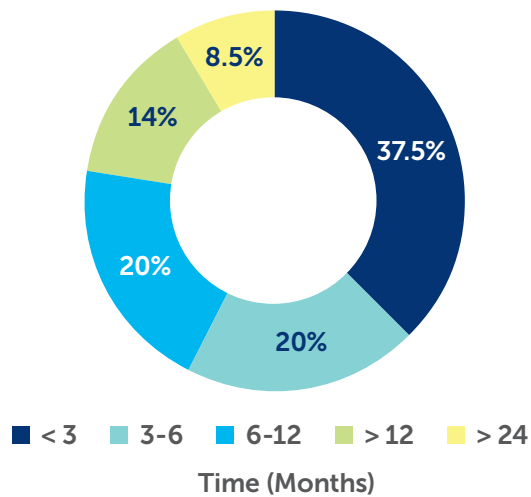
### Number of Experienced Symptoms



### First Experienced Symptom



### How long did you experience symptoms before going to the doctor?



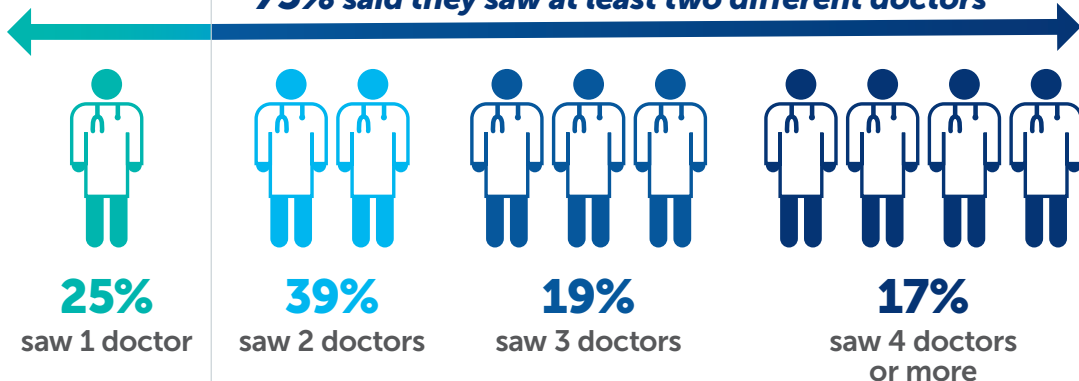
Young-onset patients often have symptoms for months or years before seeing a medical provider. In this survey,<sup>14</sup> 62% of patients and survivors reported that they waited three or more months to visit a medical professional after they noticed their symptoms.

Medical providers offered a rectal exam to fewer than half of the patients and survivors who presented with blood in their stool or rectal bleeding.

Many patients reported they had to see multiple doctors and had multiple appointments before they were correctly diagnosed with colorectal cancer.

<sup>14</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6360363/>

### 75% said they saw at least two different doctors

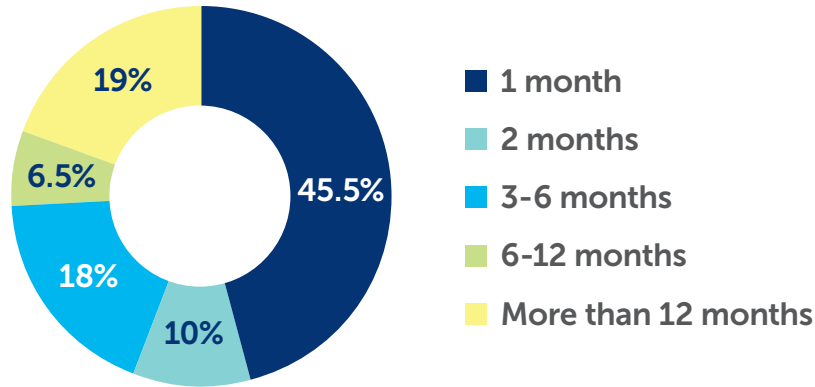


Seventy-five percent of patients and survivors reported they saw at least two different physicians, and 36% percent were seen by three or more physicians. Approximately 9% of patients indicated they were seen by at least five different physicians prior to their diagnosis.

Survey participants also reported the need for multiple appointments regardless of the number of physicians they saw. Of those who saw only one doctor, 44% were seen by the same doctor for multiple visits, and 50% were ultimately diagnosed in the Emergency Department.

As many as 45% of patients and survivors reported that once they sought medical attention, they were diagnosed with colorectal cancer within the first month of seeing their doctor. Another 10% of patients were diagnosed within two months of seeing their doctor. However, 6.5% were diagnosed with colorectal cancer 6-12 months after seeing their doctor, and 19% were not diagnosed for more than 12 months.

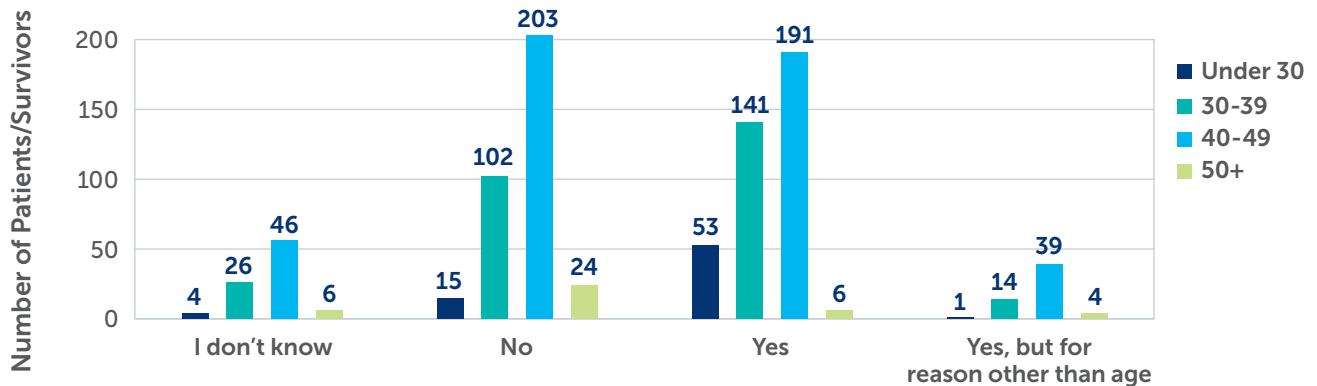
### How long did it take to be diagnosed with colorectal cancer after you first sought medical attention for your symptoms?



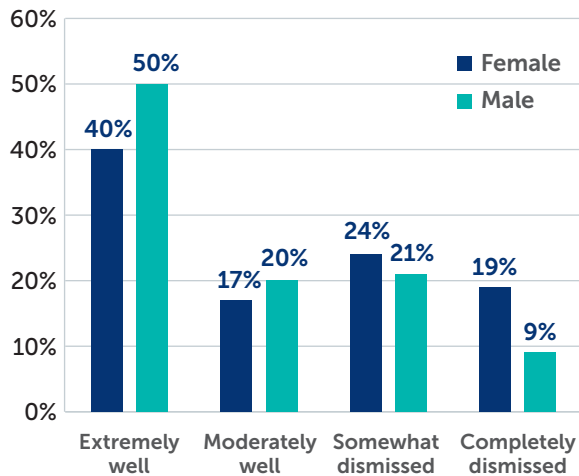
Although many patients felt that their medical provider listened to their concerns, 40% of patients and survivors still expressed that their providers dismissed their symptoms and concerns.

Younger patients diagnosed between the ages of 19-39 were more likely to report that their concerns were dismissed by their doctors than patients who were diagnosed between the ages of 40-50.

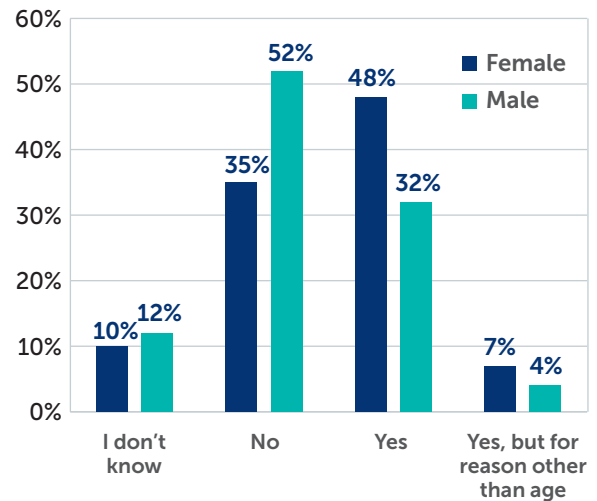
### Do you feel your doctors dismissed the signs and symptoms of colorectal cancer due to your age?



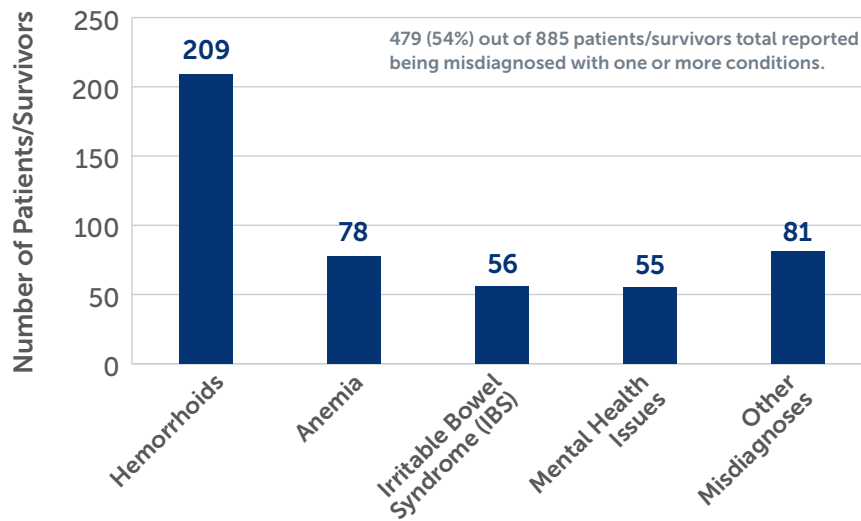
### How well did the doctors listen to your signs and symptoms?



### Do you feel the doctor dismissed symptoms due to your age? (by gender)



### Mistakenly Diagnosed Conditions



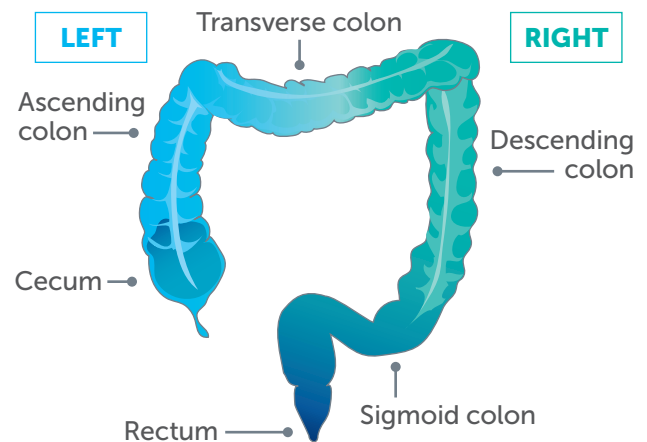
Women were more likely to report that their symptoms and concerns were dismissed by their doctor.

The survey respondents indicated that 54% or 479 were misdiagnosed, 43% or 209 with hemorrhoids alone or in combination with other conditions, 17% or 78 with anemia alone or with other conditions, 12% or 56 with irritable bowel syndrome (IBS) alone or with other conditions, and a startling 11% or 55 with mental health issues either alone or with other conditions. Patients and survivors were also misdiagnosed with appendicitis, symptoms attributed to childbirth, diverticulitis, gastric disorder, gallbladder, gluten allergy, urinary tract infection, and gynecological issues.

## DIAGNOSIS AND OUTCOME

Of the patients and survivors (59%) who were diagnosed with colon cancer, more than 50% had left-sided tumors. Rectal cancer was diagnosed in 39% of respondents, and 2% had both colon and rectal cancers. These results did not appear to be influenced by gender and/or age at diagnosis.

Many young-onset colorectal cancer patients and survivors are diagnosed at later stages.<sup>15</sup> More than 77% of respondents were diagnosed with stage III, indicating lymph node involvement, or stage IV metastatic disease. The survey found that a larger percentage of colon cancer patients and survivors were diagnosed with stage IV, and most rectal cancers were diagnosed at stage III. Only 39% of respondents sought a second opinion before starting treatment.



### Location of tumor metastases

Response	Frequency	Percentage
Liver	87	31.295%
Lungs	16	5.755%
Lymph nodes	10	3.597%
Peritoneum	9	3.237%
Combinations	156	56.115%

**Stage I:**  
7.2%

64 people

**Stage II:**  
15.1%

134 people

**Stage III:**  
46.2%

409 people

**Stage IV:**  
31.4%

278 people

<sup>15</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6360363/>

Patients and survivors were asked about their current disease stage, to which 57% reported being No Evidence of Disease (NED). The majority of those who were NED (32%) had been so for less than a year.

### Current Cancer stage

Response	Frequency	Percentage
Stage I	12	1.356%
Stage II	27	3.051%
Stage III	66	7.458%
Stage IV	276	31.186%
NED (no evidence of disease)	504	56.949%

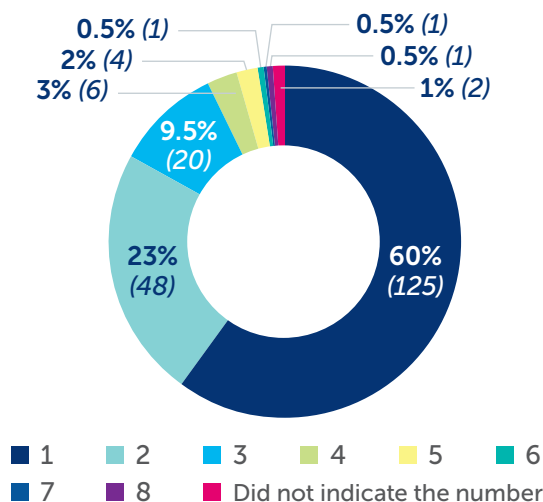
### Duration of NED status

Response	Frequency	Percentage
0-1 years	161	31.944%
1-2 years	102	20.238%
2-5 years	118	23.413%
5-10 years	77	15.278%
10+ years	46	9.127%
Total	504	

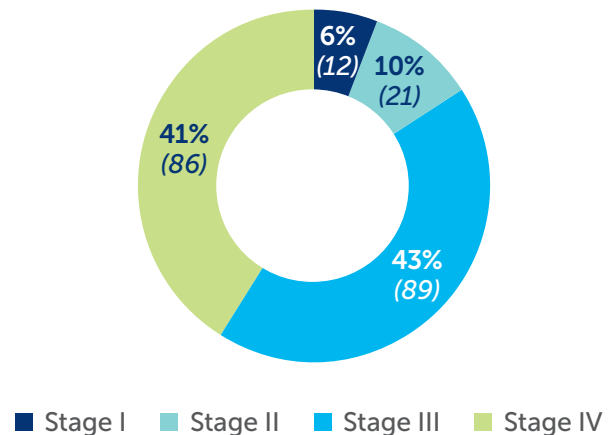
Of the 885 respondents, 208 (23.5%) had at least one recurrence. Most of the respondents (125 or 60%) had one recurrence, 48 (23%) had two recurrences, and 20 (10%) had three recurrences. The remainder had four or more recurrences with one person having greater than 10 recurrences.

Of the 208 patients and survivors who reported a recurrence, patients initially diagnosed at stage III had the most recurrences with 89 (43%), stage IV had 86 (41%), stage II had 21 (10%), and stage I had 12 (6%).

### Number of Cancer Recurrences



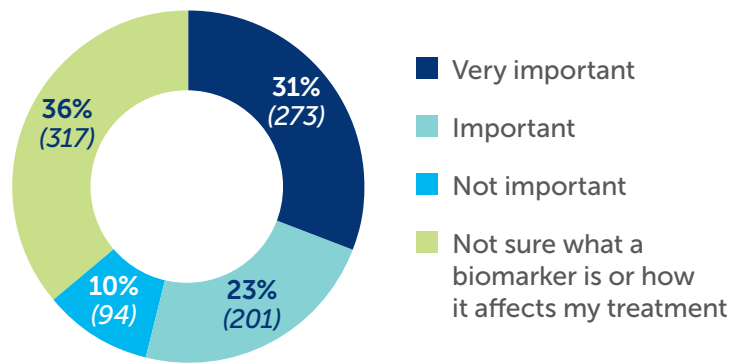
### Cancer Recurrences and Initial Stage at Diagnosis



## Biomarkers and Genetic Testing

Genetic testing is an important step in developing a customized cancer treatment plan. Test results can predict the tumor’s response to various treatments, and experts currently recommend genetic testing for all newly-diagnosed patients. In this study, 38.2% received genetic testing concurrently with treatment, while a smaller portion of patients received testing at diagnosis. This difference may be attributed to the year when these patients were diagnosed, as treatment guidelines and standards of care have changed in recent years. Slightly more than half of patients (54%) reported that they were aware of the importance of biomarker testing, while 46% were unsure or thought it was not important to know about biomarkers.

How important was it for you to know about biomarkers?



Of the 881 people who responded to the biomarker testing question, 307 (35%) had testing done at diagnosis, 22 (2.5%) had testing done prior to diagnosis, 338 (38.2%) during treatment, 184 (20.9%) never had testing, and 30 (3.4%) did not know.

### Did you have genetic testing before or after being diagnosed with colorectal cancer?

Time of testing	Number	Percentage
At diagnosis	307	35%
Before diagnosis	22	2.5%
During treatment	338	38.2%
Never	184	20.9%
I don't know	30	3.4%



## CLINICAL TRIALS

Clinical trials are used for all types and stages of colorectal cancer to learn if a new treatment is safe, effective, and possibly better than the existing treatments. Trials study and evaluate new drugs, different combinations of treatments, new approaches to radiation therapy or surgery, and new methods of treatment.

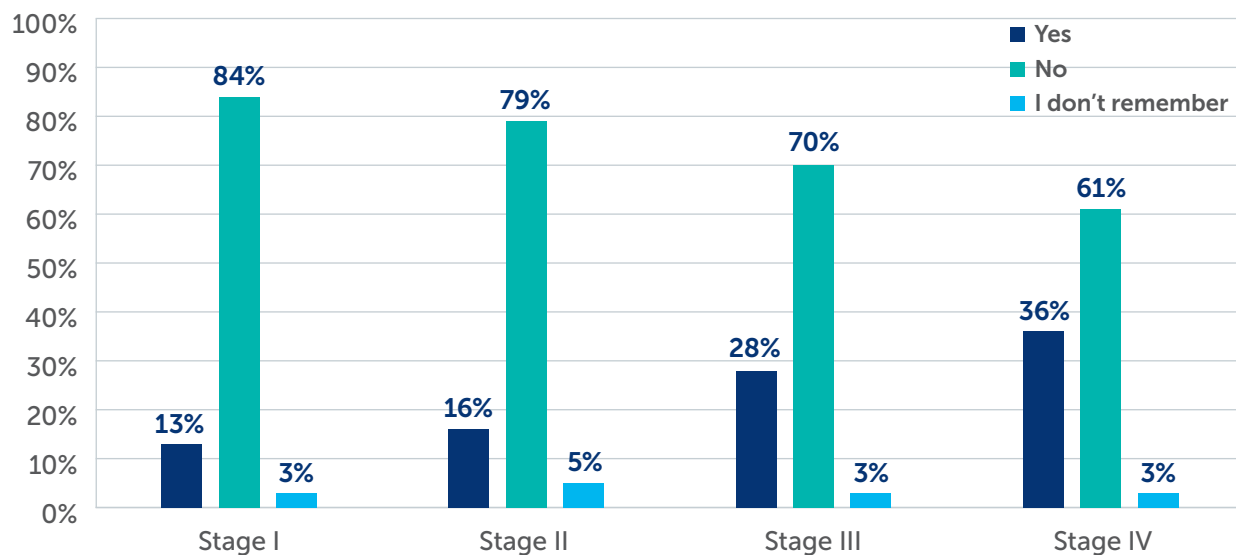
When asked about clinical trials, 87% of patients and survivors said that learning about clinical trials was important for young-onset patients. At diagnosis, only 27% of oncologists mentioned clinical trials. Thirteen percent of stage I patients and 36% of stage II patients were spoken to about clinical trials. An overwhelming number of stage III (70%) and stage IV (61%) patients did not have any discussion of clinical trials before starting treatment.

Of those who responded, 52% of patients and survivors did not feel sufficiently informed about clinical trials, and 48% found out about clinical trials through sources other than their doctor. The majority of patients and survivors said that looking for clinical trials was overwhelming regardless of the stage at diagnosis.

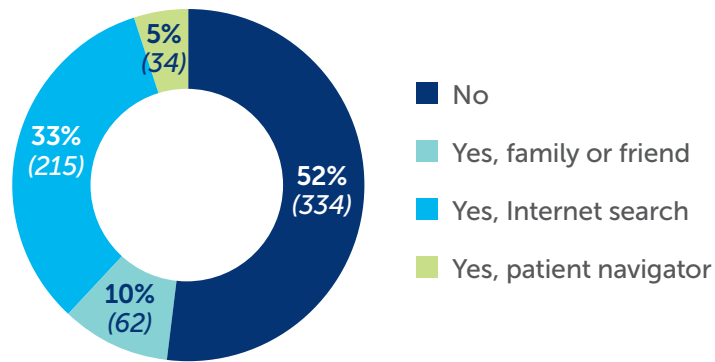
Although 46% of patients and survivors said that they would consider participating in a clinical trial, 22% of them would only participate if they were out of other options. This indicates an area where education is needed.

A surprising number of oncologists (70%) discouraged or did not discuss clinical trials with the patient or survivor. These results indicate an overall lack of knowledge about clinical trials and presents an educational opportunity for patients and survivors and the doctors who treat them.

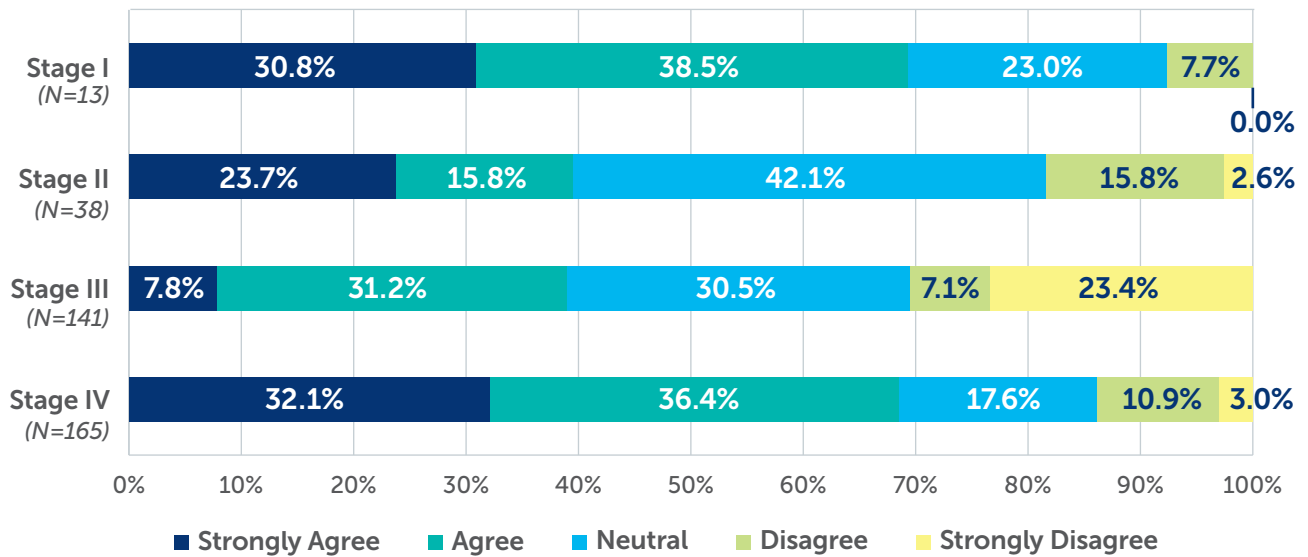
Did your oncologist mention clinical trials at diagnosis? (by stage)



### Did you hear about clinical trials from someone other than your doctor?



### The search for clinical trials was overwhelming.

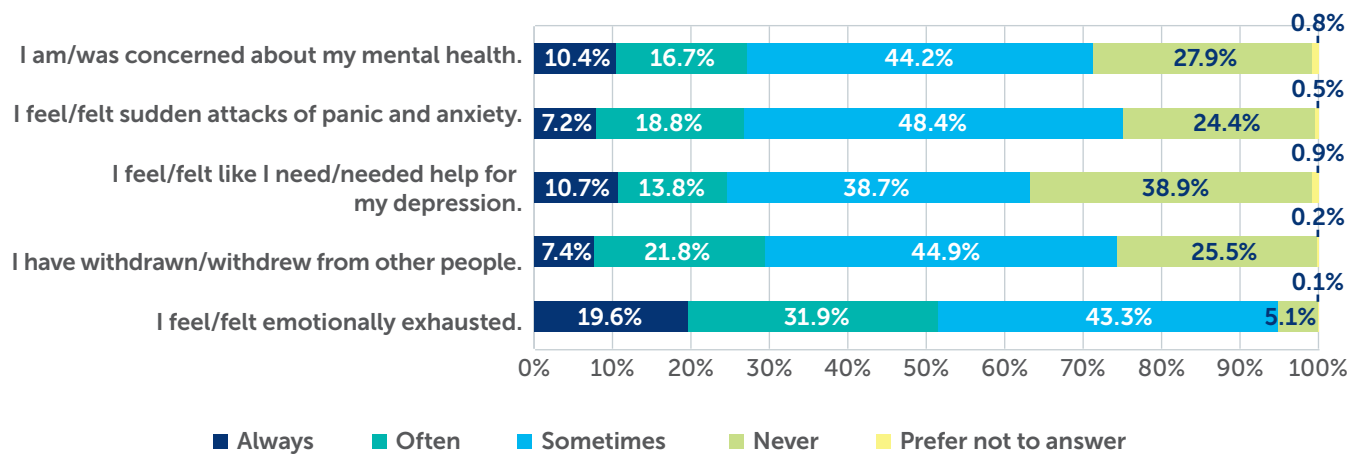


## Survivorship and Outcomes

### EMOTIONAL HEALTH

With nearly 75% of survey participants sharing that they have been concerned about their mental health and 64% responding that they have needed help for their depression, the psychological impact of young-onset colorectal cancer is clear. Further, 25% of survey participants indicated that mental health concerns are significantly impacting their lives. Ninety-five percent of respondents said that emotional exhaustion impacted their lives at least some of the time, and more than 50% said it impacted their lives always or often.

#### Emotional Health

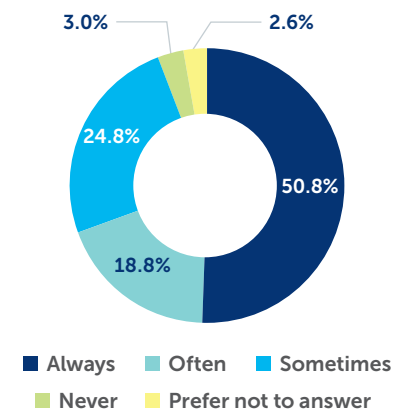


It is apparent from the survey data that there is a need for emotional support for patients and survivors in the young-onset colorectal cancer community.

### FEAR OF CANCER RECURRENCE

The majority (97%) of respondents indicated that they were afraid of their cancer recurring, and more than 50% indicated that they were always afraid that their cancer would recur. A large number of respondents (66%) indicated that thoughts of recurrence interfere with their daily activities.

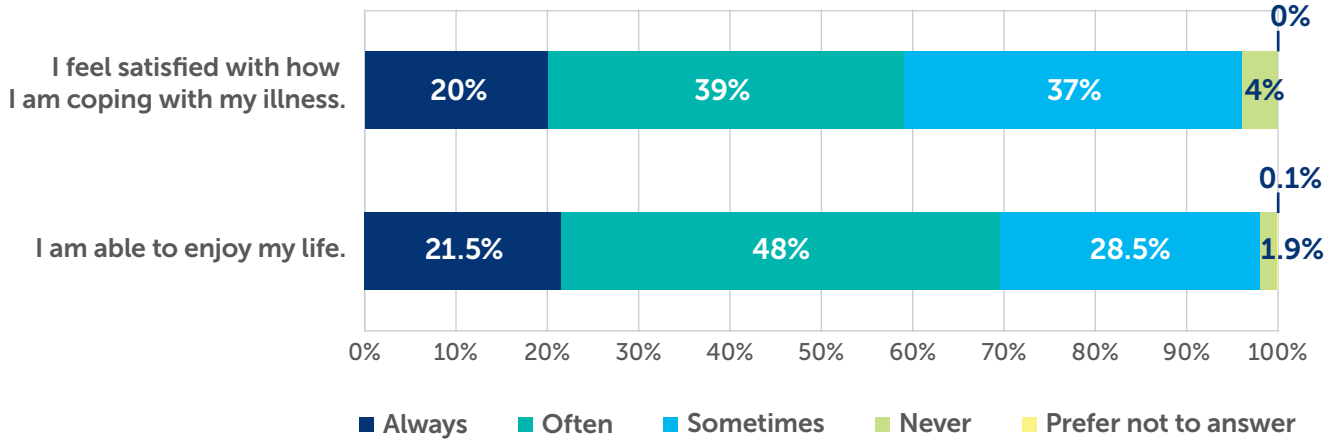
#### I am afraid that my cancer may recur.



### COPING AND ENJOYMENT OF LIFE

Despite mental health concerns which include nearly ubiquitous fear of cancer recurrence, more than 95% of survey participants reported they feel satisfied with how they are coping with their illness and are able to enjoy their lives at least some of the time; around 20% of the same group indicated that they always felt they were coping with their illness and enjoying life.

### Coping and Enjoyment

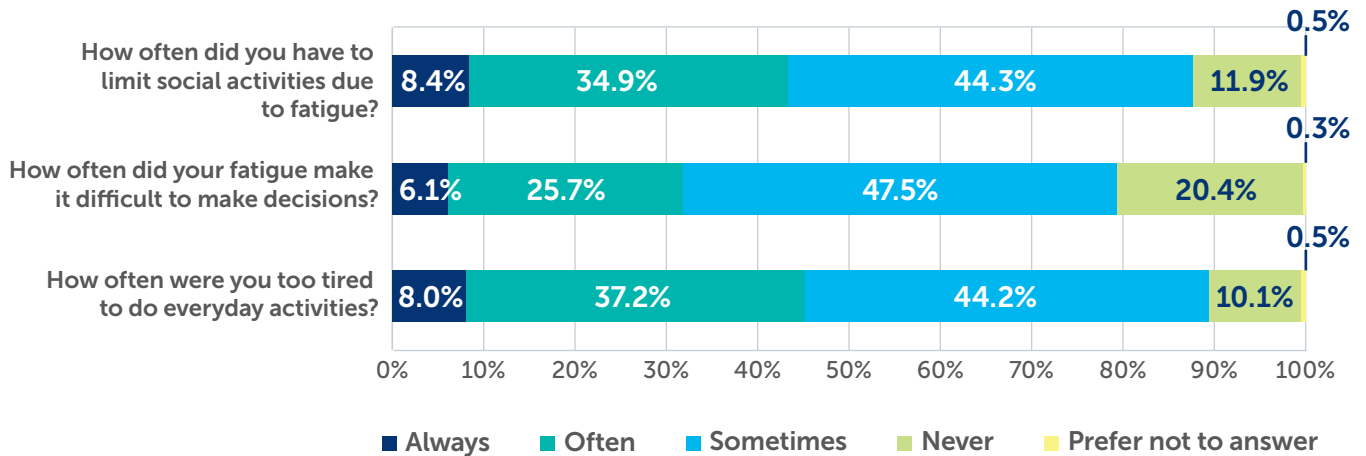


### FATIGUE

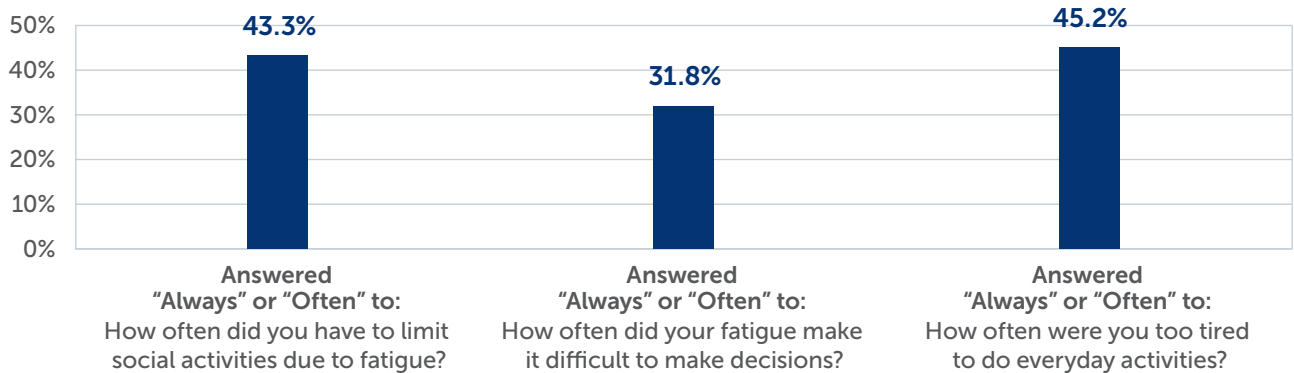
Most survey respondents indicated that they experience fatigue which impairs their ability to make decisions (80%), limits social activity (88%), and interferes with their ability to carry out everyday activities (90%).

It is apparent that fatigue can be a debilitating side effect that disrupts daily living and may contribute to emotional distress.

### Fatigue

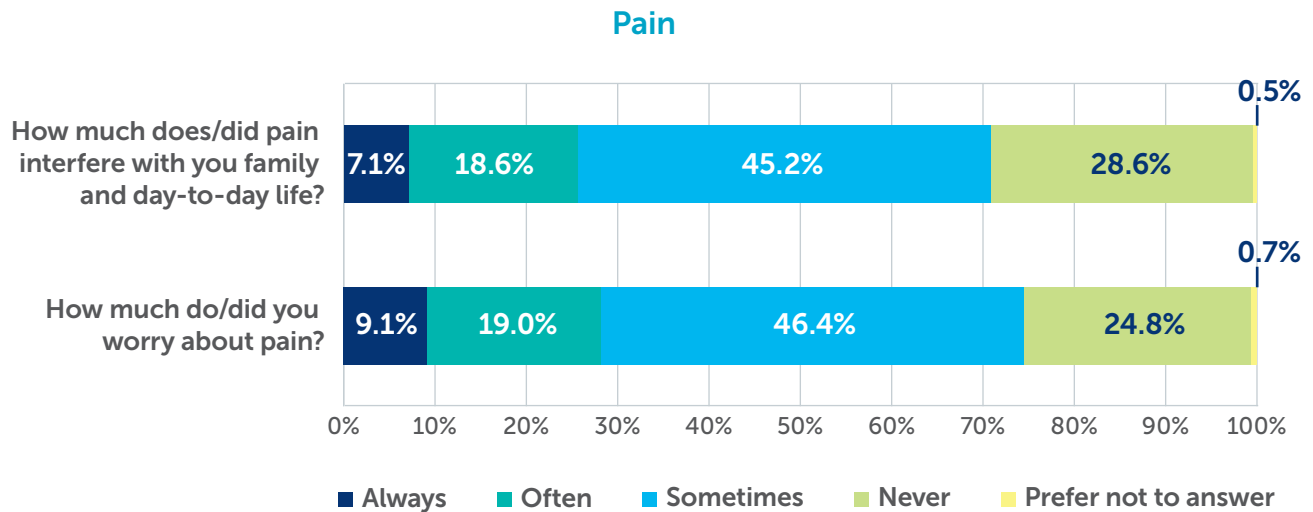


### Percentage of Respondents Who Answered "Always" or "Often" to Fatigue Questions



## PAIN

Experiencing pain or the fear of pain is prevalent in the young-onset colorectal cancer community. Most respondents (75%) indicated that they worry about pain, and 71% indicated that pain interferes with their family and day-to-day life.



## SEXUAL HEALTH

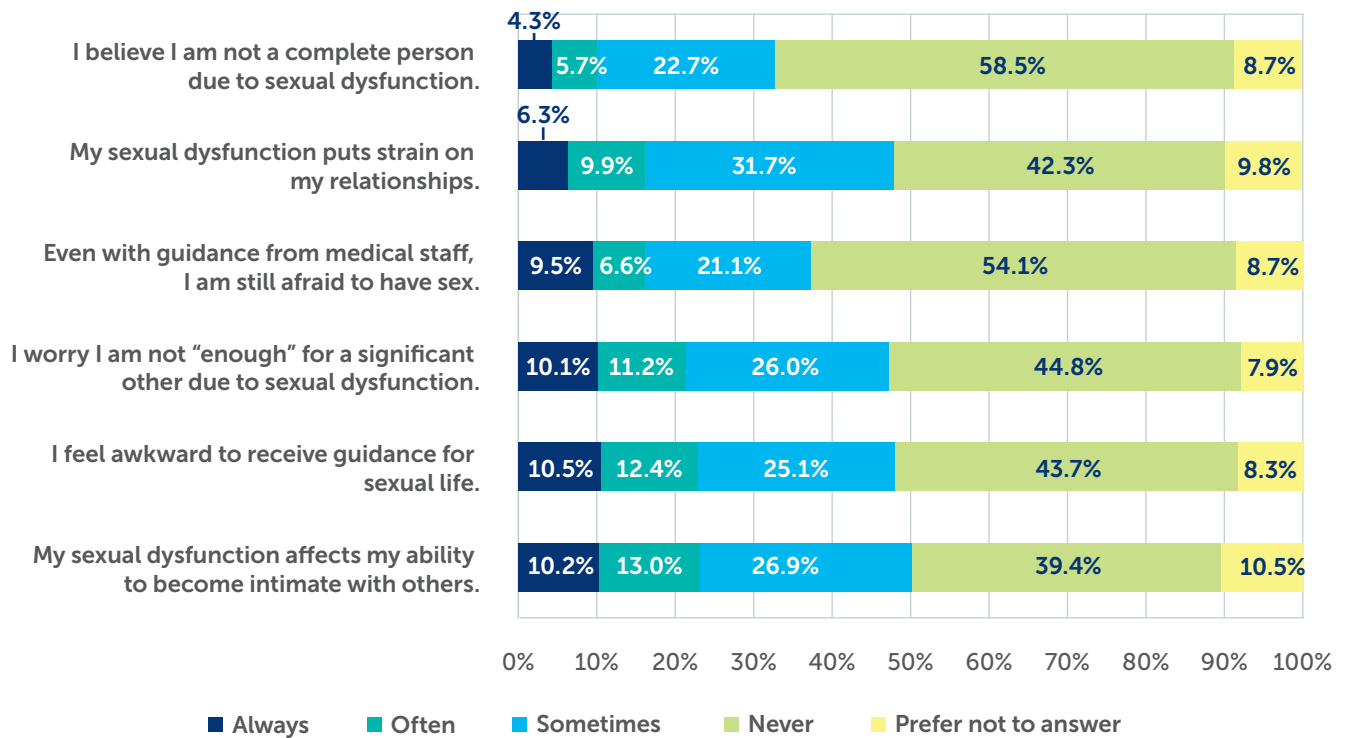
This survey found that 50% of medical providers failed to inform young-onset colorectal cancer patients of the risk of sexual dysfunction prior to the start of their treatment. This is especially concerning since 65% of respondents suffer from some level of sexual dysfunction due to treatment. In fact, more than 25% of the respondents said they would have considered alternative treatment if they would have known the risks of sexual dysfunction.

Loss of sexual function occurred in 33% of male respondents, and painful intercourse occurred in 8% of female respondents after treatment for colorectal cancer. This also affects the way the patients and survivors see themselves and their ability to be in intimate relationships. Forty-eight percent indicated that sexual dysfunction puts a strain on their relationship, and 47% worry that they are not enough for their intimate partner.

Many of the patients and survivors surveyed (48%) indicated they feel awkward and uncomfortable discussing their sexual dysfunction or receiving information from medical staff.

Again, this can negatively affect an individual’s emotional well-being, as seen by the results of the survey indicating that 33% of individuals feel that they are not a complete person due to sexual dysfunction.

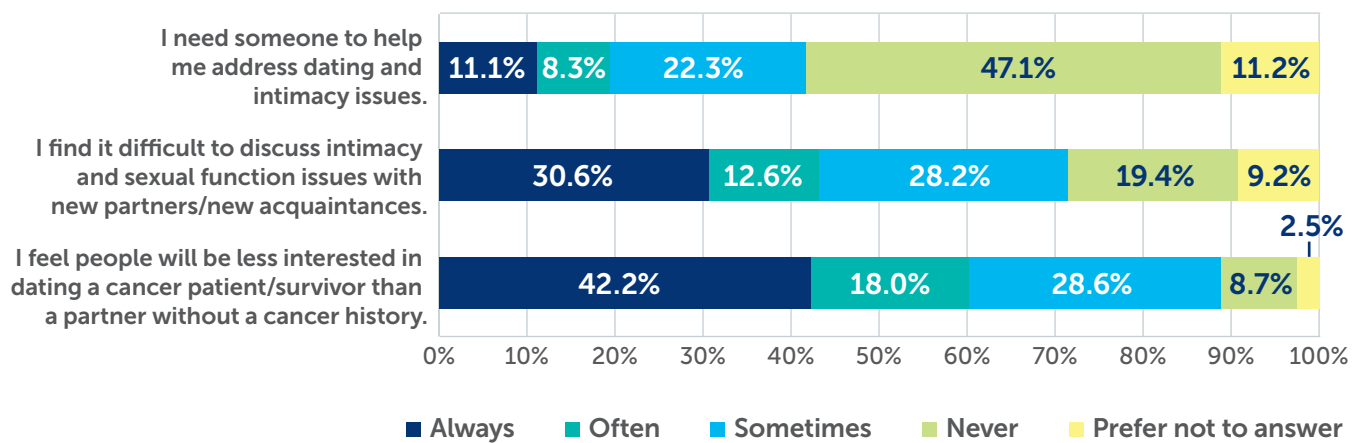
### Sexual Health



### DATING

Of the 206 single survey respondents, 60% indicated they believe that potential partners would be less interested in a relationship with a person who has a history of cancer. The survey also showed that 31% always find it difficult to discuss intimacy and sexual function issues with new partners, and 41% indicated that they need help addressing dating and intimacy issues at least some of the time.

### Dating

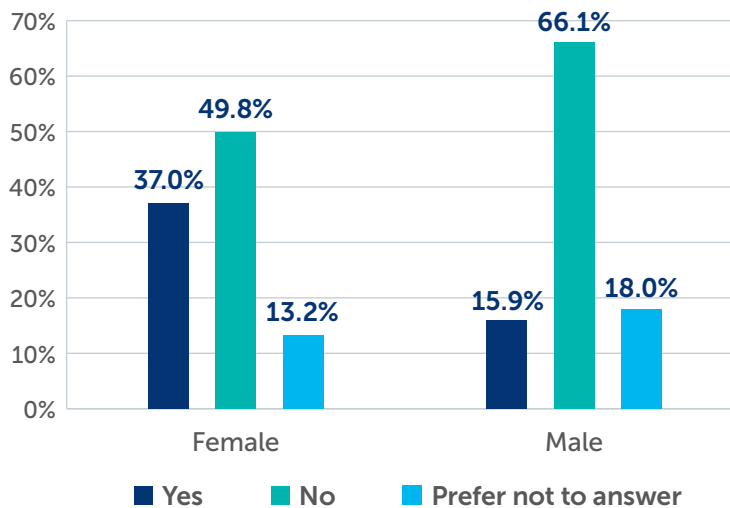


## FERTILITY

Fertility is a big issue for the young-onset colorectal cancer community. Of those who responded to this survey, only 31% said that a medical professional spoke to them about fertility preservation at the time of diagnosis and during treatment. Only 31% were referred to a reproductive endocrinologist, even though 257 women (37%) and 30 men (16%) reported that treatment left them infertile or sterile.

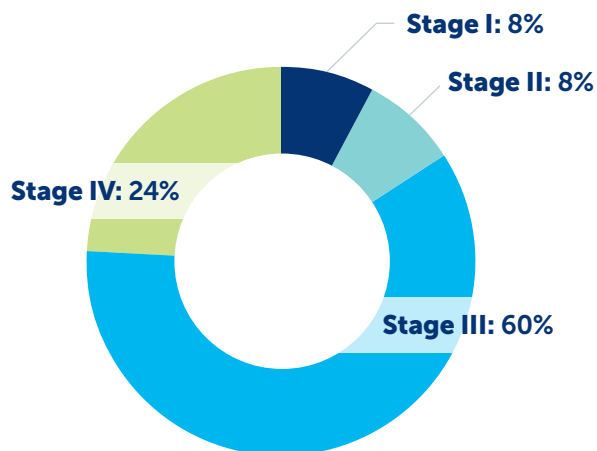
Among survey respondents, 12% of women had an egg retrieval procedure, and 36% of men had their sperm preserved prior to the start of treatment. Of the women surveyed, more than half (53%) revealed that treatment triggered early menopause.

### Are you infertile or sterile?



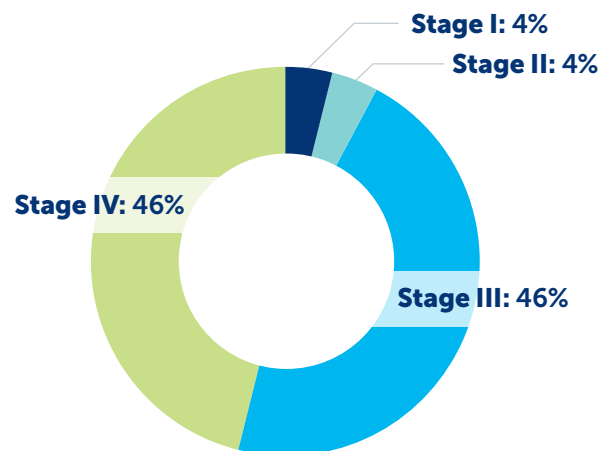
### Egg Retrieval Procedure

12% of all women surveyed had the procedure



### Sperm Preservation

36% of all men surveyed had the procedure

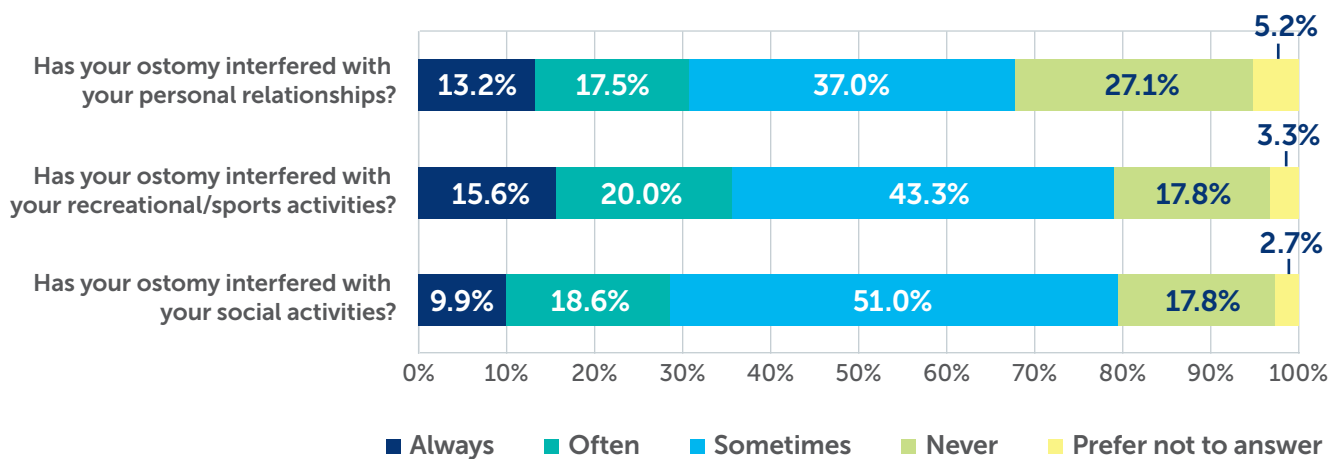


## OSTOMY

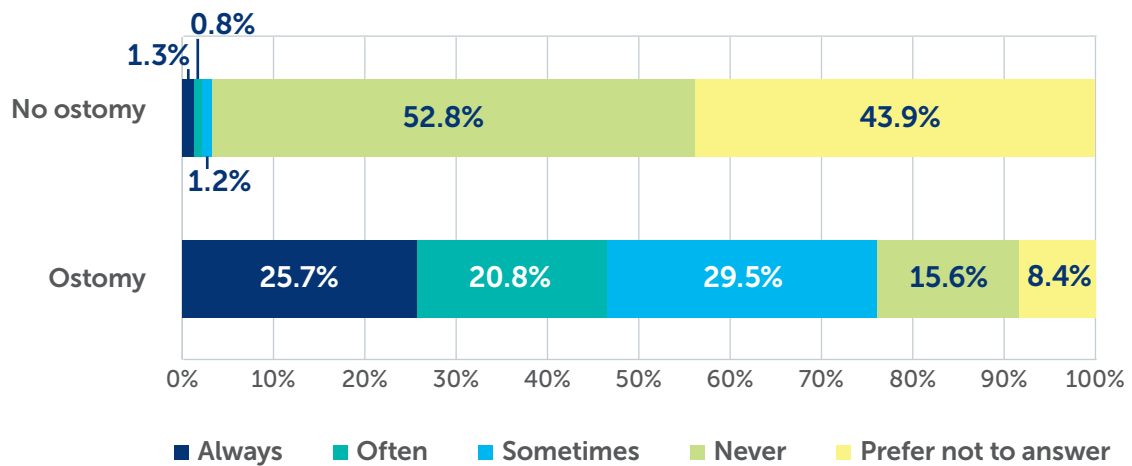
Following surgery, 365 (41%) respondents reported having had an ostomy. Of those, 100 (28%) were permanent and 265 (71%) were temporary. Respondents with ostomies were more likely to report taking a leave of absence from work, quitting their jobs, or leaving school. Of those with ostomies, 60% said they had trouble caring for their stoma, and 79% said that their ostomy interfered with social and recreational activities. People with ostomies also reported more sexual dysfunction and intimacy concerns on average, including 68% who said that their ostomy interfered with their personal relationships, and 76% said that their ostomy interfered with their ability to be intimate.

Respondents also shared that ostomies interfered with social activities and recreational/sports activities. Having an ostomy was also significantly linked with experiencing panic and anxiety, being emotionally exhausted, and wanting help for depression.

### Ostomy and Social Activities

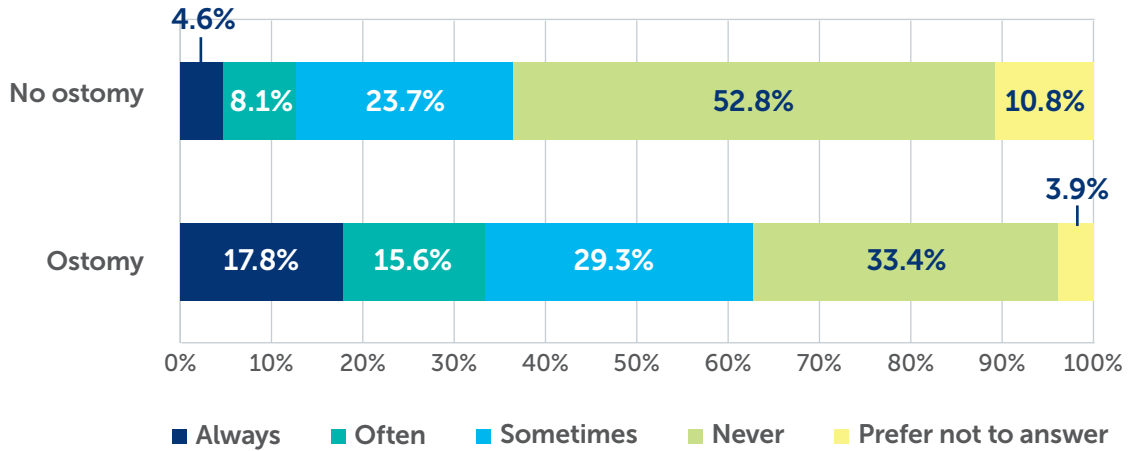


### Ostomy: My sexual dysfunction affects my ability to become intimate with others.





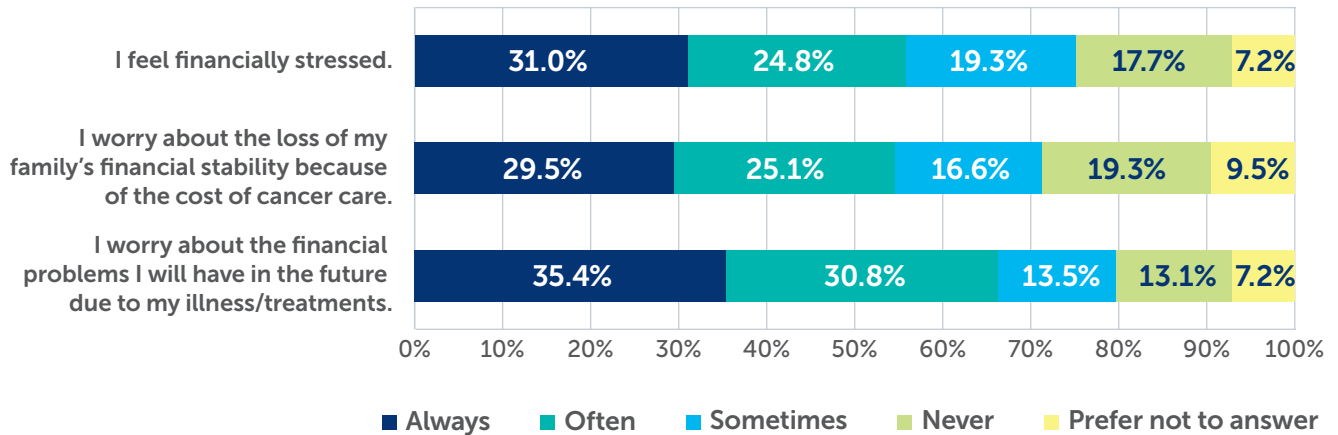
Ostomy: I worry I am not “enough” for a significant other due to sexual dysfunction.



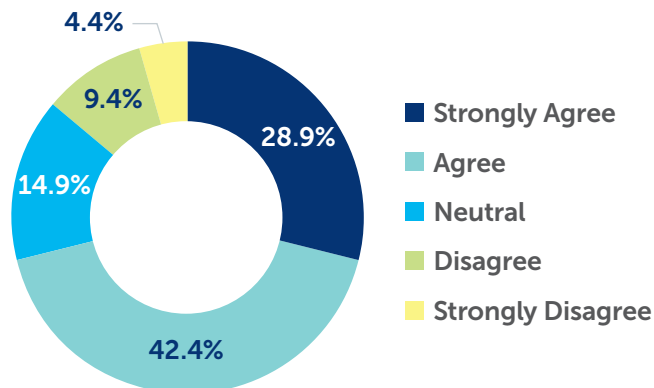
FINANCIAL HEALTH

Patients, survivors, and caregivers alike face financial hardship after a young-onset colorectal cancer diagnosis. Seventy-one percent of patients and survivors said that they felt their insurance coverage was adequate for their treatment. More than half of the patient and survivor respondents indicated they feel financially stressed and worry about the loss of their family’s financial stability, as well as the financial problems they will face in the future because of their illness and treatments.

Financial Toxicity



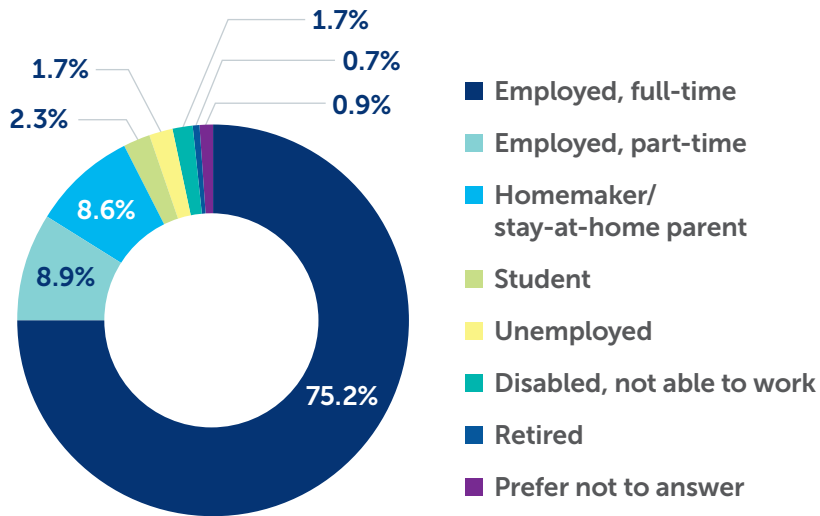
My insurance(s) offer adequate coverage for my treatment needs.



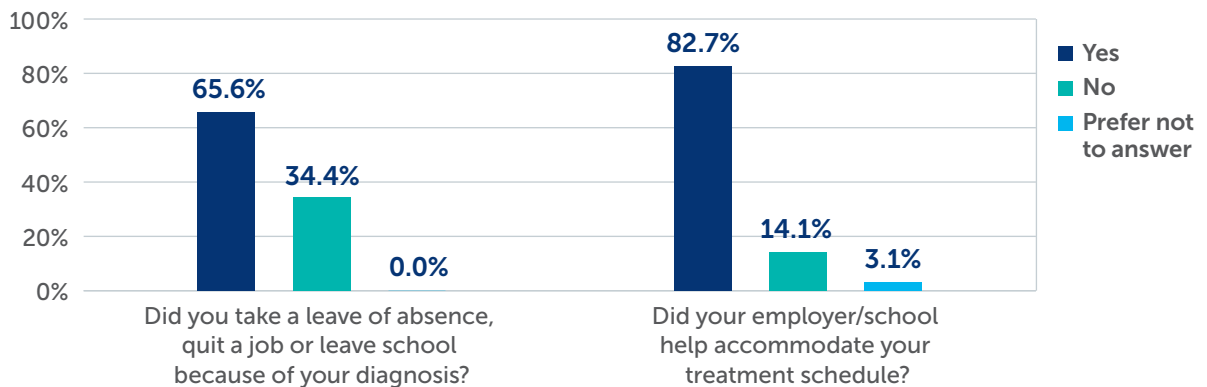
## EMPLOYMENT

This survey found that 75% of patients and survivors were employed full-time at the time of diagnosis, and only half of them were working at the time of the survey. Similarly, two-thirds of the respondents who were working part-time at diagnosis were working at the time of the survey. This suggests that a significant number of young-onset colorectal cancer patients were unable to work after their diagnosis. Of those who were working full-time at diagnosis, 28% are currently not working; of those working part-time, 35% are currently not working. Of those surveyed, 66% took a leave of absence, left their jobs, or left school due to their diagnosis and treatment. One-quarter of them have been NED (no evidence of disease) for 2-10 years.

### What was your employment status at time of diagnosis?



### Change of employment/schooling and accommodations



# Conclusion

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Several important gaps throughout the colorectal cancer journey and survivorship experience were identified through this survey. Sadly, findings further exposed a critical issue that young-onset colorectal cancer patients are being diagnosed at late stages. This occurs due to multiple challenges around misinformation and medical providers dismissing symptoms brought forward by patients. Young-onset patients also wait to see their doctor after symptoms arise, and when they do seek medical advice, they frequently find that they receive incorrect diagnoses and that it requires multiple visits and numerous providers before finally getting to an accurate diagnosis. This indicates a knowledge gap, both in the public population and the medical community, to identify early signs and symptoms of young-onset colorectal cancer. It is critical that these colorectal cancer symptoms move to the forefront of cancer education.

Additionally, this survey elucidates the existing need to change the culture around biomarker testing education, as well as sharing opportunities around clinical trials with patients. While precision medicine has opened up a world of opportunity around personalized treatment and trial options, many young onset patients are still not being sufficiently communicated with about these opportunities as early in the process as they should be. Shared decision making models are needed around clinical trial and biomarker education, as well as options around lifestyle and wellness during survivorship.

Lastly, survey findings highlight the unique challenges of cancer treatment for younger audiences around fertility and sexual dysfunction, as well as pain and wellness beyond the course of treatment. Many patients still felt uninformed prior to or during treatment, even though the majority of young onset patients indicate ongoing pain and side effects that change the trajectory of their daily life, and outcomes related to sexual function and/or reproductive health.

The journey for any cancer patient is daunting, but those with young-onset colorectal cancer face challenges that are unique to this disease. The Colorectal Cancer Alliance is dedicated to improving early diagnosis, ensuring information about biomarkers and fertility is readily available, and addressing the gaps identified in this survey.

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We acknowledge and appreciate Colontown, the Citywide Colorectal Cancer Control Coalition, and the American Cancer Society for distributing the survey to their communities and for their ongoing partnership in our shared mission to identify and support the needs of those affected by young-onset colorectal cancer.