

CADTH REIMBURSEMENT REVIEW

Patient Input

PEMBROLIZUMAB (Keytruda)
(Merck Canada Inc.)

Indication: Colorectal cancer

CADTH received patient input from:

Colorectal Cancer Canada

Colorectal Cancer Resource & Action Network

December 24, 2020

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Patient Input Template for CADTH CDR and pCODR Programs

Name of the Drug and Indication	Pembrolizumab for the first line treatment of adult patients with unresectable or metastatic microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) colorectal cancer (CRC)
Name of the Patient Group	Colorectal Cancer Canada
Author of the Submission	[REDACTED]
Name of the Primary Contact for This Submission	[REDACTED]
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1. About Your Patient Group

Colorectal Cancer Canada is registered with CADTH.

www.colorectalcancerCanada.com

2. Information Gathering

To help capture the patient perspective on the drug under review, Colorectal Cancer Canada launched an online patient/caregiver survey from October 30, 2020 to January 1, 2021 of which 8 patients and 2 caregivers on behalf of family members responded (Patient 1-8, Caregiver 1-2). Data was gathered from patients across Canada, the United States, and Malaysia. The survey was posted on the social media platforms of CCC as well as on those of international colorectal cancer organizations. CCC's patient support specialist also reached out to patients currently taking the drug under review to fill in the survey. As a result of this outreach, eight patients and two caregivers provided detailed and high quality responses to our questions:

Throughout this report, all reference to “caregivers” is on behalf of a patient unless otherwise noted. The data on patient demographics is summarized and represented in Table 1 and will serve as the basis for this submission.

Table 1: Surveyed Patients – Information Gathering

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
Connection to Cancer	Patient undergoing treatment	Patient undergoing treatment	Patient previously treated	Patient with no evidence of disease currently	Patient undergoing treatment	Patient undergoing treatment	Patient undergoing treatment	Patient previously treated
Country and Region	United States	Canada	Canada/ Quebec	United States	Canada	United States/West Virginia	Canada/ Alberta	Canada
A. Gender B. Age at Dx	A. Female B. 40-49 years	A. Male B. 60-69 years	A. Male B. 40-49 years	A. Female B. 60-69 years	A. Male B. Under 20 years	A. Female B. 30-39 years	A. Female B. 40-49 years	A. Male B. 60-69 years
Date of Dx	01/12/16	20/02/2020	7/11/2014	24/08/2017	22/12/2017	23/06/2020	25/12/2017	14/12/2015
A. Stage at Dx B. Current Stage C. Metastases	A. Stage III B. Stage IV C. Lymphatic	A. Stage IV B. Stage IV C. Liver (Hepatobiliary)	A. Stage III B. Stage IV C. Liver (Hepatobiliary), Lung, Peritoneum, Bone	A. Stage IV B. Stage IV C. Liver (Hepatobiliary)	A. Stage III B. Stage IV C. Lymph nodes	A. Stage IV B. Stage IV C. Lung	A. Stage III B. Stage IV C. Endometrial, Ovary	A. Stage II B. I don't know C. No metastases

Table 2: Surveyed Caregivers – Information Gathering

	Caregiver 1	Caregiver 2
Connection to Cancer	Caregiver on behalf of patient previously treated	Caregiver on behalf of patient undergoing treatment

	Caregiver 1	Caregiver 2
Country and Region	Malaysia	Canada
A. Gender B. Age at Dx	A. Female B. 50-59 years	A. Male B. 50-59 years
Date of Dx	03/2019	18/04/2019
A. Stage at Dx B. Current Stage	A. Stage III B. Stage III	A. Stage III B. Stage II
C. Metastases	C. Lymph nodes	C. Peritoneum

3. Disease Experience

Patients and caregivers were asked if any cancer-induced symptoms were experienced prior to diagnosis. Eight out of ten patients/caregivers (80%) had experienced symptoms, most commonly bloody stools and fatigue. Patients also reported these symptoms as the ones which were more important to control than others. Aside from caregiver 1, all patients feel that their symptoms affect their daily life. Patients felt symptoms affected their work-life, daily activities and the ability to exercise: *“Chronic fatigue limits activities, inability to exercise, lack of motivation”* (Patient 6), *“Unable to work, partake in social activities, activity level very limited”* (Caregiver 2). Additionally, symptoms had a psychological impact on six out of ten patients/caregivers (60%) including mental health issues such as anxiety, depression (Patient 1 and 3), financial stress (Patient 7) and even PTSD (Patient 3). Patient 5 reported self-confidence issues with his ostomy.

Caregivers were uniquely questioned on the difficulties faced while caring for their loved one. Caregiver 2 mentioned feelings of helplessness, and difficulties coping and travelling 9 hours for treatment every 3 weeks.

All the patients and the caregivers rated access to new effective treatments for cancer as very important.

The data on disease experience is summarized and represented in Table 3 and 4.

Table 3: Surveyed Patients – Disease Experience

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
Symptoms experienced	Yes, Bloody stools Fatigue	No	Yes	Yes, fatigue, anemia,	Yes, bloody stools, fatigue, diarrhea	No	Yes	Yes

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
from cancer prior to Dx	Abdominal cramping Diarrhea			shortness of breath				
Which symptoms of cancer were/are more important to control than others?	Blood clots even with urination, constipation, fatigue		Pain, digestive problems, fatigue	fatigue, shortness of breath, anemia	fatigue because I slept a lot and didn't know why. But I don't recall having too much pain. Just bloody stools was hard to control for me.		Fatigue, abdominal cramping, anemia, bowel perforation	Bloody stools, fatigue, diarrhea
How symptoms and problems resulting from any symptoms impact or limit quality of life	Chronic fatigue limits activities, inability to exercise, lack of motivation	Work.	Cannot work, could not drive for many years, mobility was impacted	exercise, volunteerism	"Well after the spread to my lymph nodes I completely stopped work. I was a plumbing apprentice at the time and working on that. But since finding pembrolizumab I've been able to start working out which is amazing because it helps a lot with my mental health."	Chronic fatigue limits activities, inability to exercise, lack of motivation	Inability to work full time, difficulty exercising	Inability to exercise
Psychological impact as a result of your cancer on you or your family?	Severe anxiety, depression, mood swings	None	Severe anxiety, PTSD		"With my bag it was definitely confidence for a while now I don't care what others think. Family most likely was just extremely scared and worried but I knew I was going to put up the fight as long as I could/have."		Inability to work full time and out of pocket immunotherapy expenses = financial stress	Exercise, work

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
On a scale of 1-10, how important to you is the access to new effective treatments for cancer, with 1 being “not important” and 10 being “very important”?	Very important10	8						

Table 4: Surveyed Caregivers– Disease Experience

	Caregiver 1	Caregiver 2
Symptoms experienced from cancer prior to Dx	Bloody stools	Bloody stools, fatigue, abdominal cramping, anemia, diarrhea, bowel perforation, bowel obstruction, shortness of breath
Which symptoms of cancer were/are more important to control than others?		Abdominal pain, anemia, fatigue
How symptoms and problems resulting from any symptoms impact or limit quality of life	None	Unable to work, partake in social activities, activity level very limited
Psychological impact as a result of your cancer on you or your family?	None	Unable to work, partake in social activities with family

	Caregiver 1	Caregiver 2
On a scale of 1-10, how important to you is the access to new effective treatments for cancer, with 1 being “not important” and 10 being “very important”?	Very important10	Very important10
Difficulties caregiver faced:		Coping, travelling 9 hours for treatment every 3 weeks, feeling helpless

4. Experiences With Currently Available Treatments

Nine out of ten (90%) patients/caregivers accessed previous therapies for the treatment of their colon cancer. Therapies included chemotherapy, radiation therapy, surgery and two patients are currently on other immunotherapies (nivolumab and ipilimumab) (Patient 3 and 7). We recognize that the latter patients have not taken the drug under review, but they have responded to the survey in order to best describe their experience with immunotherapy. For instance, Patient 7 now shows no evidence of disease following administration of nivolumab and ipilimumab. This indicates promising results for other immunotherapy drugs such as the drug under review.

For two out of ten patients/caregivers (20%), their previous therapies were not able to control their symptoms, and for two out of ten patients/caregivers (20%), the therapies were able to partially control them. Patients were questioned what side effects were most difficult to tolerate from their therapies and most patients reported similar side effects such as diarrhea, nausea, hair loss, vomiting, and fatigue. On a scale of 1-10 of “not important”, to “very important”, all patients rated >7 on the importance of having a choice on which drug to choose based upon each different drug’s known side effects.

Four out of ten patients/caregivers (40%) experienced difficulties accessing drugs for their cancers. Both patients 5 and 7 report that the treatments they were recommended were solely based on what was funded in their region of residence. Additionally, for previous immunotherapies, Patient 3 had to go to the US for access to the drugs, and both Patient 3 and 7 had to pay entirely out of pocket for the drugs. In addition to treatment cost, around half of the previously-treated patients noted travel as an additional expense incurred by accessing their treatments, and Patient 7 reported loss of work-time and income as an additional cost to treatment.

Paying out of pocket to access new drug therapies is dependent on the cost for most patients (70%). Patient 3 mentions although she doesn’t have the money she some would be willing to *“do anything in my power to try and get the drug”*.

Patient 7 expresses her willingness to pay out of pocket for promising drugs, and expresses her concerns of the lack of access to drugs in Canada:

“I don't think colorectal patients should have to pay for treatments with proven efficacy. There are studies that now recommend immunotherapy treatment for MSI- High/mismatch repair deficient colorectal cancers. In other countries these treatments are now first line treatments. Canadians should have access to these treatments and they should be covered. If new treatments arise that haven't had proven efficacy through peer reviewed studies, but look promising, I would consider paying out of pocket if the cost wasn't exorbitant and some financial help was available on a compassionate basis.”

The data on patients' experiences with currently available treatments is summarized and represented in Table 5 and 6.

Table 5: Surveyed Patients – Experiences With Currently Available Treatments

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
If pembrolizumab (KEYTRUDA) is not your first line treatment, what treatments have you received previously?	Chemotherapy, radiation therapy, surgery	Chemotherapy	Chemotherapy, radiation therapy, surgery	surgery	Chemotherapy	No other treatment	Nivolumab and ipilimumab	Chemotherapy, radiation therapy, surgery
Have these therapies been effective at controlling the symptoms resulting from your colorectal cancer?	Partially	No	No	Yes	Partially		Yes	Yes
What side effects have you experienced with your previous treatments?	Diarrhea, nausea, hair loss, vomiting, mouth sores, anemia, low white blood cell count, fatigue, pain	Fatigue	Diarrhea, nausea, hair loss, mouth sores, anemia, fatigue, pain, skin rash, hand and foot syndrome, neuropathy	No side effects	Hair loss, vomiting, mouth sores, fatigue, pain, hand and foot syndrome	fatigue	Fatigue, pain, skin rash	Diarrhea, nausea, fatigue, pain

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
Top two side effects that were most difficult to tolerate:	Nausea, anxiety		Nausea, neuropathy		Hand and foot syndrome and pain		Neuropathy from chemotherapy, fatigue	Pain, fatigue
Have you (or your oncologist) experienced any difficulties in accessing drugs for your colorectal cancer?	No	No	Yes, Needed to go to US for ipilimumab and nivolumab	No	Yes, For pembrolizumab I received funding through the hospital foundation that has helped me have life again!	No	Yes, I have not been able to get coverage for Nivolumab and ipilimumab, I've had to pay out of pocket for these treatments: over 155,000\$	No
Were any of your treatments recommended solely based on what was funded in your region of residence?	No	I don't know	I don't know	N/A	Yes	No	Yes	Yes
Have you had to pay out of pocket for any of your previous treatments?	No	Yes	Yes, Nivolumab and ipilimumab received in US	No	No	No	Yes, Nivolumab and ipilimumab	No
Did you receive any financial assistance from a pharmaceutical/biotech company assistance program or any	No	No	Yes, 100%	No	Yes, 100%	No	Yes	No

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
other assistance program?								
If you did receive financial assistance, what percentage of the total cost of the treatment was provided? example: 10%			100% drug cost		100%		They agreed to pay 20% of the cost. After appealing to them on compassionate grounds they've agreed to pay 100% of the cost moving forward for a total of two years. However they won't cover what I've paid out of pocket so far (\$155,000). I haven't had any treatments since they've agreed to pay 100% as I've had a complete response to treatment and am taking a break from treatments.	
In addition to the treatment cost, were there other	Yes, travel	Yes, travel	Yes, Travel, accommodation, lab	No	No	Yes, travel	Yes, parking, lost work time/income	No

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
costs incurred by you in accessing the treatment, such as travel costs, drug administration, etc.?			expenses, doctor visits, hospital expenses for administration of treatment, CT and PET scans				(I'm self employed)	
Would you be willing to pay out of pocket to access new drug therapies for the treatment of your colorectal cancer in a private clinic?	Depends on the cost	No	Yes, However, a hospital certified oncologist must be involved in case of complications, severe side effects	Depends on the cost	Depends on the cost, Of course I don't have the money but I would do anything in my power to try and get the drug	Depends on the cost	Depends on the cost, I don't think colorectal patients should have to pay for treatments with proven efficacy. There are studies that now recommend immunotherapy treatment for MSI-High/mismatch repair deficient colorectal cancers. In other countries these treatments are now first line	Depends on the cost

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
							<p>treatments. Canadians should have access to these treatments and they should be covered. If new treatments arise that haven't had proven efficacy through peer reviewed studies, but look promising, I would consider paying out of pocket if the cost wasn't exorbitant and some financial help was available on a compassionate basis. I've had to rely on the financial help from family and friends in addition to my own finances</p>	

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
							to pay for my treatments. I still owe AHS over \$50,000 for my treatments. They are asking for payment which also isn't realistic during the pandemic.	
On a scale of 1-10, with 1 being “not important” and 10 being “very important”, if you had had a choice of drugs to treat your cancer, how important was it for you to make that choice based upon each different drug’s known side effects?	8	Very important10	8	Very important 10	9	Very important10	Very important10	9

Table 6: Surveyed Caregivers – Experiences With Currently Available Treatments

	Caregiver 1	Caregiver 2
If pembrolizumab (KEYTRUDA) is not your first line treatment, what treatments have you received previously?	Chemotherapy	Chemotherapy

	Caregiver 1	Caregiver 2
Have these therapies been effective at controlling the symptoms resulting from your colorectal cancer?	No	No
What side effects have you experienced with your previous treatments?	vomiting, hand and foot syndrome	Diarrhea, hair loss, fatigue, neuropathy, low ANC
Top two side effects that were most difficult to tolerate:	Loss of appetite	Neuropathy, nausea
Have you (or your oncologist) experienced any difficulties in accessing drugs for your colorectal cancer?	No	Yes for Keytruda
Were any of your treatments recommended solely based on what was funded in your region of residence?	No	Yes
Have you had to pay out of pocket for any of your previous treatments?	No	No
Did you receive any financial assistance from a pharmaceutical/biotech company assistance program or any other assistance program?	No	No
If you did receive financial assistance, what percentage of the total cost of the treatment was provided? example: 10%		
In addition to the treatment cost, were there other costs incurred by you in accessing the treatment, such as travel costs, drug administration, etc.?	No	No
Would you be willing to pay out of pocket to access new drug therapies for the treatment of your colorectal cancer in a private clinic?	Depends on the cost	Yes
On a scale of 1-10, with 1 being “not important” and 10 being “very	Very important10	7

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
or other funder) was to fund a minimum of two therapies for the treatment of your cancer, how important is it for you that your oncologist have flexibility in deciding which of those therapies to choose?								

Table 8: Surveyed Caregivers – Improved Outcomes

Caregiver 2	
On a scale of 1-10, with 1 being “not important” and 10 being “very important”, if you were to consider taking a new therapy for your cancer, how important is it for you that:	
New therapies bring about improvement in your physical condition?	Very important10
New therapies bring about improvement in your quality of life?	Very important10
You understand the average (or median) period of	Very important10

Caregiver 2

expected benefit from that new therapy?

Would you take a drug that has been proven to provide better Quality of Life during your lifetime even if it does not extend overall survival?

Yes

On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects”, if you were to consider taking a new therapy for your cancer, what severity of side effects are you willing to tolerate in order to extend survival by:

(a) 2 months?

4

(b) 6 months?

6

(c) 1 year?

7

On a scale of 1-10, with 1 being “not important as long as there is a drug” and 10 being “very important to choose which drug would be best suited for me”, if you were to consider taking a new therapy for your cancer, how important is it for you and your physician to have a choice in

6

Caregiver 2

<p>deciding which drug to take?</p>	
<p>On a scale of 1-10, with 1 being “very limited/restrictive” and 10 being “very appropriate/fair”, to ensure the best outcome for your cancer, would you say that access to drug therapies in your province (state)/country is limited/restrictive or is it appropriate/fair?</p>	<p>3</p>
<p>On a scale of 1-10, with 1 being “not important” and 10 being “very important”, if your government or funder (such as insurance company, hospital or other funder) was to fund a minimum of two therapies for the treatment of your cancer, how important is it for you that your oncologist have flexibility in deciding which of</p>	<p>7</p>

Caregiver 2	
those therapies to choose?	

6. Experience With Drug Under Review

As evidenced in Tables 9-11, two out of six patients (33.3%) had the drug under review as first line treatment (Patient 4 and 6). Both patients were MSI-H. Patient 1 changed to the drug under review after recurrence because *“surgery/chemo/radiation were minimally effective”*. Two out of six patients (33.3%) had access to the drug under review via clinical trials, while others had access to the drug through special access programs and insurance plans. Most had no financial restrictions when accessing the drug; but both Patient 6 and Caregiver 2 reported travel costs associated with accessing treatment. Caregiver 2 also reported lack of provincial coverage as the main issue to accessing immunotherapy.

All patients were prescribed Pembrolizumab after being tested positive for MSI-H. Patients 1 and 6 were also diagnosed with Lynch Syndrome. When asked about a particular gap or unmet patient need with current therapies, Patient 1 and Caregiver 2 mentioned the unavailability of the drug under review as a major gap. Patient 1 emphasizes that *“a lot of time was wasted on other treatments”*, and believes she could have *“avoided brutal, ineffective chemo [had she] started with Keytruda instead of other treatments”*.

Most importantly, patients and caregivers rated side effects’ impact on daily living as very low (1-3) on a scale from 1-10. Common side effects experienced include hair loss, fatigue, constipation, pain in muscles, bones, joints, and fever. Patients and caregivers noted these side effects as somewhat tolerable and relatively minor. When questioned about the most difficult aspects of immunotherapy, the drug’s psychological impact on patients was the most common. Patients reported the feeling of isolation, emotional drain, anxiety, and fatigue due to long hours spent in medical appointments.

Patients and caregivers were also questioned on what they expect, or hope, that Pembrolizumab will have on the cancer and their prognoses, all patients and caregivers (100%) hope it can *“increase overall survival”* and five out of six patients (83%) hope it *“maintains and improves quality of life”*. In fact, patients presently on the drug rate their quality of life as *“high or normal living”*. They were also asked if the drug under review allowed them to fulfill or accomplish anything that they would not have otherwise been able to, had they not accessed the therapy. Patients voiced a common answer that the drug allowed them to resume all their daily activities: *“being able to go and workout”* (Patient 5), *“Without Keytruda, I*

probably wouldn't be here. I've endured this battle for four years now. I've been able to switch to the 6-week treatment making it even easier to enjoy a "normal" life" (Patient 1), "Spend time with family, do activities he loves to do" (Caregiver 2).

Patient 1 and Caregiver 2 mentioned that diarrhea, bloody stools and constipation are symptoms managed less effectively under the drug under review than the existing therapies. However to all other patients, the drug under review manages nausea, vomiting, anxiety, hair loss, bloody stools, fatigue, diarrhea, abdominal cramping and anemia better than existing therapies. Most importantly. most patients and caregivers following treatment have their tumour completely gone, shrunk or controlled:

"Without Keytruda, the mass in my pelvis that was leaning against my sacrum bone and quality of life was very, very low. Keytruda shrank the mass to a manageable size and alleviated the severe pain".

Patients and caregivers were asked if they believe the drug under review will change their long-term health and well-being for the better. All patients responded positively, saying "it already has" (Patient 6), "felt good all along treatment, and still do after terminating treatment" (Patient 4). Patient 6 is even "confident it will save [her] life". All patients appreciate the easily administered oral therapy and find it simple to integrate in their daily routine. Compared to other treatments, patients and caregivers rated their overall experience with the drug under review as "much better 10" on a scale of 1-10.

All patients and caregivers (100%) responded yes when asked if they believe the drug under review should be funded where they reside for the treatment of cancer: "Yes, Everyone should have equal access to medications if it's proven to be effective" (Patient 1), "Yes, it is effective for MSI-high tumours, improves quality of life" (Caregiver 2).

The data on the experience with drug under review is summarized and represented in Table 9 and 10. Patients 2, 3 ,7 and Caregiver 1 did not respond to questions in this section.

Table 9: Surveyed Patients – Experience with Drug under Review

	Patient 1	Patient 4	Patient 5	Patient 6	Patient 8
At the start of your discussion with your oncologist, were you informed of immunotherapy/Pembrolizumab (KEYTRUDA) by your oncologist as a potential treatment option for you?	No	Yes	Yes	No	No
Why were you prescribed Pembrolizumab (KEYTRUDA)?	As a Lynch Syndrome patient with an aggressive cancer, surgery/chemo/radiation did not work for me. As a last hope, we decided to try Keytruda as it had	I am MSI High, good reaction to Keytruda	Cuz I was msi high and there were studies that had said this had worked on previous patents with msi	Clinical trial with NOUS209 vaccine	

	just been approved for colon cancer patients three months prior.		high but different cancer		
In what line of therapy were you prescribed/given Pembrolizumab (KEYTRUDA) for the treatment of your metastatic colorectal cancer?	Fourth Line	First Line	Third Line	First Line	.
Did you participate in a clinical trial in connection to this drug? If yes, please specify clinical trial name and location (country – state/province):	No	No	I might have been but not 100% sure	Trial with NOUS209 vaccine Johns Hopkins	No
How long have you been taking Pembrolizumab (KEYTRUDA)? Please specify below:	Two years, 45 infusions	2 years	About 18 months	2 months	.
If applicable, did you change your treatment option to Pembrolizumab (KEYTRUDA) after recurrence*?	Surgery/chemo/radiation were minimally effective. Keytruda was my last option.	No	No	No	N/A
In your opinion, is there a particular gap or unmet patient need with current therapies that Pembrolizumab (KEYTRUDA) will help alleviate?	Yes, Immune therapy is just now gaining traction for the treatment of colon cancer. For patients like me, I could have avoided brutal, ineffective chemo and stopped the cancer from spreading to my lymphatic system if we started with Keytruda instead of other treatments. We lost a lot of time.	No	No	No	No
What effect do you expect (or hope) that Pembrolizumab (KEYTRUDA) will have on the cancer and your prognosis? Check all that apply.	Maintain or improve quality of life, Increase overall survival, Delay onset of symptoms, Delay need for	Maintain or improve quality of life, Increase overall survival	Maintain or improve quality of life, Increase overall survival, Reduce side effects from	Maintain or improve quality of life, Increase overall survival, Delay need for	Increase overall survival

	chemotherapy, Ease of use		current medications or treatments	chemotherapy, Ease of use	
Which symptoms does Pembrolizumab (KEYTRUDA) manage better than the existing therapies?	Nausea, vomiting, anxiety, hair loss		Bloody stools, fatigue, diarrhea		
Which symptoms does Pembrolizumab (KEYTRUDA) manage less effectively than the existing therapies?	Bloody stools, fatigue, constipation				
Was Pembrolizumab (KEYTRUDA) able to shrink/control your colorectal cancer and/or spread of the disease to other organs (metastases)?	Yes	Yes	Yes	Yes	I don't know
What are the side effects have you experienced while on Pembrolizumab (KEYTRUDA)? Please select from the list below.	Hair loss, fatigue, constipation, mouth sores	Hair loss, Pain in muscles, bones, joints	Hair loss, fatigue	fatigue, Pain in muscles, bones, joints, fever	
Of the side effects experienced with Pembrolizumab (KEYTRUDA), which ones were most difficult to tolerate? Please identify your top three.	Stomatitis, constipation, fatigue	joint pain	None really	Fatigue	
On a scale of 1-10, with 1 being "no side effects at all" and 10 being "debilitating side effects that impact daily living", how would you rate your side effects while taking Pembrolizumab (KEYTRUDA)?	2	3	no side effects at all1	3	
Did you have to stop the immunotherapy/Pembrolizumab (KEYTRUDA) earlier than planned or did you have to skip doses due to side effects?	No	No	No	No	
As an intravenous therapy (drug administered into your veins),	Yes	Yes	Yes	Yes	

has Pembrolizumab (KEYTRUDA) been easy to administer/receive?					
On a scale of 1-10, with 1 being “low/severely impacted”, and 10 being “high/normal living”, how do you rate your quality of life while taking Pembrolizumab (KEYTRUDA)?	9	9	high/normal living10	high/normal living10	
Do you find immunotherapy/Pembrolizumab (KEYTRUDA) to be easy to integrate in your daily routine?	Yes	Yes	Yes	Yes	
What is/are the most difficult aspect(s) of immunotherapy/Pembrolizumab (KEYTRUDA) for you?	Emotional drain	No particular issues	Impact on career, Anxiety/worrying	Hours spent in medical appointments, Feeling isolated (difficulty connecting with friends, geographical remoteness), fatigue	
Do you believe Pembrolizumab (KEYTRUDA) will change your long-term health and well-being for the better?	Yes, Absolutely. Without Keytruda, the mass in my pelvis that was leaning against my sacrum bone and quality of life was very, very low. Keytruda shrank the mass to a manageable size and alleviated the severe pain	Yes, Felt good all along treatment, and still do after terminating treatment	Yes, It already has	Yes, I am confident it will save my life	
Based on any experience you have had taking other drugs for your colorectal cancer: On a scale of 1-10, with 1 being “much worse” and 10 being “much better”, how would you rate your	much better10	N/A	much better10	N/A	

overall experience with Pembrolizumab (KEYTRUDA) compared to other treatments?					
Did accessing Pembrolizumab (KEYTRUDA) allow you to fulfill or accomplish anything that you would not have otherwise been able to, had you not accessed the therapy? If yes, please explain.	Yes! Without Keytruda, I probably wouldn't be here. I've endured this battle for four years now. I've been able to switch to the 6-week treatment making it even easier to enjoy a "normal" life.		Being able to go and workout while off of work		
How was Pembrolizumab (KEYTRUDA) funded for you?	Insurance Plan	Insurance Plan	Special Access program	Insurance Plan, "Clinical Trial"	
Do you believe Pembrolizumab (KEYTRUDA) should be funded where you reside for the treatment of metastatic colorectal cancer? Why or why not.	Yes, Everyone should have equal access to medications if it's proven to be effective.	Yes, It helps the spread if you have certain mutations	Yes, It has helped me have an amazing quality of life and I cannot thank the treatment enough and my doctor	Yes	
Did you experience any financial constraints due to Pembrolizumab (KEYTRUDA)? This includes issues like excessive driving expenses, loss of work etc.	No	No	No	No	
Have you had issues accessing immunotherapy/Pembrolizumab (KEYTRUDA)? If so, what issues have you experienced? Check all that apply.	I haven't had any issues accessing therapy	I haven't had any issues accessing therapy	I haven't had any issues accessing therapy	Travel costs associated with accessing therapy/treatment	

Table 10: Surveyed Caregivers – Experience with Drug under Review

Caregiver 2	
At the start of your discussion with your oncologist, were you informed of immunotherapy/Pembrolizumab (KEYTRUDA) by your oncologist as a potential treatment option for you?	No
Why were you prescribed Pembrolizumab (KEYTRUDA)?	MSI high tumour, part of clinical study
In what line of therapy were you prescribed/given Pembrolizumab (KEYTRUDA) for the treatment of your metastatic colorectal cancer?*First line treatment is the treatment regimen that are generally accepted by the medical establishment for initial treatment of a given type and stage of cancer. Second-line treatments are those tried when the first ones do not work adequately. Third line/fourth line treatment are those that are occasionally used for subsequent treatment.	Second line
Did you participate in a clinical trial in connection to this drug? If yes, please specify clinical trial name and location (country – state/province):	Yes, unsure of trial name – Montreal, Quebec
How long have you been taking Pembrolizumab (KEYTRUDA)? Please specify below:	.
If applicable, did you change your treatment option to Pembrolizumab (KEYTRUDA) after recurrence*? If yes, why?*If cancer is found after treatment, and after a period of time when the cancer couldn't be detected	N/A
In your opinion, is there a particular gap or unmet patient need with current therapies that Pembrolizumab (KEYTRUDA) will help alleviate?	Yes, not available for bowel cancer
What effect do you expect (or hope) that Pembrolizumab (KEYTRUDA) will have on the cancer and your prognosis? Check all that apply.	Maintain or improve quality of life, Increase overall survival
Which symptoms does Pembrolizumab (KEYTRUDA) manage better than the existing therapies? Check all that apply.	Bloody stools, fatigue, abdominal cramping, anemia
Which symptoms does Pembrolizumab (KEYTRUDA) manage less effectively than the existing therapies?Check all that apply.	Diarrhea

Was Pembrolizumab (KEYTRUDA) able to shrink/control your colorectal cancer and/or spread of the disease to other organs (metastases)?	Yes
What are the side effects have you experienced while on Pembrolizumab (KEYTRUDA)? Please select from the list below.	Pain in muscles, bones, joints
Of the side effects experienced with Pembrolizumab (KEYTRUDA), which ones were most difficult to tolerate? Please identify your top three.	Joint pain
On a scale of 1-10, with 1 being “no side effects at all” and 10 being “debilitating side effects that impact daily living”, how would you rate your side effects while taking Pembrolizumab (KEYTRUDA)?	2
Did you have to stop the immunotherapy/Pembrolizumab (KEYTRUDA) earlier than planned or did you have to skip doses due to side effects?	No
As an intravenous therapy (drug administered into your veins), has Pembrolizumab (KEYTRUDA) been easy to administer/receive?	Yes
On a scale of 1-10, with 1 being “low/severely impacted”, and 10 being “high/normal living”, how do you rate your quality of life while taking Pembrolizumab (KEYTRUDA)?	High/normal living 10
Do you find immunotherapy/Pembrolizumab (KEYTRUDA) to be easy to integrate in your daily routine?	No
What is/are the most difficult aspect(s) of immunotherapy/Pembrolizumab (KEYTRUDA) for you? Check all that apply.	Monetary concerns (absence at work, driving expenses, etc.) - Driving many hours to receive drug through clinical trial
Do you believe Pembrolizumab (KEYTRUDA) will change your long-term health and well-being for the better?	Yes
Based on any experience you have had taking other drugs for your colorectal cancer: On a scale of 1-10, with 1 being “much worse” and 10 being “much better”, how would you rate your overall experience with Pembrolizumab (KEYTRUDA) compared to other treatments?	Much better10

Did accessing Pembrolizumab (KEYTRUDA) allow you to fulfill or accomplish anything that you would not have otherwise been able to, had you not accessed the therapy? If yes, please explain.	Spend time with family, do activities he loves to do
How was Pembrolizumab (KEYTRUDA) funded for you?	No
Do you believe Pembrolizumab (KEYTRUDA) should be funded where you reside for the treatment of metastatic colorectal cancer? Why or why not.	Yes, it is effective for MSI-high tumours, improves quality of life
Did you experience any financial constraints due to Pembrolizumab (KEYTRUDA)? This includes issues like excessive driving expenses, loss of work etc.	Yes
Have you had issues accessing immunotherapy/Pembrolizumab (KEYTRUDA)? If so, what issues have you experienced?	No provincial coverage Travel costs associated with accessing therapy/treatment

7. Companion Diagnostic Test

Four out of seven (57%) patients confirmed they tested positive for the unique biomarker, MSI-H. Most patients had their biomarker testing done after diagnosis, which emphasizes the need to adopt biomarker testing as a standard practice at diagnosis. After biomarker testing was done, three patients were first treated with chemotherapy, while two patients were first treated with immunotherapy immediately. Most patients were also tested for hereditary colorectal cancer syndromes, of which two patients were tested positive for Lynch Syndrome.

The data on the companion diagnostic test is summarized and represented in Table 11 and 12. For this section, Patients 2 and 3 and Caregiver 1 did not respond.

Table 11: Surveyed Patients – Companion Diagnostic Test

	Patient 1	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8
What methods were used to diagnose the colorectal cancer?	Colonoscopy, Reporting of symptoms and/or discomfort	CT scan, Reporting of symptoms and/or discomfort	Colonoscopy	Incidental Finding / Physical Exam at Family Doctor, Colonoscopy, CT scan, Biopsy, blood work	I had a bowel perforation and was diagnosed after an emergency right hemicolectomy. The tumour was sent to pathology and I also had genetic testing done as I have had breast cancer 16 years ago.	Colonoscopy, biopsy

Did you have one or more biopsies to further investigate the make-up of your tumour(s)?	Yes	No	I don't know	Yes	Yes	No
Prior to your diagnosis, were you aware that biomarkers can help to determine a specific treatment option for you?	No	No	No	Yes	No	No
Did your oncologist or any other member of your medical team explain biomarker testing (or tumor profiling) before treatment started?	I don't recall	Yes	I don't recall	Yes	yes	No
Do you recall having biomarker testing before or after being diagnosed with colorectal cancer?	I don't recall	After diagnosis	I don't recall	After diagnosis	After diagnosis	I don't recall
If you have you been tested for any other biomarkers, which biomarker did you test positive for?	I Don't know	BRAF, NRAS, KRAS, MSI-H, TMB-H		MSI/dMMR, MLH1/PMS2	MSI/dMMR	
If you had your biomarkers tested, what treatment did your oncologist first select?	Chemotherapy	Immunotherapy		Chemotherapy, FOLFOX	Immunotherapy, I did chemo first with FOLFOX regimen, after chemo it was discovered I had metastases to ovary and endometrium. Genetic testing revealed dMMR and then I was	

					offered chemo, or immunotherapy if I paid out of pocket.	
Have you been tested for hereditary colorectal cancer syndromes?	Yes	I don't know	Yes	Yes	Yes	No
If yes, have you tested positive for any of the syndromes? If yes, please specify.	Lynch Syndrome			Lynch		
Did your family members get tested as well? If yes, were they positive for the syndrome?	Yes, and negative for syndrome	Yes, and negative for syndrome	Yes, and positive for syndrome	Yes, and positive for syndrome	No	No

Table 12: Surveyed Caregivers – Companion Diagnostic Test

Caregiver 2	
What methods were used to diagnose the colorectal cancer?	Surgery
Did you have one or more biopsies to further investigate the make-up of your tumour(s)?	Yes
Prior to your diagnosis, were you aware that biomarkers can help to determine a specific treatment option for you?	Yes
Did your oncologist or any other member of your medical team explain biomarker testing (or tumor profiling) before treatment started?	No
Do you recall having biomarker testing before or after being diagnosed with colorectal cancer?	After diagnosis

If you have you been tested for any other biomarkers, which biomarker did you test positive for?	MSI/dMMR
If you had your biomarkers tested, what treatment did your oncologist first select?	Chemotherapy
Have you been tested for hereditary colorectal cancer syndromes?	Yes
If yes, have you tested positive for any of the syndromes? If yes, please specify.	No
Did your family members get tested as well? If yes, were they positive for the syndrome?	No

8. Biosimilar

N/A

9. Anything Else?

The ten patients/caregivers provide evidence that the drug under review prolongs overall survival, improves quality of life, and majorly reduces their cancer symptoms with tolerable side effects from the drug. The drug under review, Pembrolizumab, serves as an effective example for treatment based on tumour biomarkers (specifically MSI-h/dMMR) rather than tissue-specific status. Patients' and caregivers' positive experiences with Pembrolizumab propels oncology toward the goal of precision medicine that can greatly enhance cancer patients' lives, and provides evidence of the promising future of cancer immunotherapy.

Patients and caregivers provided heartfelt and compelling comments on why Pembrolizumab should be accessible to patients with the MSI-H or dMMR biomarker:

“Please make this treatment more widely accepted. I endured so much suffering, fear of leaving my young children alone, and treatments that made me incredibly ill. That can all be avoided.” (Patient 1).

“If Keytruda can help patients instead of the other Chemo drugs, it will help with the outcome and quality of life during and hopefully after treatment.” (Patient 4).

Patient 1 tells her story: *“Tumor Board deemed me “inoperable.” I underwent 25 radiation, 25 oral chemo. Nothing. I was told to get my affairs in order. Two months later Keytruda became an option. Here I am 45 treatments later and still kicking...working full-time, working part-time, two teenage sons, a single mom taking care of the household. Without Keytruda, I would be dead.”*

CCC also had the privilege to interview Patient 5, a young man who has had immense progress under the drug under review. He shares his story here: <https://globalnews.ca/news/6252384/st-marys-cancer-patient-dylan-fournier-fights-for-coverage/>
"It's a way better quality of life. I basically feel like I am 100 per cent me, but it's just the fact I still obviously have (cancer) inside of me,"
(Patient 5)

Based on the objective research carried out as represented herein, Colorectal Cancer Canada strongly urges that a positive funding recommendation be issued for Pembrolizumab for the treatment of patients with the MSI-H or dMMR. We believe it is essential to provide these patients equitable access of such an effective drug that improves their quality of life and outcomes as well as the impact on their families, unaccompanied by any financial restrictions. Providing molecularly targeted therapies that are easily administered with minimal side effects, and permit patients to carry on normal lives is fundamental for basic and high quality care in Canada.

Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

No

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

No

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Abbvie Corp			X	
Amgen Canada				X
AstraZeneca Canada				X
Bayer Inc				X
Boehringer Ingelheim Ltd			X	
Bristol Myers Squibb Canada				X
Celgene Corporation			X	
Eli Lilly Canada			X	
GlaxoSmithKline				X
Hoffman-La Roche				X
Janssen Inc			X	
Merck Canada Inc.			X	
Novartis Pharma Canada			X	
Pfizer Canada				X
Taiho Pharma Canada				X

Name: Barry D. Stein
Position: President
Patient Group: Colorectal Cancer Canada
Date: January 11, 2021

Name of the Drug and Indication	Pembrolizumab (Keytruda®) for the First Line Treatment of Adult Patients with Unresectable or Metastatic Microsatellite Instability-High (MSI-H) or Mismatch Repair Deficient (dMMR) Colorectal Cancer (CRC)
Name of the Patient Group	Colorectal Cancer Resource & Action Network (CCRAN)
Author of the Submission	████████████████████
Name of the Primary Contact for This Submission	████████████████████ ████████████████████
Email	████████████████████
Telephone Number	1 833 79 CCRAN (22726)

1. About Your Patient Group

Colorectal Cancer Resource & Action Network (CCRAN) is a national non for profit patient advocacy group registered with CADTH. www.ccran.org

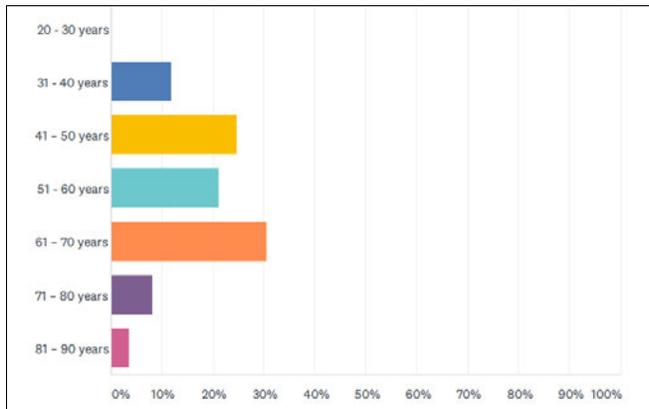
2. Information Gathering

To help capture the critically important patient and caregiver perspective on the colorectal cancer journey and drug therapy under review, CCRAN issued a national online survey from **December 6th – December 30th, 2020** surveying colorectal cancer patients and caregivers residing in Canada. To encourage survey completion, CCRAN reached out to its support group members across the country as well as an online colorectal cancer support group (**Colon Town**) who kindly promoted the survey to its membership.

63 patients, 17 caregivers and 5 patients, who are also caregivers, completed the survey through Survey Monkey, totaling **85 respondents**. Disease stage distribution captured in the survey results, was as follows:

Stage 0	2 (2.35%)
Stage I	3 (3.53%)
Stage II	9 (10.59%)
Stage III	25 (29.41%)
Stage IV*	37 (43.53%) (*The survey results identify 3 patients and 1 caregiver who cite their experience with the therapy under review)

58.8% of respondents were female, while 41.1% of respondents accounted for the male respondents. Survey respondents varied widely in age. The age distribution of survey respondents is shown in the figure below:



Adults between the ages of 31 and 80 are well represented in the survey sample, while young adults ages 20-30 years are under-represented. A copy of the survey results, which includes both closed and open-ended replies, is attached (**APPENDIX 2**).

To ensure the perspectives of the metastatic patient population were well captured regarding the disease journey, specifically, metastatic disease-induced symptoms, CCRAN conducted a zoom focus group on **Sunday, November 15, 2020** between 7:00 and 8:30 p.m. after its regularly held monthly colorectal cancer information/support group meeting. 7 metastatic patients participated and were tasked with answering the question: ***“What symptoms, if any, did***

you experience from your metastatic colorectal cancer?”. Their thoughtful replies were captured and entered into **TABLE 2** appearing within the second half of **APPENDIX 1**.

Additionally, CCRAN developed a thorough and comprehensive patient telephone interview questionnaire intended for patients who were identified to have **first hand experience with the therapy under review**. CCRAN reached out to **members of CCRAN’s national colorectal cancer information/support groups** via email on **November 20th, 2020** to help identify patients who would be willing to provide details of their experience with Pembrolizumab by participating in a telephone interview. CCRAN also reached out to **members of its Medical Advisory Board** on **November 11 – December 4, 2020** to respectfully request their patients, who have undergone or are currently undergoing treatment with Pembrolizumab, contact CCRAN if interested in providing their experience with the therapy. Three patient perspectives were secured with these outreach methods and telephone interviews were conducted between **December 8 and December 21, 2020**. Patients provided first hand, compelling, relevant and high quality input through the telephone interviews in the following treatment settings:

- **Patient A (CCRAN Member):** Second Line Therapy – Accessed Pembrolizumab through a Clinical Trial (in combination with Cyclophosphamide and Survivac Vaccine)
- **Patient B (CCRAN Member):** Second Line Therapy – Accessed Pembrolizumab as **monotherapy** through a private infusion clinic
- **Patient C (Medical Advisory Board Referral):** First Line Therapy – Accessed Pembrolizumab through a Clinical Trial (in combination with Cyclophosphamide and Survivac Vaccine)

The qualitative data generated from the three telephone interviews was captured and is represented entirely in **TABLE 1** appearing within **APPENDIX 1**, which is attached.

3. Disease Experience

The online patient and caregiver survey results identified **bloody stools, fatigue, and diarrhea** as the most prevalent colorectal cancer-induced symptoms (Q9). **Fatigue** resulting from the cancer was reported to be the most important symptom to control according to patients and caregivers (Q10). In Q11, patients relayed that their colorectal cancer-induced symptoms interfere with their quality of life (QoL) and their daily activities. They are unable to function “normally” in their family or work setting: 51% are unable to work and 42% are unable to fulfill their family obligations. There are limitations that are imposed upon them resulting directly from their cancer. Limitations such as:

- “Chemo-brain makes me feel forgetful” (42%)
- “An inability to plan for the future or think about the future” (39%)
- “Constant fatigue makes it difficult to function normally – can’t think straight” (24%)

One patient thoughtfully commented:

“All of these things (limitations) at various times... Currently afraid to make future plans as historically, I have done so many times and had to stop and restart my life over and over again. Anxiety is high and not inappropriate for someone in my position. The less I talk or have to think about cancer and the more I engage with people and life pursuits outside of a cancer focus, the healthier I get, so it is a self care balance. “

Metastatic colorectal cancer patients who participated in the focus group identified the following metastatic colorectal cancer-induced symptoms:

- Pressure and discomfort from high volume disease in the liver
- Discomfort/pain and abdominal distention resulting from ascites induced from peritoneal metastases
- Breathing issues, difficulties and chest pain resulting from lung metastases
- Debilitating fatigue, constant diminished appetite and excruciating pelvic nerve pain – all of which are induced from pelvic disease
- Painful bone metastasis, and abdominal pain due to peritoneal disease

One focus group participant provided the following input:

“I think the metastatic disease that caused me the most painful symptoms were the tumours in my abdomen and the tumor in my hip. The one in my hip was really painful which is why I needed radiation to help bring it under control. And the tumours in my abdomen were uncomfortable. I needed surgery for that too. And still, they came back so as you know, I am on chemo and Pani to help shrink them. You don’t really feel anything until the disease gets out of control. I find that to be really problematic with this disease.”

Two of the focus group participants experienced no metastatic disease-induced symptoms. One patient provided the following compelling quote which underscores the fact that the disease, for the most part, has no warning signs until it is quite advanced and consequently far more difficult to treat:

“After my liver was resected in 2017, my oncologist kept a close eye on me. He monitored my CEA and gave me regular CT scans. I never really had any symptoms from my liver metastases. And it was the CEA that picked up the second recurrence in the porta hepatis and lymph nodes. I felt fine. You would never know that I have stage four disease. I guess that’s why they call it the silent killer. I am doing chemo plus biologic therapy to help shrink this second recurrence. But to answer your question, I never really had any symptoms from my mets.”

Approximately 25% of the colorectal cancer population is diagnosed with metastatic disease and an additional 25% of the early stage population will at some point develop metastatic disease. It calls to attention the need for a greater armamentarium of therapies to treat metastatic disease for this patient population in whom there is an eruption of symptoms when the disease is quite advanced and most difficult to treat.

4. Experiences With Currently Available Treatments

Colorectal cancer most often spreads to the liver, lungs, peritoneum or to distant lymph nodes. In most cases, surgery may be unlikely to cure these cancers due to volume, size, challenging location, or multiple organ involvement. In such cases, drug therapies, such as chemotherapies and biologic therapies, will help to relieve symptoms and control the cancer.

According to the patient and caregiver survey results, patients accessed the following drug therapies to help reduce the burden of their disease or relieve symptoms (Q14):

- FOLFOX/FOLFIRI
- XELODA
- BEVACIZUMAB / MVASI
- CETUXIMAB / PANITUMUMAB
- REGORAFENIB
- TRIFLURIDINE + TIPIRACIL
- LAROTRECTINIB
- **PEMBROLIZUMAB**
- ENCORAFENIB

Close to 100% of surveyed patients accessed combination chemotherapies (such as FOLFOX/FOLFIRI) whose side effects were deemed to be toxic and at times intolerable (Q16); 20% accessed Bevacizumab/MVASI with combination chemotherapy, 15% of patients accessed the anti-epidermal growth factor receptor (EGFR) therapy Panitumumab vs 6% having accessed its counterpart Cetuximab. The EGFR therapies were accessed with combination chemotherapies or as monotherapy. Regorafenib and Trifluridine + Tipiracil were accessed by approximately 2% and 4% of surveyed patients respectively. Three patients accessed the therapy under review (in addition to one caregiver identifying that his wife had accessed the therapy) and one patient was able to access Encorafenib. No one accessed Larotrectinib. Most patients cited fatigue, nausea, diarrhea, hand and foot syndrome and neuropathy as the most commonly induced side effects from these colorectal cancer treatments (Q16). The two treatment-induced side effects that were most difficult to tolerate as identified by patients were fatigue (42%) and nausea (33%) (Q18).

According to the first 2 telephone interviews conducted, first line therapy for **Patients A and B** consisted of five cycles of Bevacizumab + FOLFIRI and 4 cycles of FOLFOX respectively. Both patients reported a diminished QoL on those therapies, which significantly failed to control their cancers for their cancer progressed after 2.5 and 2 months respectively..

Patient A commented:

“I felt tired all the time, I had mouth sores and weight loss. I experienced a blood clot in my left leg which I was told was quite common from my type of cancer. And it was so painful. And that pain limited me and my activities. I had to be home all the time. My everyday life was restricted. I was so very depressed because I was not feeling well. I am a big thinker and I got into my head a lot and therefore became even more depressed. I couldn’t find the light at the end of the tunnel which was so hard for me. Chemo took a lot out of me and it took a long time each time I was at the center – the infusion time was sooooo long. I was there all day long. It wipes you out. I tried to keep positive, I couldn’t stay positive.”

And **Patient B** commented:

“My quality of life was atrocious. It was so awful. I had no appetite and no energy. I was fatigued all the time. As embarrassed as I am to admit this, I couldn’t take a shower for almost 11 days while I was on the FOLFOX. I couldn’t get off the couch or even bed. I was just too sick and weak. I couldn’t even put on my own shoes or clothes. I was so heartbroken and depressed all the time because I was so ill.”

The third interviewed patient (**Patient C**) accessed FOLFOX in the adjuvant setting for the treatment of his Stage III Proximal MSI-High Colon Cancer. The patient’s metastatic disease was detected **4 months** post completion of FOLFOX therapy. The patient maintains the adjuvant treatment was a complete waste of time. Yet, from April - November 2019, while undergoing the adjuvant treatment, he endured horrible side effects which significantly compromised his quality of life, impairing his ability to be a husband to his wife and father to his children. He was ultimately forced to shut down his business due to debilitating nausea and fatigue which bound him to his bed or couch. The patient maintains he needlessly endured toxic, traumatic and debilitating therapy, supplying no benefit or value whatsoever for his particular type of colon cancer. He states:

“Horrible! That’s how I would describe my quality of life while I was on the Folfox. It was not good at all. FOLFOX took a lot out of me. I had to shut down my business because I was so ill. I was nauseated all the time and so my quality of life was brutal.

After receiving the therapy, I would be in bed for 5 days. I wasn't able to do anything or go anywhere and as soon as I was feeling a bit better, I had to undergo the therapy again and start the cycle all over again. I felt like I was in hell. I promised myself and my wife and children that I would never do that again. The side effects were just too debilitating. That was no life to live. And it did nothing for my cancer."

5. Improved Outcomes

The patient survey results (Q35) clearly highlight the patients' desire to access therapies that will effectively control their disease with respect to improvements in their physical condition (i.e. tumour shrinkage/stability, reduction of pain, improved breathing). Patients found these improvements to be of paramount importance, and it was reflected in the weighted average score of **9.56** out of a possible 10. A therapy that also provides improvements in a patient's quality of life (i.e. improved mobility, sense of wellness, and relief from side effects) scored almost equally as high in Q36, with a weighted average of **9.28**. **92.75%** of patients would take a therapy that could provide better quality of life during their lifetime even if it does not extend survival (Q38). And after being told there is no other available treatment for their cancer, patients would be prepared to access a toxic therapy provided an appropriate survival benefit is realized (Qs 39, 40, 41): The greater the survival benefit (i.e. one year survival benefit vs six or two months), the more likely the patient was willing to endure a highly toxic therapy (Q41). A 2 month extension in survival garnered little enthusiasm from survey respondents (Q39) while a survival benefit of 6 months was marginally better (Q40).

When asked what improvements patients would like to see in a drug therapy that are not currently available in other therapies for the treatment of metastatic colorectal cancer (Q45), **94.2%** of survey respondents maintain a therapy should provide a cure, if possible. **85.5%** maintain a therapy should prolong life for a substantial amount of time, and promote good quality of life with no side effects. Other replies included: an oral therapy that can be taken at home, an easy form of administration, a therapy that improves or resolves disease-induced symptoms and should be funded by provincial/territorial health care plans.

The 3 interviewed patients (Patients A-C) provided their perspective on the improvements they would like to see in a drug therapy that are currently not available in other therapies. They maintain a therapy should regress disease with minimal to no side effects. They prefer a therapy that is designed to cure a patient's cancer. And while the therapy is destroying the cancer, it should not be destroying the balance of the body's healthy tissues. The patient's quality of life should be maintained at all times to ensure they are living their life well and not a former glimpse of what used to be their life. If a therapy cannot provide a cure, it should indeed provide significant extension in survival. A drug therapy should also be conveniently administered: It should be an orally administered therapy in the comfort of a patient's home. This would eliminate considerable travel and stress for the patient, their caregiver and the entire family. When these patients were asked if their life would be any different if the drug therapies had these desired improvements, **Patient A and B** replied as follows respectively:

"Yes, of course and that is what I have with Pembro. Immunotherapies give you that. It works so very well by shrinking your cancer and giving you few to no side effects. If all the therapies had these improvements, I wouldn't have gone through what I did at the beginning of my journey. I would have led a better life, one with better quality of life, where I wouldn't be isolated, or bed ridden."

"Yes, of course it would. I wouldn't be stuck at home and riddled with side effects. I know I have to take one drug for one thing and another for another thing but if there was just one drug to take that could just correct your cancer, it would be wonderful and outstanding."

All three interviewed patients (Patients A, B and C) believe Pembrolizumab has the desired improvements (save the oral administration component). According to the patients, it is capable of significantly regressing disease, prolonging life while providing improved quality of life, with minimal to no side effects. This is a therapy that can permit patients to resume normal activities, be gainfully employed, spend time with their family and friends and permit them the freedom to "appreciate life so much more in light of what they have been through".

6. Experience With Drug Under Review

TABLE 1 in **APPENDIX 1** captured the demographics and treatment-related experiences for three adult patients who have undergone or are currently undergoing the therapy under review. Two of the three patients (**Patients A and C**) accessed the therapy through a Clinical Trial in combination with cyclophosphamide and the Survivac vaccine in second and first line therapy, respectively. And **Patient B** accessed the therapy through private insurance in a private infusion clinic as monotherapy in the second line setting. All three patients had been identified to be MSI-High which qualified them for the therapy. Determination of MSI tumour status was made through Immunohistochemistry (IHC) testing. A positive Mismatch Repair Deficiency (dMMR) / Microsatellite Instability-High (MSI-H) test supports use of Pembrolizumab in the metastatic setting.

Patient B (MLH1/PMS2 loss) was diagnosed with bone, adrenal gland, chest wall, lymph nodes and brain metastases in addition to her colon primary. She underwent 4 cycles of FOLFOX therapy to which she had no response and then proceeded to second line therapy: Pembrolizumab. She received **42 cycles** (July 4/17 – April 29/20) and experienced no side effects from the therapy whatsoever. She claims it was the “*best thing I have ever done!*” and “*the best therapy I have ever been on!*”. While on the therapy, she ranked her quality of life a 13/10 and insisted her score be displayed as such because of the extraordinary benefits imparted by Pembrolizumab. After having received only 2 cycles, her quality of life had improved significantly as she was able to resume many aspects of her life again: visiting with family and friends, spending time at her cottage and as she put it, “*being my old jovial self again*”. The first two cycles of therapy were able to resolve her cancer-induced symptoms which were debilitating and caused much emotional turmoil: She experienced considerable fatigue, achy bones, and was “*shaky*” all the time as a result of her cancer. The patient achieved a remarkable response to the therapy – a **70% shrinkage** in her tumours, some of which disappeared entirely, as per the CT scan findings. She cites the drug as having been “miraculous”, highly convenient due to its shorter infusion time relative to chemotherapy, and in her opinion, it was well worth accessing for it:

“saved my life! It brought me back to the woman I used to be who used to play and love life. I felt like nothing was going to happen for me and my cancer and then, bang, Keytruda came along and pulled off a miracle for me. It gave me a second chance at life”.

Patient B meticulously highlighted events and objectives in her life she was able to fulfill because of Pembrolizumab. Pembrolizumab’s therapeutic benefits made it possible for her to feel well enough to renovate her cottage: she was able to paint, replace flooring, and do a great deal of the manual labor herself. She thoughtfully expresses:

“Our cottage is newly restored and looking beautiful for our children and grandchildren to use long after I am gone. Keytruda did that for me. I worked hard on that cottage renovation. It’s not easy to do that under the best of health conditions, let alone a cancer diagnosis. But I was able to achieve it because I was provided with something to look forward to in life, a goal, an objective to focus on because I was feeling well enough to do it. I was also able to enjoy my precious family, my sons and grandchildren who I adore and cherish more than life itself. There is no greater gift than that.”

Patient B had a durable and remarkable response to Pembrolizumab (**33 months – 42 cycles**) and the therapy was most effective at reducing the bulk of her disease. It is worth noting she experienced no side effects from the therapy which allowed for an excellent quality of life throughout that time.

Patient C underwent a right hemicolectomy and 10 cycles of FOLFOX with an additional 3 cycles of 5FU in the adjuvant setting. His metastatic disease was detected approximately 4 months post completion of his adjuvant therapy. He was diagnosed with tumours in the area of his anastomosis and 2 regional lymph nodes. His MSI-High status (determined through IHC testing) qualified him for the Pembrolizumab/Survivac Vaccine/Cyclophosphamide Clinical Trial which he started on **July 3, 2020**, and continues to receive to date. The patient receives the Pembrolizumab infusion every 3 weeks, an oral chemotherapeutic (Cyclophosphamide) twice daily every day, one week on and one week off, and the Survivac vaccine injection every 9 weeks. He has received **9 cycles** to date which he claims have been outstanding in comparison to the toxic and brutal chemotherapy regimen he previously received – truly a life altering experience. He rates his quality of life a **10** and does not believe he has experienced any side effects from the therapy under review. The CT scan findings confirmed response to the therapy with a **50% shrinkage in tumours** after having received only 5 cycles of the trial drugs (including the therapy under review) and, clinically, he is now feeling like his old self again. “*I was so thrilled and grateful for this therapy. It gave me my life back. It gave my family their life back.*” The patient explains the ease of use and the benefits that are generated from that ease of use:

“Yes, it has. Pembro is only half an hour infusion. And there is no toxicity at all, except for being a little tired, there are no side effects. I am able to walk, live my life as I wish, I can drive, I can go to work, do everything I should be doing. I enjoy extracurricular activities such as fishing, hunting, hikes, and most of all I get to enjoy my young children who are so active. The other chemos were so toxic and the infusions lasted all day, every two weeks. And I had to go home with a baby bottle. What a pain! I couldn’t do anything. What a difference.”

The patient was able to resurrect his business due to his improved health which is now successful and thriving, resume household chores and responsibilities such as grocery shopping and care for his two children with ease and great affection. Shortly before his diagnosis, he was married and saw the birth of his youngest daughter who was born with a birth affliction but was not able to celebrate neither his nuptials nor could he properly care for his ill daughter. He was devastated to learn of his daughter’s illness and how he could not comfort his wife during this challenging time nor take active measures to properly support/find treatments for his daughter. That all changed when he accessed Pembrolizumab. The therapy permitted the young couple to celebrate their second wedding anniversary and it also permitted the patient to properly care for both his daughters, including his youngest who is not well.

“Now we get to take the kids to the cottage and be a family and take care of the little one who is sick. That in and of itself is a huge accomplishment. Being able to take care of your child is a parent’s responsibility and I am so appreciative of the fact that I can fulfill that responsibility. Pembro allowed me to do that for my child – to take care of her as a parent should.”

Patient C continues to respond to Pembrolizumab through the clinical trial. When asked if it was worth accessing Pembrolizumab, **Patient C** articulately replied:

“Oh my God, yes it was worth it, 300%. Everything I do is a testament to why it was worth it. Aside from COVID-19, I have been able to get my business back up and running. I am a general contractor doing renovations/alterations and I couldn’t even begin to imagine getting my business up and running when I was on folfox. I have been able to go up to the cottage, do work around the house, I get to do every day things that most people take for granted, but I don’t anymore – such as grocery shopping. I get to do things with my beautiful children with ease now. This is the biggest thing for me, no more burden for me anymore. (PATIENT TEARED). My quality of life has just gone through the roof in comparison to the previous therapies I was on. I took so much for granted, but not anymore. This therapy means so much to me because I can appreciate life now so much more.”

Patient A is our featured patient for this submission in light of the extraordinary response observed to the therapy under review – a response that has **continued well beyond treatment cessation**. She was diagnosed with MSI-High metastatic transverse colon cancer in August 2019 at the age of 48 years with metastatic disease to her liver and peritoneum. She underwent 5 cycles of Bevacizumab + FOLFIRI from **September 10, 2019 to October 29, 2019** which then revealed disease progression according to the first CT scan results. She experienced significant chemotherapy-induced toxicities which included mouth sores, deep vein thrombosis in her legs, weight loss, debilitating fatigue, and hot flashes from early onset menopause. Depression immediately set in. She shared the following:

“I felt tired all the time, I had mouth sores and weight loss. I experienced a blood clot in my left leg which I was told was quite common from my type of cancer. And it was so painful. And that pain limited me and my activities. I had to be home all the time. My everyday life was restricted. I was so very depressed because I was not feeling well. I am a big thinker and I got into my head a lot and therefore became even more depressed. I couldn’t find the light at the end of the tunnel which was so hard for me. The treatment wasn’t lifting me up. I was going back and forth to the cancer center and it was so very draining. Chemo took a lot out of me and it took a long time each time I was at the center – the infusion time was soooo long. I was there all day long. I think it took 4 hours in that chair. It wipes you out. I tried to keep positive, encouraging myself, but I found it difficult even though I had great support from my family and friends. Even with the help of my partner and CCRAN, I couldn’t stay positive and with menopause, I think I was going through, I couldn’t handle it. Honestly, I could not keep doing it anymore.”

Her MSI-High status qualified her for a clinical trial which was administering Pembrolizumab in combination with Cyclophosphamide and the Survivac Vaccine. While she was devastated that her disease progressed so quickly (after only 2 months) on first line, she was quite relieved to learn that she qualified for an immunotherapeutic that could potentially change the course of her disease in second line therapy. **Patient A** initiated therapy on **December 3, 2019 and continued therapy for six months (May 26, 2020)**. She received infusions of Pembrolizumab every 3 weeks, daily oral treatments of cyclophosphamide (twice per day for one week on and one week off) and Survivac Vaccine injections every 6 weeks. She received a total of **9 cycles**. She claims she never felt any treatment-induced toxicities and rated her quality of life while on the therapy as a **10**. The cancer-induced symptoms she experienced before initiating the therapy under review were deep vein thromboses (DVT) and fatigue and claims both resolved immediately as soon as she began the Pembrolizumab treatment:

“They actually completely resolved and ended as soon as I started my Pembro and I was a brand-new person. I was in the garden doing work and I was outside enjoying fresh air and exercise, being social despite the pandemic. I was my regular self again. I was restored to the person I used to be.”

The patient did not stop therapy because of disease progression or treatment-induced toxicity per se. The patient claims she never once felt ill or experienced any side effects from the therapy. The patient did, however, experience elevated lipase levels and was asked to refrain from taking all three drugs for awhile till the lipase level resumed normalcy. The patient’s last infusion of Pembrolizumab was **May 26th, 2020** and since then, remarkably enough, the **patient has continued to experience disease regression**. She has continued to feel healthy, vibrant, and is living life with tremendous appreciation for the therapy that continues to provide a meaningful benefit and true value, and in her own words, she claims:

“According to the CT scans, all my disease has either shrunk significantly or disappeared altogether. A lot of tumours have shrunk such that they can no longer be identified. Isn’t that great? And for those that are still there, they used to be so big, and now they are either 2 cm or less and most are scar tissue. Way too small to identify. My oncologist feels my disease is well under control. I am so happy.”

Additionally,

“I have never resumed Pembro treatment, but I have to tell you that my CANCER HAS CONTINUED TO SHRINK JUST THE SAME AND BEEN UNDER CONTROL EVER SINCE MAY 26, 2020. I AM JUST BESIDE MYSELF WITH GRATITUDE. Again, what a gift, I have been given.”

Much like the other interviewed patients who accessed Pembrolizumab, **Patient A** was pleased with Pembrolizumab’s quick infusion time and the fact that it is conveniently administered every 3 weeks vs every 2 weeks (for chemotherapy). She claims she was able to accomplish something she would not have otherwise been able to do had she not accessed Pembrolizumab and that’s because Pembrolizumab not only regressed her disease, but allowed her to feel like her old self again: she **was able to lead a massive fundraiser and spread much needed awareness about her disease to the general public in the hopes of sparing others a fate and journey to which she has been destined**. In her own

words, “she is living an extraordinary life and was able to launch this extraordinary event that she would not have been able to do otherwise were it not for Pembrolizumab”.

“People from the general public got to benefit from that awareness campaign.....I had an ambitious goal and I got to do it because of Pembro and the energy that I had. I live an extraordinary life because of Pembro.”

While durable responses to immunotherapy in MSI-High metastatic colon cancer are not unusual, **Patient A’s** case is exceptional because she has enjoyed *over 14 months and counting of progression free survival, despite stopping Pembrolizumab treatment over 8 months ago (May 2020)*, wherein only 9 cycles of treatment had been delivered. **Patient A** showed excellent tolerance to Pembrolizumab despite suffering so terribly with standard chemotherapy. She did, however, experience significantly elevated lipase levels, (*whose cause was not determined*) which necessitated cessation of the clinical study. The positive effects of the study drugs have continued, however, and the patient is beyond delighted with those benefits observed. Perhaps a more in depth molecular analysis of the MSI-High population may hold the answer as to why certain patients, such as **Patient A**, enjoy prolonged responses to Pembrolizumab **post treatment cessation**, while other patients experience shorter, yet still meaningful responses.

7. Companion Diagnostic Test

Pembrolizumab use in metastatic colorectal cancer is limited to patients with MSI-H/dMMR tumours. Cancers characterized as MSI-H/dMMR are typically identified through **immunohistochemical (IHC)** analyses that reveal deficient quantities of specific proteins involved in DNA or as noted in our survey results (**Q29**) next generation sequencing (NGS) assays that show changes in the microsatellite sequences. Patients whose tumours are MSI-H/dMMR positive are likely to benefit from Pembrolizumab.

All interviewed patients (**Patients A, B, C**) confirmed they tested positive for the MSI-H biomarker which allowed them to access the therapy under review. Determination of MSI-H status for all three patients was made through IHC based testing. In two cases, their MSI-H positive colorectal cancers rendered them candidates for a clinical study which permitted access to Pembrolizumab (**Patient A and C**), ultimately altering the course of their disease. IHC testing was performed at the first, original treating centre for all three patients but **Patients A and C** did undergo additional testing at the new treatment centre (Odette Cancer Centre) to confirm candidacy for the clinical trial which included:

- a biopsy to confirm MSI-H status,
- bloodwork and
- CT scan.

Patient C cites anxiety in anticipation of the test results being generated, for he knew the implications of being rejected from the trial: imminent and immediate death. He comments:

“I did experience anxiety waiting for the...results. I really wanted to access Pembro. I knew this would be really good for me. I wanted to get into this trial. I was grateful when my oncologist at [REDACTED] referred me to [REDACTED] who was part of this trial.”

All three interviewed patients did not wait very long for test results to be generated because their MSI-H status had been determined through upfront testing. Nor did they pay out of pocket for the testing and the test (IHC), which identified them as MSI-H, was easily accessible through their local treatment centre. Patients were grateful to have accessed the test for it allowed them to qualify and experience a life-saving/life-prolonging therapy based on the identification of a unique biomarker. This underscores the need to conduct upfront testing in the metastatic cancer population. While only a small subset of the metastatic colorectal cancer population are identified to be MSI-H positive (approximately 5%), testing early on to identify the patients who qualify for this therapy will ultimately change the treatment paradigm and guide treatment decisions which will undeniably be life altering for patients and their families. The result according to **TABLE 1** in **APPENDIX 1** is **improved quality of life, few to no treatment-induced toxicities, significant disease regression, and reduced infusion time**. To this point, **Patient C** commented that his cancer should have been treated based on his tumour’s genetic profile and his personal set of circumstances. His cancer should have been targeted accordingly at a much earlier point. He shared the following:

“Had I known about Pembro at the beginning, I would have 100% pushed and gone the Pembro route even though chemo has certain results, I would have chosen the Pembro route. It is the best therapy. I do not want anyone to go through what I went through when we have treatments like Pembro to give you results like minor side effects and improved quality of life and it allows you to carry on and lead joy-filled and productive lives. It is not fair that we have this therapy, and you are not having access to it. I am so lucky to be able to access it through a trial. It helps so many, patients and doctors, and caregivers and researchers etc. I would have paid out of pocket to access this treatment and put me in a privileged position of disease regression. Everyone deserves to have this feeling of elation so that they can get on with their life and enjoy their family for as long as possible.”

The therapy under review undeniably delivers on the promise of precision medicine guiding treatment decisions: the identification of a biomarker defining the treatment approach for a colorectal cancer patient’s disease.

8. Anything Else?

Patients who were interviewed provided thoughtful and compelling examples of why Pembrolizumab was worth accessing. Their values and preferences were captured in **TABLE 1** of **APPENDIX 1**. Most of those values and preferences have already been highlighted throughout this submission. We would, however, like to summarize the astounding benefits experienced by patients as well as share some additional input provided by patients as to why accessing Pembrolizumab is so critically important to them and other patients and caregivers.

Patient A's disease has either significantly regressed or disappeared completely and continues to respond 8 months post treatment cessation. She is thriving, grateful, and continues to enjoy a prolonged, durable and robust response to Pembrolizumab, despite having stopped treatment. She is an active, joy-filled young woman who spends time with friends and family determined to spread the message that colorectal cancer is preventable through screening. She states: *"Pembro was the best gift I have ever received. I thank the manufacturer every day. It has saved my life. I am here today because of it and I am living a great life. And it should be available for whoever is a match. In my heart, I am going to be around for a long time and that means a lot for me, my family and friends. Sometimes I forget that I have cancer because of being on Pembro and how well I feel. How extraordinary is that?? Most people can't believe I have cancer. Isn't that wonderful! There is no better feeling. Everyone should be experiencing the same elation. Please fund the drug."*

Patient B enjoyed 33 months (42 cycles) of Pembrolizumab. She claims that while on the therapy it saved her life and restored her to optimal health. She experienced tremendous disease regression with virtually no side effects and as a result she was able to renovate her cottage throughout that time which she plans to leave as a legacy to her children and grandchildren, who are the most precious gifts in her life. Pembrolizumab also afforded her the ability to spend time with her sons and play with her grandchildren – time she would not have otherwise been afforded were it not for Pembrolizumab. She states: *"Keytruda has been a god sent. All drugs should be just like Keytruda."*

Based on the qualitative data supplied, Pembrolizumab has the potential to change the treatment paradigm for the first-line treatment of patients with MSI-H/dMMR positive colorectal cancer. Patients' input clearly demonstrated Pembrolizumab's superior progression free survival compared to standard of care chemotherapy (either FOLFIRI or FOLFOX, with or without a biologic therapy). Treatment responses lasted longer among those treated with the therapy under review – one patient (**Patient B**) responded to the therapy for 33 months while another continues to respond well after treatment cessation. Patients with unresectable or metastatic MSI-H colorectal cancer have historically faced poor outcomes. Typically, chemotherapy-containing regimens were the only approved first line treatment options. The approval of Pembrolizumab would help address an unmet need to provide a new treatment option for these patients with a superior quality of life due to fewer and less severe side effects.

This targeted therapy clearly highlights the era of precision medicine in which we now find ourselves: it is guiding the treatment of metastatic colorectal cancer for a patient population who historically have not responded well to standard of care therapies. Of noteworthy importance is the fact that Pembrolizumab delivered a durable, sustainable or lasting response during treatment or **well after treatment cessation** according to our qualitative data. And when compared to previously accessed treatment, Pembrolizumab delivered the most robust and durable response – this includes chemotherapy, radiation therapy, and biologic therapy (Bevacizumab) with a favorable toxicity profile, and shorter infusion time. To deny patients access to this highly effective drug would be a shame.

All interviewed patients had failed previous treatments for their colon cancer, including surgery, chemotherapy, biologic therapy and radiation therapy (for brain metastases). However, Pembrolizumab demonstrated a level of benefit unlike any other previously accessed therapy. To have observed the magnitude of responses in our interviewed patients who had progressed so quickly following prior treatments confirms that Pembrolizumab is effective and amenable for long term administration.

If publicly funded, Pembrolizumab would be an extremely important first line therapeutic option for patients whose tumours test positive for MSI-H/dMMR, and whose disease has been deemed to be inoperable or metastatic. Funding a targeted therapeutic that treats patients based on the presence of a specific biomarker aligns well with the patient perspectives captured within this submission. We, therefore, strongly support and urge that a positive funding recommendation be issued for Pembrolizumab for the treatment of unresectable or metastatic MSI-H/dMMR colorectal cancer. We believe Pembrolizumab aligns well with the identified patient need for a new, effective, quickly administered, less toxic treatment option that is capable of maintaining a high quality of life. It provides a clinically meaningful improvement in progression free survival and quality of life versus chemotherapy as a first line treatment for patients with MSI-H/dMMR metastatic colorectal cancer, with fewer treatment-related adverse events observed and should be the new standard of care for this patient population.

Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

No

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

No

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Bayer			X	
Taiho			X	
Amgen			X	

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name: Filomena Servidio-Italiano
 Position: President & CEO
 Patient Group: Colorectal Cancer Resource & Action Network (CCRAN)
 Date: Friday, January 8, 2020

APPENDIX 1

TALBE 1: PEMBROLIZUMAB SUBMISSION: PATIENT/CAREGIVER INTERVIEW QUALITATIVE DATA

INTERVIEW QUESTION	PATIENT A	PATIENT B	PATIENT C
PART A: DEMOGRAPHICS/INFORMATION GATHERING			
1. INTERVIEW DATE, TIME & METHOD	December 8, 2020 11:00 am – 12:10 pm Telephone	December 8, 2020 1:30-3:00 p.m. Telephone	December 21, 2020 2:30-3:30 p.m. Telephone
2. PATIENT'S AGE OF DIAGNOSIS, CURRENT AGE AND GENDER (M, F, NON-BINARY)	-46 years -48 years -Female	-51 years -55 years -Female	-29 years -31 years -Male
3. CITY & PROVINCE/STATE	██████████	██████████	██████████
4. A. MARITAL STATUS (S/M/D)	A. Common Law	Widow, Husband passed away last year	Married
B. CHILDREN?	B. None	3 children: ages 31, 34, 36 years and 4 grandchildren (1 boy and 3 girls)	2 Children, (both girls), ages 7 and 3 years
5. OUTREACH METHOD? - CCRAN MEMBER - COLONTOWN - CANADIAN CLINICIAN - OTHER?	CCRAN MEMBER	CCRAN Member	Canadian Clinician and CCRAN Member
6. TREATMENT CENTRE	██████████	██████████	██████████
PART B: DISEASE EXPERIENCE & EXPERIENCE WITH CURRENTLY AVAILABLE THERAPIES			
7. A. TYPE OF PRIMARY CANCER?	A. TRANSVERSE COLON CANCER, MSI-HIGH (ADENOCARCINOMA)	Colorectal Cancer, Adenocarcinoma, MLH1/PMS2 Loss, RAS/RAF Wild Type	Right sided MSI-High colorectal cancer (adenocarcinoma) – No Lynch Syndrome
B. DATE OF FIRST DIAGNOSIS?	B. June 16, 2019	February 2016	January 2019
C. DATE OF METASTATIC DIAGNOSIS	C. August 2019	March 2017	April 2020
8. A THERAPIES RECEIVED BEFORE PEMBROLIZUMAB (VITRAKVI)?	A. 5 Cycles of Avastin + FOLFIRI spanning from September 10, 2019 to October 29, 2019	"I received 4 cycles of Folfox starting in February 2017. I also had a craniotomy and radiation to my brain for brain metastases in March 2018."	"In February 2019, I underwent a right hemicolectomy for my primary tumour. Then in April 2019, after recovering from my surgery, I started FOLFOX and had 10 cycles of FOLFOX and 3 cycles of 5FU. I suffered really bad neuropathy so I couldn't undergo the full FOLFOX. Those chemo treatments ended in November 2019. All those treatments took place at ██████████."
B. DID THOSE TREATMENTS CONTROL YOUR CANCER? Y/ N (PLEASE EXPLAIN)	B." No, not all. I progressed on Avastin + folfiri. I had no tumor shrinkage at all."	"Oh, my, not even a little. The folfox did nothing. My cancer just got worse! I had to come off the folfox because it was doing nothing to help my cancer. "	"Absolutely not and here is why. My disease came back so quickly. It was noted to have come back and spread by about February-March of 2020. Less than 4-5 months after having completed adjuvant therapy. The disease came back in the area of my anastomosis and in my regional lymph nodes. So no the therapies were not successful."
C. DESCRIBE QOL ON THOSE TREATMENTS?	C. "I felt tired all the time, I had mouth sores and weight loss. I experienced a blood clot in my left leg which I was told was quite common from my type of cancer. And it was so painful. And that pain limited me and my activities. I had to be home all the time. My everyday life was restricted. I was so very depressed because I was not feeling well. I am a big thinker and I got into my head a lot and therefore became even more depressed. I couldn't find the light at the end of the tunnel which was so hard for me. The treatment wasn't lifting me up. I was going back and forth to the cancer center and it was so very draining. Chemo took a lot out of me and it took a long time each time I was at the center – the infusion time was sooooo long. I was there all day long. I think it took 4 hours in that chair. It wipes you out. I tried to keep positive, encouraging myself, but I found it difficult even though I had great support from my family and friends. Even with the help of my partner and CCRAN, I	"My quality of life was atrocious. It was so awful. I had no appetite and no energy. I was fatigued all the time. As embarrassed as I am to admit this, I couldn't take a shower for almost 11 days while I was on the Folfox. I couldn't get off the couch or even bed. I was just too sick and weak. I couldn't even put on my own shoes or clothes. I was so heartbroken and depressed all the time because I was so ill."	"Horrible! That's how I would describe my quality of life while I was on the Folfox. It was not good at all. Folfox took a lot out of me. I had to shut down my business because I was ill. I was nauseated all the time and so my quality of life was brutal. After receiving the therapy, I would be in bed for 5 days. I wasn't able to do anything or go anywhere and as soon as I was feeling a bit better, I had to undergo the therapy again and start the cycle all over again. I felt like I was in hell. I promised myself and my wife and children that I would never do that again. The side effects were just too debilitating. That was no life to live. And it did nothing for my cancer."

	couldn't stay positive and with menopause, I think I was going through, I couldn't handle it. During the crc support group meetings that I would attend, I would have to stand up because of the hot flashes I was going through at such a young age due to chemo. But I tried to put my best foot forward. Honestly, I could not keep doing it anymore. "		
D. APPROXIMATELY HOW LONG DID IT TAKE BEFORE YOU PROGRESSED ON THOSE PREVIOUS THERAPIES?	D. "It took 2.5 months for my disease to advance on folfiri and Avastin. I had no tumour reduction on that therapy whatsoever. I had 5 cycles and no shrinkage in disease. And I was so sick on that treatment."	"It took 2 months for my disease to get worse. Just two months and that was it. That treatment folfox gave me no benefit whatsoever! What was the use of going on it?"	"I started the therapy in April 2019 and finished it in November 2019. We discovered my recurrence in approximately March 2020. So, I guess it took about 4 months for my disease to progress. My CEA was up by end of February, so we knew something was not right. The CT in March confirmed it.
9. WAS THERE ANY PARTICULAR ASPECT OF THE DISEASE THAT WAS DIFFICULT TO CONTROL WHILE ON THOSE TREATMENTS?	"The disease itself was difficult to control. I have a particular type of colorectal cancer. I have something called MSI-High colorectal cancer and it doesn't necessarily respond to normal chemo so trying to control it through chemo was impossible. Nothing shrank on folfiri and Avastin. I was devastated but at the same time, when my oncologist told me that I qualified for immunotherapy, I was also elated."	"Yes. The chest wall mass has always been difficult to control. It just kept getting bigger and bigger. And those dam lymph nodes all over – like those above my collar bone and the bones tumours have been really hard to deal with."	"No, not really. Everything was ok at the time. Everything just blew up in February-March 2020. "
PART C: EXPERIENCE WITH PEMBROLIZUMAB			
10. LOCATION OF YOUR METASTATIC DISEASE?	"Besides my primary which is located in the transverse colon, I have metastatic disease in the: -Liver -Peritoneum"	"In addition to my colon primary, I have: -bone -adrenal gland -chest wall -supraclavicular lymph nodes -brain	"My recurrence is in the area of my anastomosis (2 tumours) and there are 2 regional lymph nodes as well."
11. A. WHERE WERE YOU TESTED FOR PEMBROLIZUMAB CANDIDACY?	A." I was tested at ██████████."	██████████	"My MSI-High status was determined at the first center where I was initially treated. And that was ██████████. My candidacy for the Pembrolizumab trial (Survivac Trial) was determined at the current center that I am at and that's ██████████"
B. WAS IT DIFFERENT THAN YOUR TREATMENT CENTRE?	B. No.	No	"MSI status at ██████████. Survivac Trial was done at ██████████: I had to undergo a biopsy, bloodwork and CT scan."
C. HOW WERE YOU TESTED FOR PEMBROLIZUMAB CANDIDACY THROUGH WHAT TECHNOLOGY?	C. "IMMUNOHISTO-CHEMICAL STAINING. AND THEN THE CLINICAL TRIAL I WENT ON REQUIRED THAT I UNDERGO ADDITIONAL TESTING TO CONFIRM MY CANDIDACY."	IHC	"At the first center where I was being treated, they did IHC testing and genetics testing and confirmed I was MSI-High but not a Lynch patient."
D. DID YOU HAVE TO TRAVEL TO GET TESTED?	D. "No I didn't."	No	No
E. DID YOU HAVE TO PAY OUT OF POCKET TO GET TESTED?	E. No	No	No
F. DID YOU HAVE TO WAIT LONG FOR THE TEST RESULTS?	F. No.	No	"Not for the MSI results. I had to wait a couple of weeks for all the results to come in for the Survivac test results to come in to see if I was a candidate for the therapy."
G. DID YOU EXPERIENCE ANY ANXIETY WAITING FOR THE RESULTS?	G. "No, not really, because I think my results were available as soon as I progressed, so I went on the clinical trial almost immediately."	No	"I did experience anxiety waiting for the Survivac results. I really wanted to access Pembro. I knew this would be really good for me. I wanted to get into this trial. I was grateful when my oncologist at ██████████ referred me to ██████████ who was part of this trial."
12. HOW WERE YOU ABLE TO ACCESS PEMBROLIZUMAB? IE CLINICAL TRIAL? PRIVATE INSURANCE? SPECIAL ACCESS? SELF PAY?	"I accessed it through the Survivac Clinical trial that had literally just opened up. I believe it had opened up just for me! This trail was delivers 3 drugs: Pembro, DPX-Survivac vaccine and the chemo cyclophosphamide."	"I managed to get it through my husband's private insurance coverage. My husband was a cancer patient too and he was being treated by my medical oncologist as well. And my husband made him promise to help me as	"I qualified for the Survivac Clinical Trial offered by ██████████. I was so lucky to get in. I managed to get in by the skin of my teeth apparently. I thank God every day and my former oncologist who referred me."

		much as possible after he death. My oncologist has kept his promise.”	
13. A. WHEN DID YOU RECEIVE PEMBROLIZUMAB (DATE)?	A. “I started it on December 3, 2019 and went right through to May 26, 2020. I had it every 3 weeks with Cyclophosphamide. I had Survivac injection every 6 weeks.”	“I started Keytruda on July 4, 2017 and it was the best thing I have ever done! My last treatment was April 29, 2020 . It was the best therapy I have ever been on.”	“I received Pembro on July 3, 2020 and I receive it every 3 weeks. I also receive the oral chemo Cyclophosphamide (twice a day, every day), one week on and one week off. And I get Survivac vaccine injection every 9 weeks.”
B. AND IN WHAT LINE OF THERAPY?	B. “It was in Second Line therapy. ”	“It was second line therapy. ”	“ First line therapy for metastatic disease.”
C. HOW MANY CYCLES DID YOU RECEIVE?	C. “I had a total of 9 cycles. My last cycle was on May 26, 2020. “	“I received 42 cycles. ”	“I guess I have had 9 cycles to date. ”
15.A. HAVE YOU EXPERIENCED ANY SIDE EFFECTS WHILE ON PEMBROLIZUMAB? Y/N	A. Well, not really but kinda.	“ No, not all. ”	“Nothing severe at all.”
B. IF SO, WHAT ARE THOSE SIDE EFFECTS?	B. “I had elevated lipase enzyme levels. But other than that, NOTHING. I have felt nothing while on this treatment.”	N/A.	“I do not believe I have had any side effects from Pembro but I can’t really tell seeing that I also take two other drugs. But here are the minor effects I have experienced: I had a reaction in my leg from what we believe was the first injection of the Survivac vaccine. I think I overdid it and that’s what really caused the reaction. I have experienced minor incontinence and slight shortness of breath after cyclophosphamide. Also, a little wee bit of lightheadedness. But other than that, nothing.”
16. ON A SCALE OF 1-10, HOW WOULD YOU RATE YOUR QOL WHILE ON PEMBROLIZUMAB? 1 REPRESENTING VERY POOR AND 10 REPRESENTING VERY GOOD QUALITY OF LIFE.	10 “It has been fantastic in comparison to chemo.”	13 <i>(Patient insisted author insert metric beyond scale)</i> “Within 2 cycles of Keytruda, I could dance again! And I felt alive again. I felt as though I had been given a second chance at life. I was living life to the fullest, visiting people again, going to the cottage again and being my old jovial self.”	10 “In comparison to what I have been through, for sure I would have to say a 10. Folfox was brutal in comparison to this therapy. My life is so much better. 200 times better.”
17. DID YOU HAVE ANY CANCER SYMPTOMS BEFORE STARTING PEMBROLIZUMAB? IF SO, WHAT WERE THEY?	“Yes, I had horrible fatigue, and a blood clot in my leg which was due to my cancer. “	“Yes, I had horrible fatigue, achy bones, shaky all the time. I felt like I was having outer body experiences because of the cancer and always feeling very heavy.”	“Well.....Just a bit of fatigue. That’s it.”
18. IF YOU DID HAVE CANCER SYMPTOMS BEFORE STARTING PEMBROLIZUMAB, DID PEMBROLIZUMAB HELP RESOLVE THOSE CANCER SYMPTOMS? IF SO, WHICH ONES? PLEASE EXPLAIN.	“They actually completely resolved and ended as soon as I started my Pembro and I was a brand-new person. I was in the garden doing work and I was outside enjoying fresh air and exercise, being social despite the pandemic. I was my regular self again. I was restored to the person I used to be.”	“Yes! All of them resolved after the 2 nd cycle and I had so much energy because of the Keytruda. I could skip down the street because of the Keytruda. I was so slow due to the chemo but not on Keytruda. I was more alert and functioning on the Keytruda. And I was more acutely aware of my surrounding and more intuitive because of being on Keytruda. It brought me back to life – sorta like the Jesus and Lazarus story.”	“Oh, ya, and then some!! My life did a total turn around. I have more energy and feeling more like myself today than ever, cancer notwithstanding.”
19. A. HOW WAS RESPONSE CONFIRMED TO PEMBROLIZUMAB: CLINICALLY (SYMPTOMS RESOLVED), BIOCHEMICALLY, OR RADIOGRAPHICALLY (SUCH AS CT, MRI)?	A. “I had regular CEA readings and regular CT scans performed in addition to MRI scans to evaluate my disease. Plus, I kept telling everyone on my healthcare team how I felt. I felt normal again. They kept asking to give them a number from 1-10, initially it was 6 but then it went to 10 and now it is 100!! “	“My doctor was measuring my CEA and giving me CT scans. He was also asking me how I was feeling. I told him I was feeling normal. That was the best indicator for me! I knew I was responding based on that alone.”	“It was a CT scan that told us that I was responding to the Pembro. Plus, I was feeling great!”
B. WHAT WAS YOUR RESPONSE TO PEMBROLIZUMAB?	B. “According to the CT scans, all my disease has either shrunk significantly or disappeared altogether. A lot of tumours have shrunk such that they can no longer be identified. Isn’t that great? And for those that are still there, they used to be so big, and now they are either 2 cm or less and most are scar tissue. Way too small to identify. My oncologist feels my disease is well under control. I am so happy.”	“The CT scan showed no more lymph nodes on my neck – they have literally disappeared. I now have only 30% of disease left in my body due to Keytruda. So, I had 70% shrinkage because of Keytruda. It was absolutely a miracle.”	“That CT scan showed 50% shrinkage in all my tumours and lymph nodes after just 5 rounds of Pembro!! And remember that I started Pembro in July of 2020 and that first CT scan was done in September of 2020. I was so thrilled and grateful for this therapy. It gave me my life back. It gave my family their life back.”
20. DID YOU HAVE TO STOP PEMBROLIZUMAB? IF SO, WHY?	“Yes, I did. I had to stop after May 26, 2020. Because my lipase level was too high. I had to start steroid treatment to bring my level under control. I have never resumed Pembro	“Yes, I had to stop Keytruda for one month while I had radiation to my brain on March 1, 2018.	“No, never.”

	treatment, but I have to tell you that my CANCER HAS CONTINUED TO SHRINK JUST THE SAME AND BEEN UNDER CONTROL EVER SINCE MAY 26, 2020. I AM JUST BESIDE MYSELF WITH GRATITUDE. Again, what a gift, I have been given."		
21. HAS PEMBROLIZUMAB BEEN EASIER TO USE THAN PREVIOUS THERAPIES? WHY OR WHY NOT?	"One million percent it has. Because, it has worked; and every 3 weeks I get to access it as opposed to every 2 weeks. It has reduced my disease. It has brought back my quality of life. I feel great again. And it is quicker to infuse. It is done in 1.5 hours on my treatment days. It is so easy to receive, not long at all. When you feel better, your outlook is better and you can endure so much more and you can heal better and do better. It has helped my healing, my mindset which has been there to help me fight this disease."	Yes. It's a much shorter infusion time than the chemo I used to have. And I have had no side effects whatsoever. This therapy was great, and it made me feel that I was taking nothing at all. It was so easy on my body."	"Yes, it has. Pembro is only half an hour infusion. And there is no toxicity at all, except for being a little tired, there are no side effects. I am able to walk, live my life as I wish, I can drive, I can go to work, do everything I should be doing. I enjoy extracurricular activities such as fishing, hunting, hikes, and most of all I get to enjoy my young children who are so active. The other chemos were so toxic and the infusions lasted all day, every two weeks. And I had to go home with a baby bottle. What pain! I couldn't do anything. What a difference."
22. WAS IT WORTH ACCESSING PEMBROLIZUMAB? WHY OR WHY NOT?	"Oh yes, it has been the best gift I could have received. When I received the news that chemo did not work for me, it was the best news I could have received because it led to Pembro. What a gift I was given, and I got to benefit from. My oncologist delivered wonderful news that day at 6 p.m."	"Oh, yes, yes, yes, it was very worth it. It saved my life! It brought me back to the woman I used to be who used to play and love life. I felt like nothing was going to happen for me and my cancer and then, bang, Keytruda came along and pulled off a miracle for me. It gave me a second chance at life. So it was very worth it for me to have accessed it."	"Oh my God, yes it was worth it, 300%. Everything I do is a testament to why it was worth it. Aside from COVID-19, I have been able to get my business back up and running. I am a general contractor doing renovations/alterations and I couldn't even begin to imagine getting my business up and running when I was on folfox. I have been able to go up to the cottage, do work around the house, I get to do everyday things that most people take for granted, but I don't anymore – such as grocery shopping. I get to do things with my beautiful children with ease now. This is the biggest thing for me, no more burden for me anymore. (PATIENT TEARED). My quality of life has just gone through the roof in comparison to the previous therapies I was on. I took so much for granted, but not anymore. This therapy means so much to me because I can appreciate life now so much more."
23. DID ACCESSING PEMBROLIZUMAB ALLOW YOU TO FULFILL OR ACCOMPLISH ANYTHING IN LIFE THAT YOU WOULD NOT HAVE OTHERWISE BEEN ABLE TO DO HAD YOU NOT ACCESSED THE THERAPY? IS YES, PLEASE EXPLAIN.	"If I was on chemo, I wouldn't have been able to lead the massive fundraiser that I did for CCRAN or spread the awareness about this horrible disease. I was so happy to do this for other people in the hopes of saving lives. I had energy because of Pembro and was able to do this remarkable event. I am living an extraordinary life and I could do this extraordinary thing that I could not have done otherwise. People in the general public got to benefit from that awareness campaign and so did CCRAN. I had an ambitious goal and I got to do it because of Pembro and the energy that I had. I live an extraordinary life because of Pembro. Everyone else should too."	"It sure did. Let me tell you why. We were supposed to build another cottage but decided to give our current one a renovation or facelift. Because of Keytruda, I was able to do that. I was able to paint, do flooring and so much more that I would not have been able to do if on chemo. Our cottage is newly restored and looking beautiful for our children and grandchildren to use long after I am gone. Keytruda did that for me. I worked hard on that cottage renovation. It's not easy to do that under the best of health conditions, let alone a cancer diagnosis. But I was able to achieve it because I was provided with something to look forward to in life, a goal, an objective to focus on because I was feeling well enough to do it. I was also able to enjoy my precious family, my sons and grandchildren who I adore and cherish more than life itself. There is no greater gift than that. "	"Yes. Let me explain. Just shortly, before I got diagnosed, I had just gotten married. And then bang, I got diagnosed with cancer. And my little one was born with defects and was going through so many challenges and difficulties. During my diagnosis, my wife and I had to forgo a honeymoon and during my treatments, there was never a celebration because I was just too ill and my wife had to take care of me and my youngest daughter who was undergoing challenges of her own. But when I started Pembro, I started to feel like myself again. So, my wife and I got to celebrate our honeymoon when our 2 nd anniversary came up and I got to do things I wouldn't have been able to do and I got to be a husband to my wife again. Now we get to take the kids to the cottage and be a family and take care of the little one who is sick. That in and of itself is a huge accomplishment. Being able to take care of your child is a parent's responsibility and I am so appreciative of the fact that I can fulfill that responsibility. Pembro allowed me to do that for my child – to take care of her as a parent should."
24. WHAT IMPROVEMENTS WOULD YOU LIKE TO SEE OVERALL IN A DRUG THERAPY THAT ARE NOT AVAILABLE CURRENTLY IN OTHER THERAPIES?	"First of all, a therapy should work to shrink disease, be effective and have no side effects. It should be nothing like chemo. It should reduce your cancer. I would sign up for bad side effects if it could just work at getting rid of your cancer completely. But if it can't then it should have no side effects. "	"No side effects would be great. Such as no nausea and no loss of appetite and of course, I would love to see a cure. Let's enjoy what life we have left while taking a drug. I wish we could do something about therapies that harm parts of the body while helping other parts of the body. (Became emotional....) "	"Well, I would like to see an oral treatment for sure versus an infusion so that I have no travel. And I guess while there may be some side effects in a drug, I would like to see minimal or fewer side effects in a therapy. And I would like to see overall quality of life maintained and extend survival."
25. WOULD YOUR LIFE BE ANY DIFFERENT IF THE DRUG THERAPIES HAD THOSE DESIRED IMPROVEMENTS?	"Yes, of course and that is what I have with Pembro. Immunotherapies give you that. It works so very well by shrinking your cancer and giving you few to no side effects. If all the therapies had these improvements, I wouldn't have gone through what I did at the	"Yes, of course it would. I wouldn't be stuck at home and riddled with side effects. I know I have to take one drug for one thing and another for another thing but if there was just one drug to take that could just correct your cancer, it would be wonderful and outstanding."	"I guess my life would be fine today if the previous therapies would have had all that."

	beginning of my journey. I would have led a better life, one with better quality of life, where I wouldn't be isolated, or bed ridden."		
27. DO YOU BELIEVE PEMBROLIZUMAB HAS THOSE DESIRED IMPROVEMENTS? WHY OR WHY NOT?	"Yes, 1000% for sure . Pembro works and gives you quality of life with no side effects. It is a remarkable therapy. It shrinks your cancer, allows you to lead a normal life with no side effects. It is the best therapy for cancer."	"Yes, it has been wonderful. It did so much for me. Keytruda saved my life. It kept me alive for so long. For 3 years. My husband told my oncologist that he needs to take care of me after his passing and he has been. I just want to live and walk because I need to be active, cut grass, paint my house, be social but now, I am stuck, and I don't want to bother my kids. But Keytruda has been a god sent. All drugs should be just like Keytruda. "	"Ahha.... Absolutely! Without a doubt. Aside from the oral therapy, Pembro is infused in half an hour which doesn't take very long at all. I am in and out of that chair so very quickly. I do not waste time at all. The process is not draining at all like chemo. My life is so much better with this therapy Pembro. "
28. DO YOU WISH TO ADD ANYTHING ABOUT WHY ACCESSING PEMBROLIZUMAB IS SO IMPORTANT TO PATIENTS AND CAREGIVERS?	"It is important to fund this therapy for patients who qualify so that they too can get the results they need. All of my disease has either disappeared or shrunk. Pembro was the best gift I have ever received. I thank the manufacturer every day. It has saved my life. I am here today because of it and I am living a great life. And it should be available for whoever is a match. With chemo, my life would be potentially shortened and so compromised. So brutal. For now, I am so happy. In my heart, I am going to be around for a long time and that means a lot for me, my family and friends. Sometimes I forget that I have cancer because of being on Pembro and how well I feel. How extraordinary is that?? Most people can't believe I have cancer. Isn't that wonderful! There is no better feeling. Everyone should be experiencing the same elation. Please fund the drug."	"I wish it was free for everyone because they could be missing out on their lives. If the government could feel our pain and anguish, they would approve this drug because this drug has saved my life and taken me out of the barrels of hell and depression. I am here today because of Keytruda and it deserves to be approved so that others just like me can be I the privileged position that I am in today – ALIVE."	"Had I known about Pembro at the beginning, I would have 100% pushed and gone the Pembro route even though chemo has certain results, I would have chosen the Pembro route. It is the best therapy. I do not want anyone to go through what I went through when we have treatments like Pembro to give you results like minor side effects and improved quality of life and it allows you to carry on and lead joy filled and productive lives. It is not fair that we have this therapy, and you are not having access to it. I am so lucky to be able to access it through a trial. It helps so many, patients and doctors, and caregivers and researchers etc. I would have paid out of pocket to access this treatment and put me in a privileged position of disease regression. Everyone deserves to have this feeling of elation so that they can get on with their life and enjoy their family for as long as possible."

TABLE 2: METASTATIC COLORECTAL CANCER FOCUS GROUP (NOVEMBER 15, 2020)

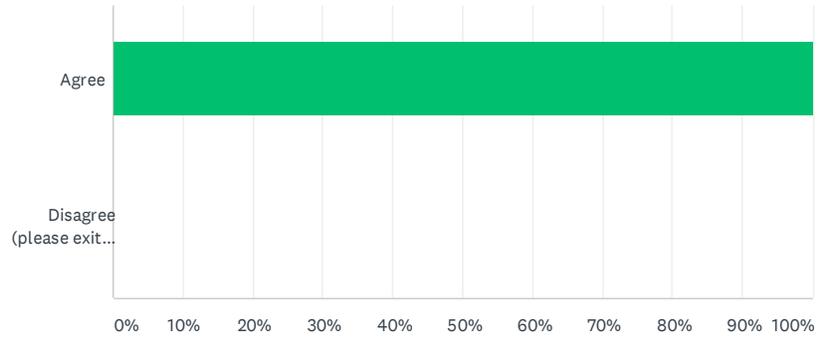
QUESTION: "WHAT SYMPTOMS, IF ANY, DID YOU EXPERIENCE FROM YOUR METASTATIC COLORECTAL CANCER?"

PATIENT D, 39-Year-Old Female, [REDACTED] Diagnosed March 2020 Sigmoid Colon Cancer Liver Metastases	"I had been experiencing anemia and bloody stools for about 10 years before I was actually diagnosed with metastatic colon cancer. I had low back pain that I kept complaining about to my GP for well over 2 years, but nothing was done about it, I think because of my young age. My upper right abdomen hurt, and this was due to the 20 metastatic tumours in my liver. It felt like pressure, deep pressure that just kept gnawing constantly in my right side. And with every passing day, it hurt more and more."
PATIENT E, 60-Year-Old Male [REDACTED] Diagnosed February 2019 Sigmoid Colon Cancer Peritoneal Metastases	"My primary tumours (two) in the sigmoid colon caused a horrible obstruction which necessitated a trip to the ER. But I had been feeling really awful long before that because my lower abdomen was quite bloated. I felt like a balloon, and tight – as though I were going to bust. There were days where I felt as though I was going to bust, and it was quite painful at times. I later found out it was due to the peritoneal disease and the ascites that had developed. Fluid buildup is not fun."
PATIENT F, 47-Year-Old Female, [REDACTED] Diagnosed June 2019 Right Sided Colon Cancer, MSI-H, KRAS-MT, BRAF-WT Lung Metastases, Peritoneal Metastases Liver Metastases	"When I was diagnosed, I was diagnosed with metastatic disease to my lungs, my liver and in my peritoneal lining. I was so sick, I had to go to the emergency because I required prompt surgical intervention. I also needed an ileostomy. I had pain everywhere because I was septic. My primary mass was 14 cm and it burst. I was having difficulty breathing and my chest hurt and so did my stomach. But everything sorta happened at once, it came quickly and severely. I am lucky to be alive today. So, I guess the symptoms I had were not only due to the huge primary tumour I had, but also due to the mets I had in my lungs and the peritoneal mets too because I had difficulty breathing and I had pain in my stomach. I was really a mess. "
PATIENT G, 59-Year-Old Female, [REDACTED] Diagnosed March 2017 Rectal Cancer, RAS WT, BRAF-WT	"When I was diagnosed with metastatic disease, I suffered and have been suffering with so much pain, fatigue, and poor appetite. I won't get into the incessant treatment-induced complications, because those are endless. But since the cancer recurrence, the pain has been severe, and I have been suffering debilitating fatigue and constant diminished appetite which makes it quite challenging for me to endure my therapies. One of my tumours is along the nerve root, so

<p>Pelvic Disease (Anterior to vagina, attached to urethra, in levator muscle, pelvic floor)</p>	<p>the pelvic nerve pain is excruciating. And the pain from the pressure of the tumour volume is at times unbearable. I also experience pain from having other organs impacted through collapse such as the neorectum.”</p>
<p>PATIENT H, 52-Year-Old Male ██████████ Diagnosed January 2018 Rectal Cancer, RAS WT, BRAF WT Lung Metastases, Retroperitoneal Metastases</p>	<p>“When I was diagnosed with my recurrence, I really didn’t feel much. I had been fine for well over 10 years being under surveillance after completing my treatment for my stage III disease. My CEA picked up my metastatic disease. I felt just a little funny though in my pelvis area, that’s about it. I was really grateful to have continued the surveillance, though. Were it not for the CEA, I don’t know where I would be today. So, did I have symptoms from my metastatic colorectal cancer? Not really. I guess it’s because it was really early on in the stage IV journey.”</p>
<p>PATIENT I, 70 Years Old Female, ██████████ Diagnosed June 2018 Rectal Cancer, RAS WT, BRAFWT Lung Metastases, Liver Metastases, Peritoneal Metastases, Bone Metastases</p>	<p>“I think the metastatic disease that caused me the most painful symptoms were the tumours in my abdomen and the tumor in my hip. The one in my hip was really painful which is why I needed radiation to help bring it under control. And the tumours in my abdomen were uncomfortable. I needed surgery for that too. And still, they came back so as you know, I am on chemo and pani to help shrink them. You don’t really feel anything until the disease gets out of control. I find that to be really problematic with this disease. So, it’s important to try to get a handle on it before it gets to that point. This is why I tell everyone to get screened for it so that they can prevent it and not get to the point that I am at today. Yes, it’s treatable, but it might not be curable if it becomes metastatic. And when it does become metastatic, the symptoms may be delayed for quite some time, like they were for me. ”</p>
<p>PATIENT J, 58-Year-Old Female, ██████████ Diagnosed October 2017 Rectal Cancer, RAS WT, BRAF WT Liver metastases Porta hepatis metastases Extrahepatic Lymph nodes</p>	<p>“After my liver was resected in 2017, my oncologist kept a close eye on me. He monitored my CEA and gave me regular CT scans. I never really had any symptoms from my liver metastases. And it was the CEA that picked up the second recurrence in the porta hepatis and lymph nodes. I felt fine. You would never know that I have stage four disease. I guess that’s why they call it the silent killer. I am doing chemo plus biologic therapy to help shrink this second recurrence. But to answer your question, I never really had any symptoms from my mets.”</p>

Q1 “I agree that this information is being provided voluntarily, and by providing this information, I consent to its use by CCRAN for statistical purposes.”

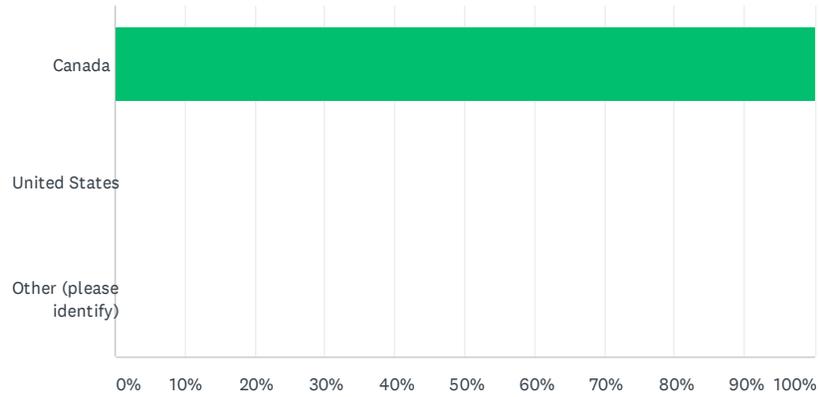
Answered: 85 Skipped: 0



ANSWER CHOICES	RESPONSES	
Agree	100.00%	85
Disagree (please exit survey)	0.00%	0
TOTAL		85

Q2 Please indicate your country of residence:

Answered: 85 Skipped: 0

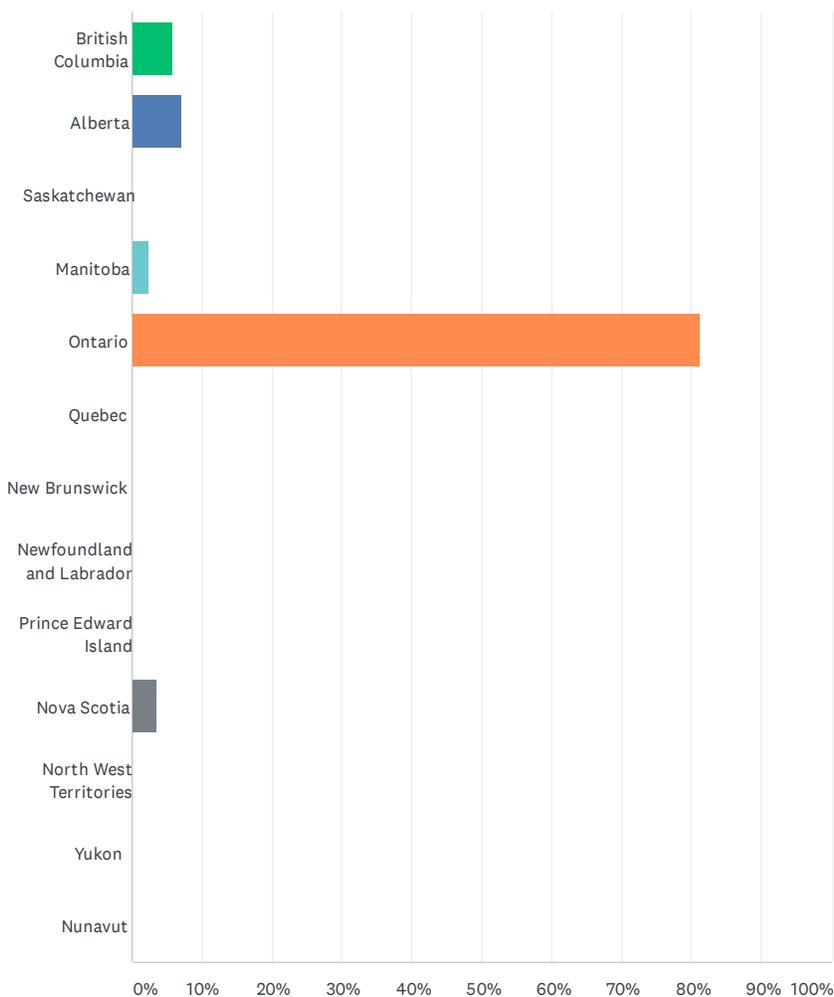


ANSWER CHOICES	RESPONSES
Canada	100.00% 85
United States	0.00% 0
Other (please identify)	0.00% 0
TOTAL	85

#	OTHER (PLEASE IDENTIFY)	DATE
	There are no responses.	

Q3 If Canada, please indicate your province or territory:

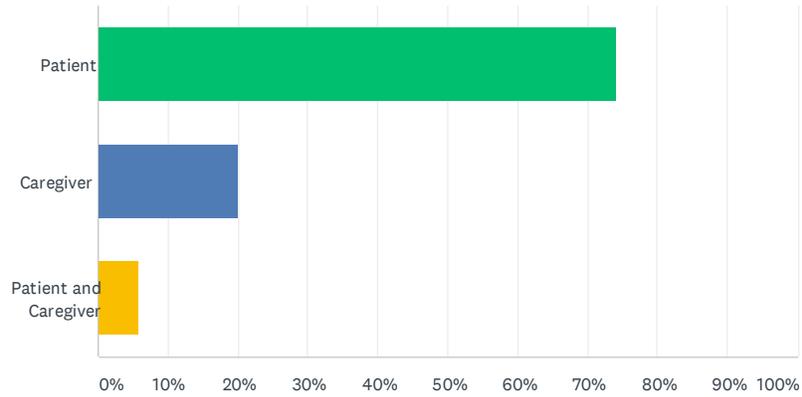
Answered: 85 Skipped: 0



ANSWER CHOICES	RESPONSES	
British Columbia	5.88%	5
Alberta	7.06%	6
Saskatchewan	0.00%	0
Manitoba	2.35%	2
Ontario	81.18%	69
Quebec	0.00%	0
New Brunswick	0.00%	0
Newfoundland and Labrador	0.00%	0
Prince Edward Island	0.00%	0
Nova Scotia	3.53%	3
North West Territories	0.00%	0
Yukon	0.00%	0
Nunavut	0.00%	0
TOTAL		85

Q4 Are you a:

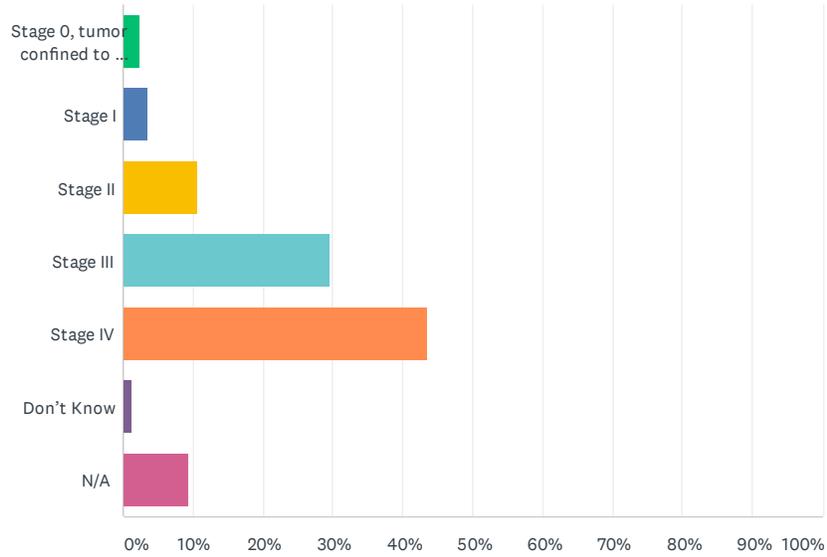
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ANSWER CHOICES	RESPONSES	
Patient	74.12%	63
Caregiver	20.00%	17
Patient and Caregiver	5.88%	5
TOTAL		85

Q5 If you are a patient or were once a patient, with what stage disease were you diagnosed?

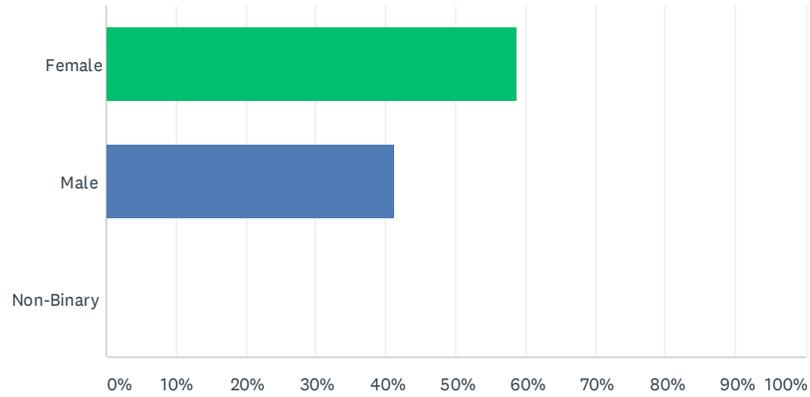
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ANSWER CHOICES	RESPONSES	
Stage 0, tumor confined to the site from which it started	2.35%	2
Stage I	3.53%	3
Stage II	10.59%	9
Stage III	29.41%	25
Stage IV	43.53%	37
Don't Know	1.18%	1
N/A	9.41%	8
TOTAL		85

Q6 Are you:

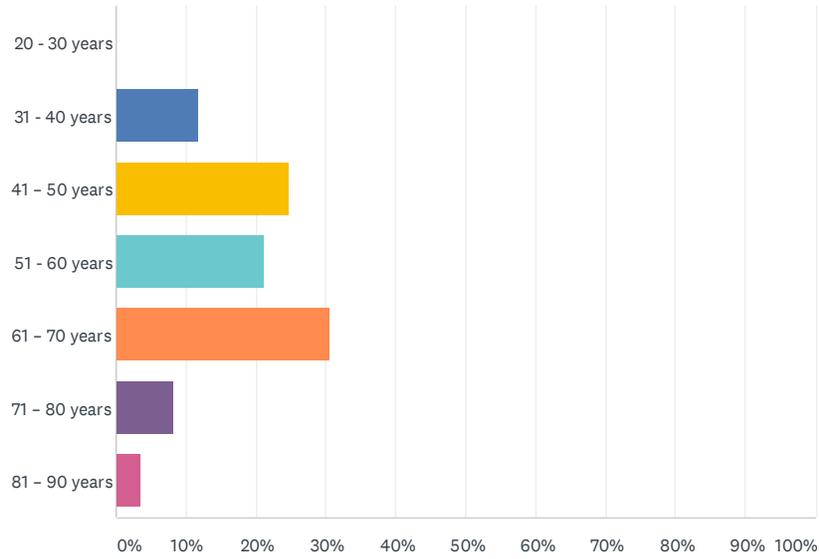
Answered: 85 Skipped: 0



ANSWER CHOICES	RESPONSES	
Female	58.82%	50
Male	41.18%	35
Non-Binary	0.00%	0
TOTAL		85

Q7 How old are you:

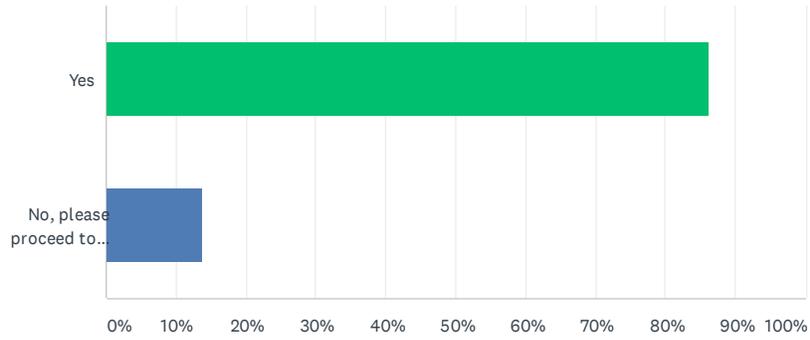
Answered: 85 Skipped: 0



ANSWER CHOICES	RESPONSES	
20 - 30 years	0.00%	0
31 - 40 years	11.76%	10
41 - 50 years	24.71%	21
51 - 60 years	21.18%	18
61 - 70 years	30.59%	26
71 - 80 years	8.24%	7
81 - 90 years	3.53%	3
TOTAL		85

Q8 Have you experienced any symptoms from colorectal cancer?

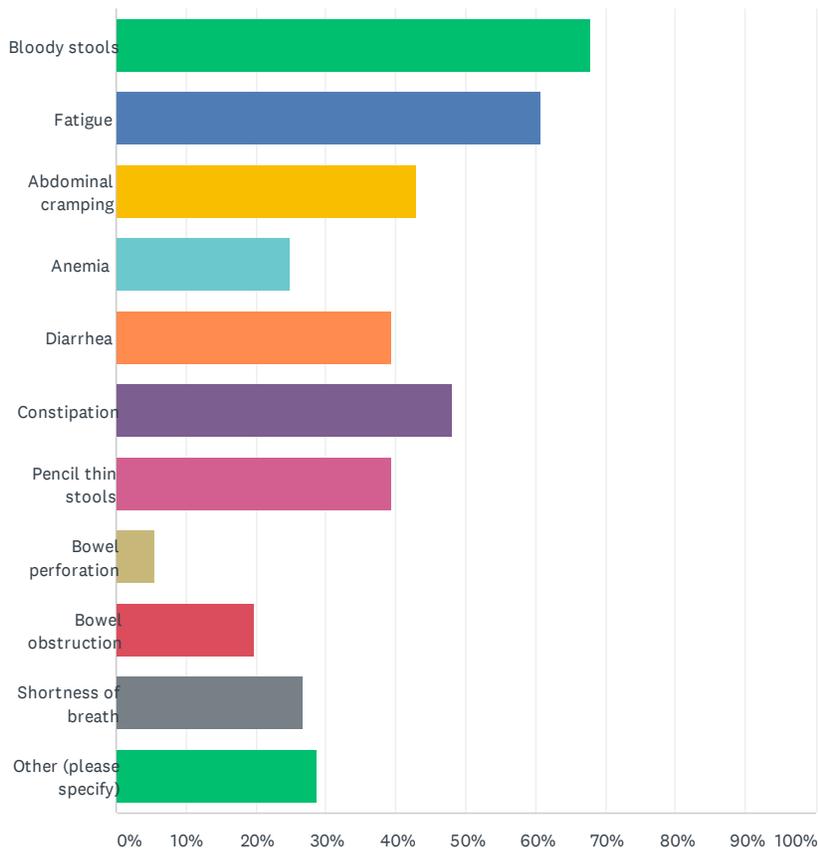
Answered: 65 Skipped: 20



ANSWER CHOICES	RESPONSES	
Yes	86.15%	56
No, please proceed to Question 12	13.85%	9
TOTAL		65

Q9 If so, please select the symptoms experienced from your colorectal cancer. Check all that apply.

Answered: 56 Skipped: 29



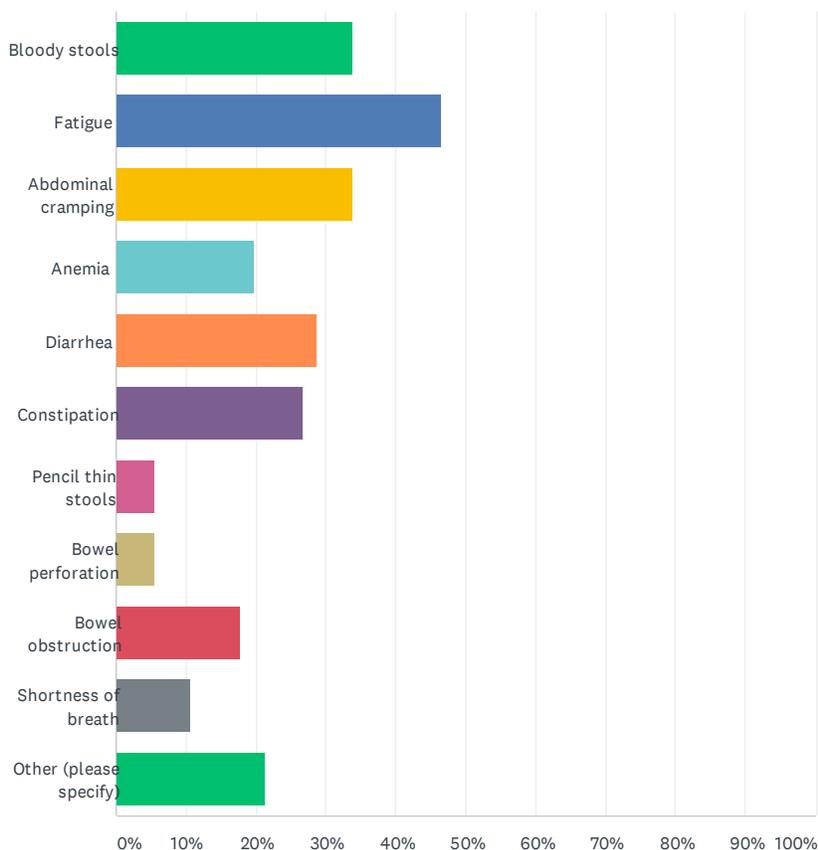
ANSWER CHOICES	RESPONSES
Bloody stools	67.86% 38
Fatigue	60.71% 34
Abdominal cramping	42.86% 24
Anemia	25.00% 14
Diarrhea	39.29% 22
Constipation	48.21% 27
Pencil thin stools	39.29% 22
Bowel perforation	5.36% 3
Bowel obstruction	19.64% 11
Shortness of breath	26.79% 15
Other (please specify)	28.57% 16
Total Respondents: 56	

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE SPECIFY)	DATE
1	Acute pain	12/15/2020 4:17 PM
2	Neuropathy	12/14/2020 9:27 AM
3	Pink tinged mucous	12/11/2020 12:29 PM
4	mucous in stool was the most noticeable, there was just a couple with a bit of blood prior to testing	12/10/2020 8:47 PM
5	Low Potassium, some nausea and emesis	12/9/2020 10:21 PM
6	Increased frequency of urge	12/9/2020 11:01 AM
7	Feeling like the bowl doesn't fully empty, bloating	12/8/2020 10:34 PM
8	Nausea,light headed,dizzy	12/8/2020 11:28 AM
9	irregular and frequent bowel movement	12/7/2020 10:40 AM
10	hemorrhoids	12/7/2020 9:22 AM
11	ribbon like stools	12/7/2020 8:12 AM
12	Sciatic nerve abd rectal nerve pain at tumor site prior to LAR surgery	12/6/2020 10:51 PM
13	bloated	12/6/2020 9:44 PM
14	Permanent colostmy	12/6/2020 7:01 PM
15	Bloating	12/6/2020 6:07 PM
16	General malaise	12/4/2020 9:46 AM

Q10 About your colorectal cancer and its impact on your life: Which symptoms of colorectal cancer were/are more important to control than others? Please select your top three.

Answered: 56 Skipped: 29



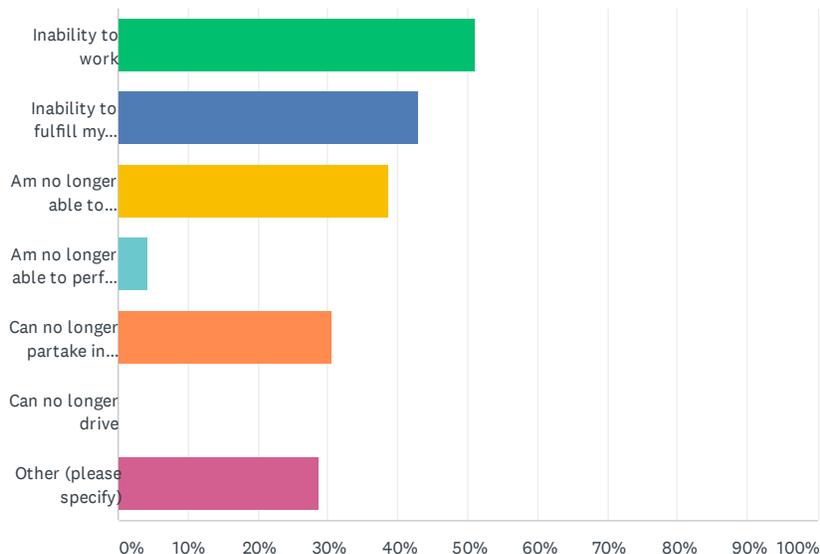
ANSWER CHOICES	RESPONSES
Bloody stools	33.93% 19
Fatigue	46.43% 26
Abdominal cramping	33.93% 19
Anemia	19.64% 11
Diarrhea	28.57% 16
Constipation	26.79% 15
Pencil thin stools	5.36% 3
Bowel perforation	5.36% 3
Bowel obstruction	17.86% 10
Shortness of breath	10.71% 6
Other (please specify)	21.43% 12
Total Respondents: 56	

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE SPECIFY)	DATE
1	Acute pain	12/15/2020 4:17 PM
2	Neuropathy	12/14/2020 9:27 AM
3	Urgency and frequent bowel movements	12/11/2020 12:29 PM
4	There was no impact	12/10/2020 8:47 PM
5	Potassium	12/9/2020 10:21 PM
6	Increased frequency of urge	12/9/2020 11:01 AM
7	weight loss	12/8/2020 7:48 PM
8	Frequency of going to the bathroom	12/7/2020 4:59 PM
9	frequency and urgency of bowel movements	12/7/2020 10:40 AM
10	hemorrhoids	12/7/2020 9:22 AM
11	Incontinence, neuropathy	12/6/2020 10:51 PM
12	Permanent colostomy	12/6/2020 7:01 PM

Q11 About your colorectal cancer and its impact on your life: How do your symptoms and problems resulting from any symptoms impact or limit your quality of life? Please select from the list appearing below the impacts or limitations on your quality of life (a maximum of 3).

Answered: 49 Skipped: 36



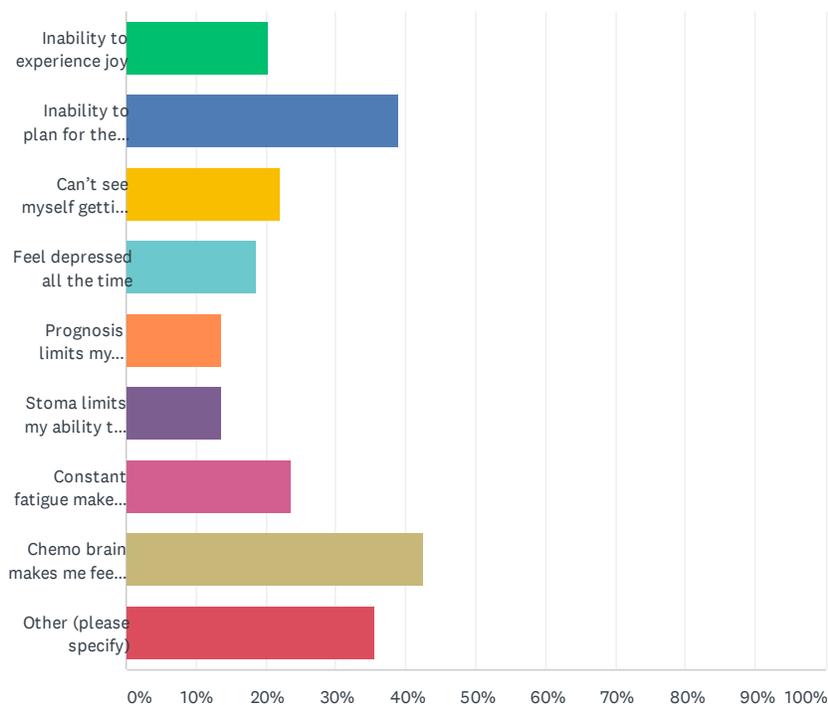
ANSWER CHOICES	RESPONSES	
Inability to work	51.02%	25
Inability to fulfill my family obligations	42.86%	21
Am no longer able to exercise	38.78%	19
Am no longer able to perform volunteer work	4.08%	2
Can no longer partake in social activities	30.61%	15
Can no longer drive	0.00%	0
Other (please specify)	28.57%	14
Total Respondents: 49		

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE SPECIFY)	DATE
1	No longer able to plan events	12/14/2020 9:27 AM
2	Limitations on exercise and social activities	12/11/2020 12:29 PM
3	no impact on quality of life	12/10/2020 8:47 PM
4	sore joints	12/10/2020 10:44 AM
5	Had to go for additional treatments so more time.	12/9/2020 10:21 PM
6	Must have bathroom close by	12/9/2020 2:14 PM
7	Have to consider every activity in light of symptom	12/9/2020 11:01 AM
8	Constant bowel issues	12/8/2020 8:25 PM
9	unable to go on long trips	12/8/2020 7:48 PM
10	Had to have the "bag", also erectile disfunction, less energetic ic then before, discomfort when I have bowel blockage, fortunately temporary,	12/7/2020 4:45 PM
11	no impact	12/7/2020 8:12 AM
12	All of the above at times depending on different stages of my treatment path. Incontinence neurophy and medical obligations interfere with qol.	12/6/2020 10:51 PM
13	Adjusting to a life with a permanent colostomy	12/6/2020 7:01 PM
14	Only can work part time instead of full time	12/6/2020 6:07 PM

Q12 Please list any limitations that have had a psychological impact as a result of your colorectal cancer. Please select from the list below (maximum of 3).

Answered: 59 Skipped: 26



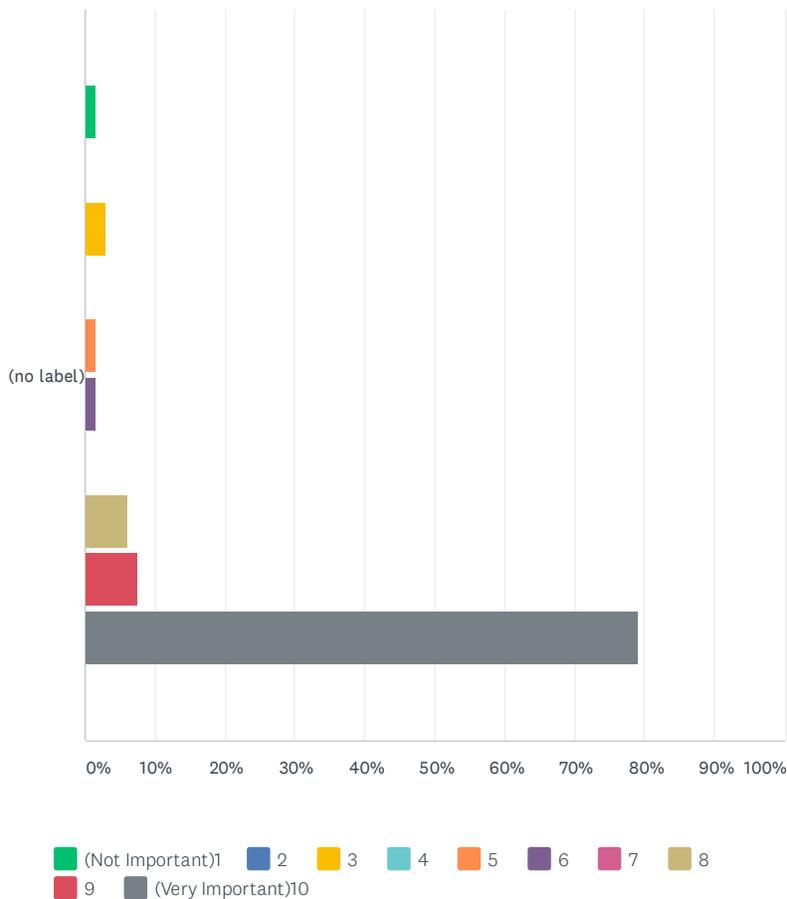
ANSWER CHOICES	RESPONSES	
Inability to experience joy	20.34%	12
Inability to plan for the future or think about the future	38.98%	23
Can't see myself getting better	22.03%	13
Feel depressed all the time	18.64%	11
Prognosis limits my ability to cope	13.56%	8
Stoma limits my ability to leave the house and my outlook on life	13.56%	8
Constant fatigue makes it difficult to function normally – can't think straight	23.73%	14
Chemo brain makes me feel forgetful, "less than"	42.37%	25
Other (please specify)	35.59%	21
Total Respondents: 59		

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE SPECIFY)	DATE
1	N/a	12/15/2020 4:22 PM
2	Ability to be spontaneous	12/14/2020 9:27 AM
3	worry of recurrence	12/10/2020 8:47 PM
4	nothing	12/10/2020 10:44 AM
5	Just tired and did not do as much physically. Couldn't eat as well either.	12/9/2020 10:21 PM
6	I've not had any psycho symptoms	12/9/2020 11:01 AM
7	None of the above	12/8/2020 8:26 PM
8	Neuropathy resulting from chemo. Extreme bowel issues causing limitations to leaving the house	12/8/2020 8:25 PM
9	neuropathy on toes	12/8/2020 7:48 PM
10	limit my ability to be there for others	12/8/2020 12:22 PM
11	None of the above	12/7/2020 5:31 PM
12	Fear it will get worse.	12/7/2020 4:59 PM
13	my girl friend and daughter do not like occasional odor -	12/7/2020 4:45 PM
14	unable to always predict how your bowel is going to react that day and will it impact daily activities	12/7/2020 3:15 PM
15	occasional feelings of stress and concern about future	12/7/2020 8:12 AM
16	All of these things at various times, currently afraid to make future plans as historically i have done so many times and had to stop and restart my life over and over again. Anxiety is high and not inappropriate for someone in my position. The less I talk or have to think about cancer and the more I engage with people and life pursues outside of a cancer focus, the healthier I get so its a self care balance	12/6/2020 10:51 PM
17	terrified of recurrence	12/6/2020 9:44 PM
18	Worrying about the colostomy leaking in public	12/6/2020 7:01 PM
19	mood swings were prevalent	12/6/2020 6:54 PM
20	None of the above	12/6/2020 5:55 PM
21	No limitations	12/6/2020 5:38 PM

Q13 On a scale of 1-10, how important to you is the access to new effective treatments for colorectal cancer, with 1 being “not important” and 10 being “very important”?

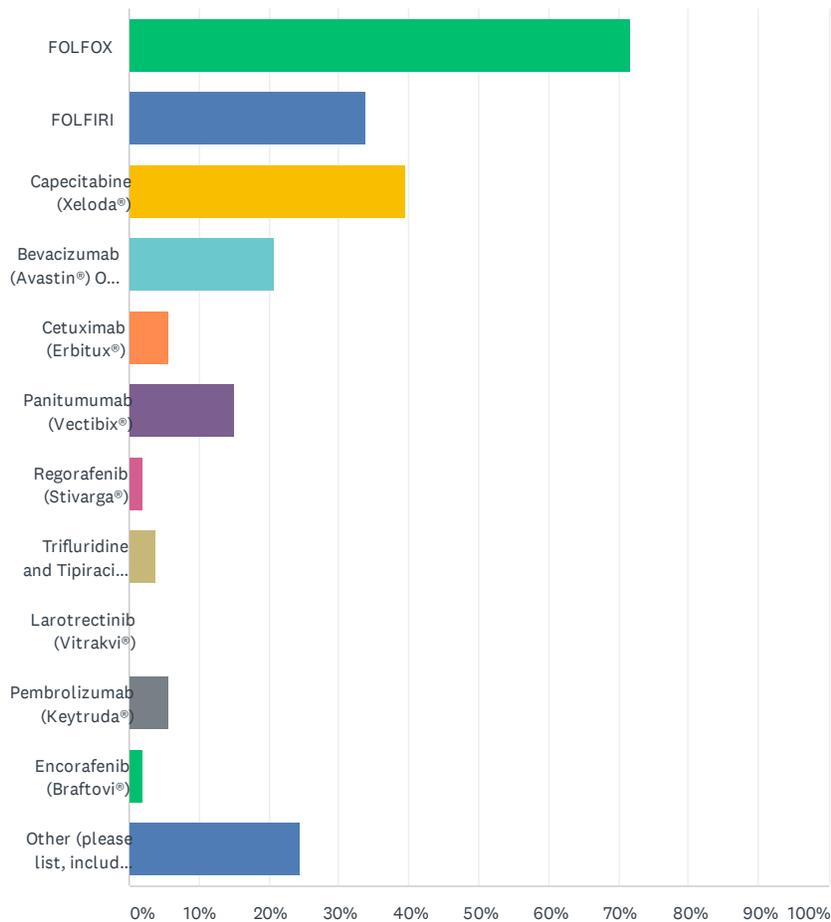
Answered: 67 Skipped: 18



	(NOT IMPORTANT)1	2	3	4	5	6	7	8	9	(VERY IMPORTANT)10	TOTAL	WEIGHTED AVERAGE
(no label)	1.49%	0.00%	2.99%	0.00%	1.49%	1.49%	0.00%	5.97%	7.46%	79.10%	67	9.33
	1	0	2	0	1	1	0	4	5	53		

Q14 What drug therapies have you used to treat your colorectal cancer? Please check all that apply.

Answered: 53 Skipped: 32



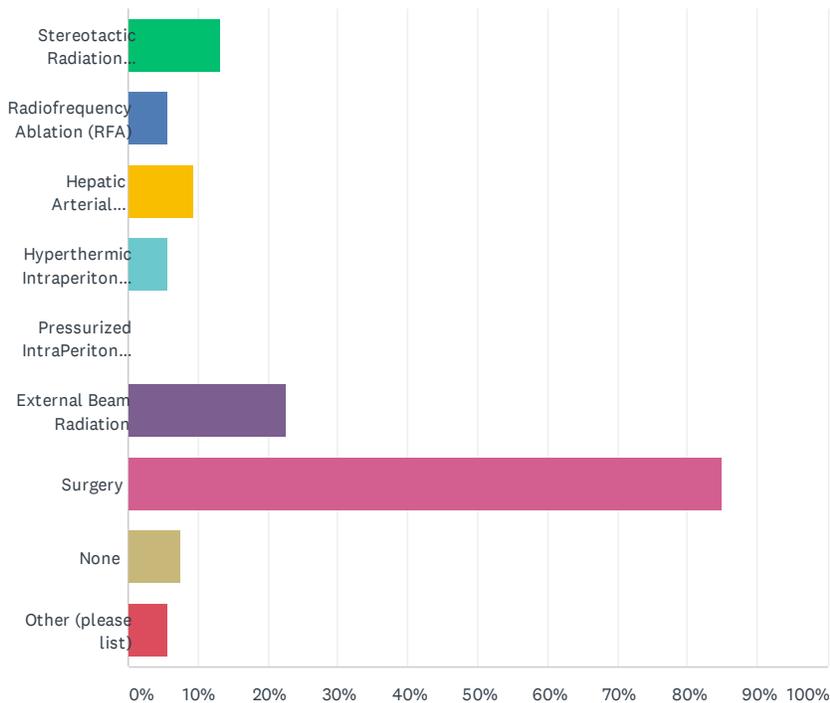
ANSWER CHOICES	RESPONSES	
FOLFOX	71.70%	38
FOLFIRI	33.96%	18
Capecitabine (Xeloda®)	39.62%	21
Bevacizumab (Avastin®) OR MVASI	20.75%	11
Cetuximab (Erbix®)	5.66%	3
Panitumumab (Vectibix®)	15.09%	8
Regorafenib (Stivarga®)	1.89%	1
Trifluridine and Tipiracil (Lonsurf®)	3.77%	2
Larotrectinib (Vitrakvi®)	0.00%	0
Pembrolizumab (Keytruda®)	5.66%	3
Encorafenib (Braftovi®)	1.89%	1
Other (please list, including combination therapies)	24.53%	13
Total Respondents: 53		

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE LIST, INCLUDING COMBINATION THERAPIES)	DATE
1	Cyclophosphamide/DPX Survivac	12/18/2020 12:03 PM
2	5FU	12/15/2020 4:03 PM
3	combo but cannot remember	12/10/2020 10:51 AM
4	5FU	12/9/2020 10:15 AM
5	Oxaliplatin	12/8/2020 10:40 PM
6	CAPOX, Oxaliplatin	12/8/2020 7:47 PM
7	Lonsurf	12/8/2020 7:44 PM
8	Cyclophosphamide, SURVIVAC	12/8/2020 1:07 PM
9	Oxaliplatin	12/7/2020 5:05 PM
10	I do not remember them all, and now not that interested, that was in the past	12/7/2020 4:53 PM
11	Oxaliplatin	12/7/2020 2:28 PM
12	oxaliplatin	12/7/2020 10:49 AM
13	CAPIRI	12/7/2020 1:38 AM

Q15 What other therapies have you accessed, other than drug therapies, to treat your colorectal cancer? Please choose from the list below.

Answered: 53 Skipped: 32

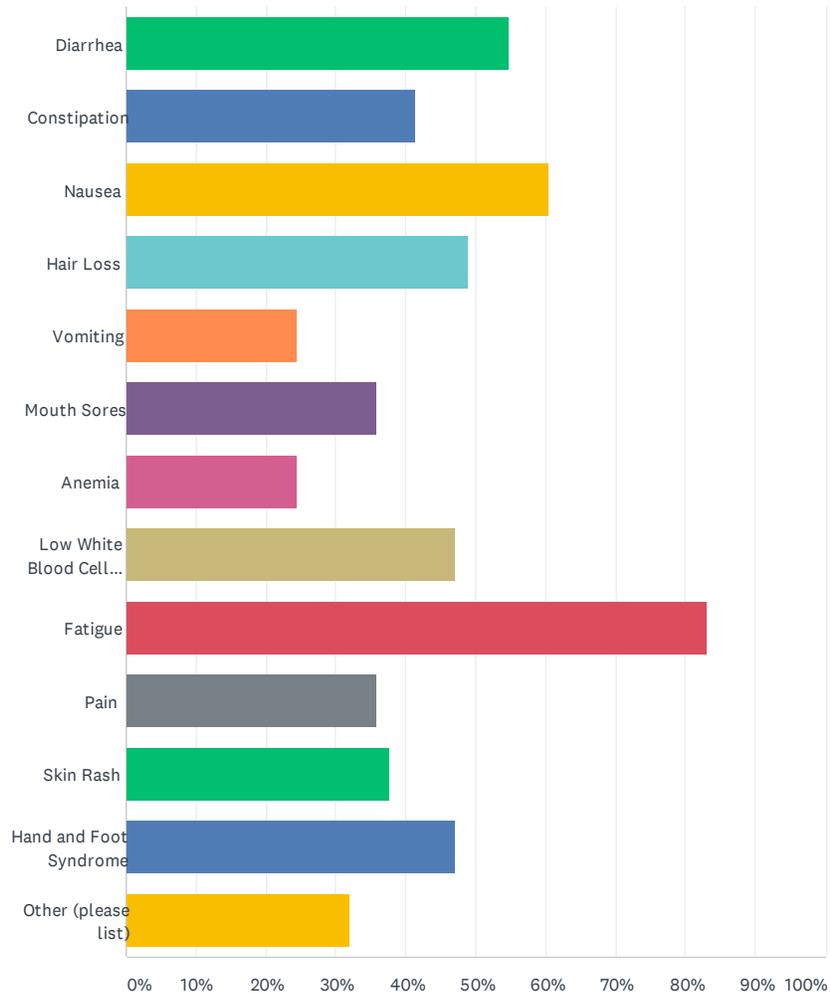


ANSWER CHOICES		RESPONSES	
Stereotactic Radiation Therapy (SRT)		13.21%	7
Radiofrequency Ablation (RFA)		5.66%	3
Hepatic Arterial Infusion Pump (HAIP) Chemotherapy		9.43%	5
Hyperthermic Intraperitoneal Chemotherapy (HIPEC)		5.66%	3
Pressurized IntraPeritoneal Aerosol Chemotherapy (PIPAC)		0.00%	0
External Beam Radiation		22.64%	12
Surgery		84.91%	45
None		7.55%	4
Other (please list)		5.66%	3
Total Respondents: 53			

#	OTHER (PLEASE LIST)	DATE
1	Radiation in 2 different areas, not sure which type	12/14/2020 11:26 AM
2	radiation and chemo	12/8/2020 7:55 PM
3	I am told nothing else is available to me.	12/6/2020 7:37 PM

Q16 What side effects have you experienced with your drug therapies? Please check all that apply.

Answered: 53 Skipped: 32



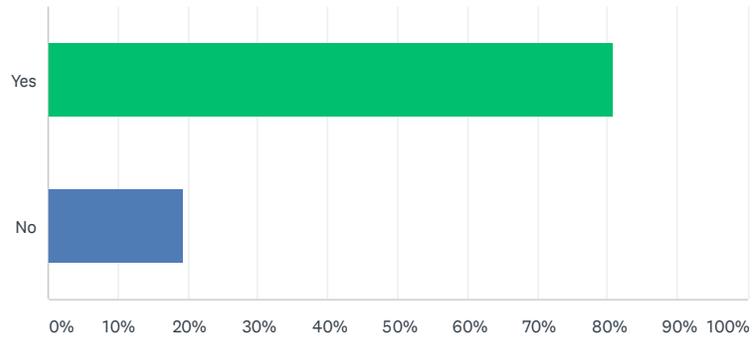
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

ANSWER CHOICES	RESPONSES	
Diarrhea	54.72%	29
Constipation	41.51%	22
Nausea	60.38%	32
Hair Loss	49.06%	26
Vomiting	24.53%	13
Mouth Sores	35.85%	19
Anemia	24.53%	13
Low White Blood Cell Count	47.17%	25
Fatigue	83.02%	44
Pain	35.85%	19
Skin Rash	37.74%	20
Hand and Foot Syndrome	47.17%	25
Other (please list)	32.08%	17
Total Respondents: 53		

#	OTHER (PLEASE LIST)	DATE
1	Split tops of fingers, like paper cuts	12/23/2020 12:12 PM
2	Neuropathy	12/15/2020 4:22 PM
3	neuropathy	12/11/2020 1:48 PM
4	Bowel obstruction, slurred speech	12/9/2020 4:44 PM
5	Heart attack	12/9/2020 2:18 PM
6	Mild neuropathy	12/9/2020 11:13 AM
7	First bite syndrome, neuropathy	12/9/2020 10:43 AM
8	Cold sensitivity, muscle cramping	12/8/2020 10:40 PM
9	Neuropathy	12/8/2020 9:25 PM
10	neuropathy on toes and hands	12/8/2020 7:55 PM
11	Hair thinning, skin pigmentation changes, temporary loss of taste and smell, peripheral neuropathy, loss of appetite, severe weight loss, dehydration, low red blood cell count, raised liver enzymes	12/8/2020 7:47 PM
12	depression, fear	12/8/2020 1:07 PM
13	Extreme sensitivity to cool or cold	12/7/2020 5:05 PM
14	neuropathy, fatigue, liver issues	12/7/2020 10:49 AM
15	Severe neuropathy	12/6/2020 10:54 PM
16	Heartburn	12/6/2020 6:13 PM
17	neuropathy hands and feet	12/6/2020 6:08 PM

Q17 Were some of your side effects from the drug therapies more difficult to tolerate than others?

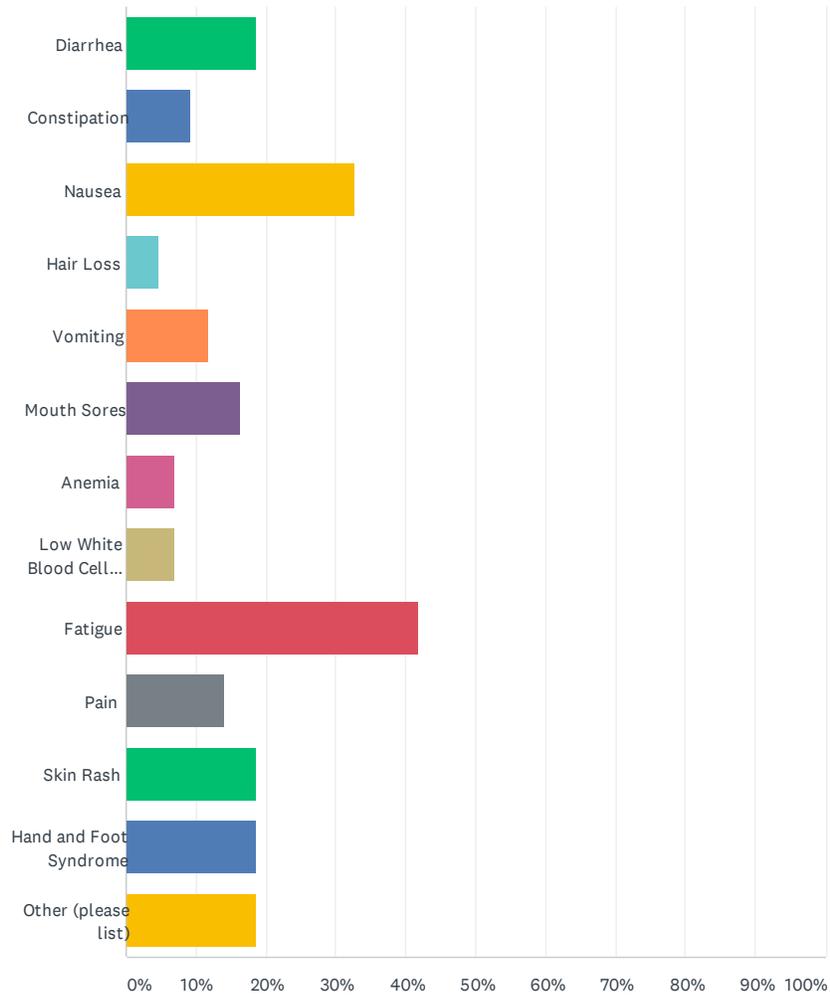
Answered: 52 Skipped: 33



ANSWER CHOICES	RESPONSES	
Yes	80.77%	42
No	19.23%	10
TOTAL		52

Q18 If you answered yes to the question above, please identify the top two side effects that were most difficult to tolerate from the list below:

Answered: 43 Skipped: 42



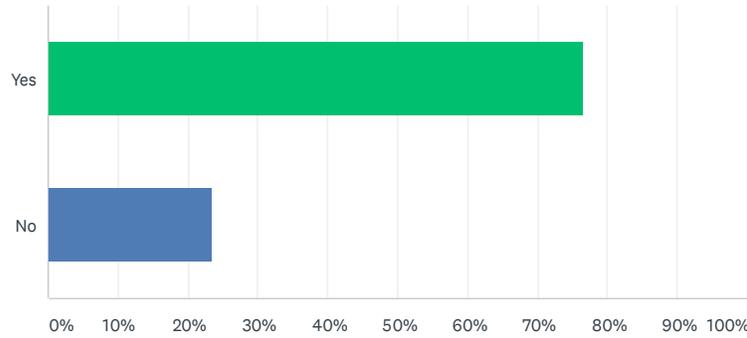
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

ANSWER CHOICES	RESPONSES
Diarrhea	18.60% 8
Constipation	9.30% 4
Nausea	32.56% 14
Hair Loss	4.65% 2
Vomiting	11.63% 5
Mouth Sores	16.28% 7
Anemia	6.98% 3
Low White Blood Cell Count	6.98% 3
Fatigue	41.86% 18
Pain	13.95% 6
Skin Rash	18.60% 8
Hand and Foot Syndrome	18.60% 8
Other (please list)	18.60% 8
Total Respondents: 43	

#	OTHER (PLEASE LIST)	DATE
1	Neuropathy	12/9/2020 10:43 AM
2	Cold sensitivity	12/8/2020 10:40 PM
3	Neuropathy	12/8/2020 9:25 PM
4	Neuropathy	12/8/2020 7:47 PM
5	Hands sensitive to cold	12/8/2020 9:04 AM
6	neuropathy	12/7/2020 10:49 AM
7	Neuropathy	12/6/2020 10:54 PM
8	neuropathy of hands and feet	12/6/2020 6:08 PM

Q19 Were you prescribed medications to help treat some or all of your treatment-induced side effects (for example, Neupogen for low white blood count or antibiotics to help treat skin rash)?

Answered: 51 Skipped: 34



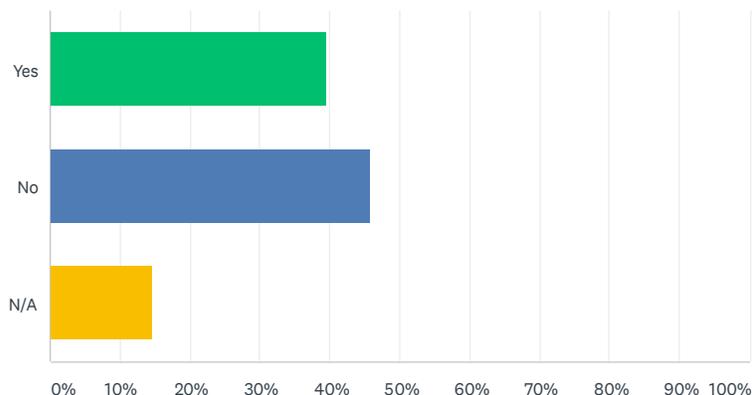
ANSWER CHOICES	RESPONSES	
Yes	76.47%	39
No	23.53%	12
TOTAL		51

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	IF YES, PLEASE LIST THE SIDE EFFECTS AND MEDICATIONS PRESCRIBED.	DATE
1	Face rash, white pustules Doxycycline 100mg, Benzoyl Peroxide 10%, Clindamycin Pho's 1%, Hydrocortisone ACET 1%	12/23/2020 12:12 PM
2	Stool softeners Anti Nausea medication	12/18/2020 12:03 PM
3	Can't remember	12/15/2020 4:22 PM
4	Skin rash-betamethasone cream Vomiting-dexamethasone, zofran, olanzapine	12/15/2020 4:03 PM
5	Grastofil	12/14/2020 11:26 AM
6	don't remember	12/11/2020 1:48 PM
7	mouth wash for mouth sores and thrush	12/10/2020 8:52 PM
8	can not remember had skin - adult acne had bladder infections took meds	12/10/2020 10:51 AM
9	Neutrogena and a special mouth rinse.	12/9/2020 10:45 PM
10	Pain pills	12/9/2020 2:18 PM
11	No side effects. Mini cyclone, Hyderm&clindamycin ointment, sucralfate	12/9/2020 11:13 AM
12	Neupogen	12/9/2020 10:43 AM
13	Nausea - ondansetron Fatigue - dexamethasone	12/8/2020 10:40 PM
14	Fatigue, constipation	12/8/2020 9:25 PM
15	meds for nausea, cream	12/8/2020 7:55 PM
16	Nothing was prescribed for neutropenia and treatment was ultimately cancelled due to that. IV hydrocortisone for rash. Metaclopramide, dexamethasone, ondansetron for nausea.	12/8/2020 7:47 PM
17	Filgrastim	12/8/2020 7:44 PM
18	Peripheral neuropathy- gabapentin and lyrica	12/8/2020 7:35 PM
19	Doxycycline for rashes - upset stomach Prednisone prior to chemo - kept me awake	12/8/2020 6:46 PM
20	Lapelga - Pegfilgrastim - low white Blood count Eliquis- Blood clot A mouth wash drug	12/8/2020 1:07 PM
21	Something for constipation, something for mouth ulcers	12/7/2020 5:05 PM
22	None	12/7/2020 5:05 PM
23	Nausea medication	12/7/2020 2:28 PM
24	Neupogen	12/7/2020 12:26 PM
25	nausea = olanzapine, metoclopramide, pain = hydromorphone, constipation = senakot, liver issues = IV hydration, low white blood cells = injection of filgrastim / grastofil	12/7/2020 10:49 AM
26	Diarrhea - Imodium	12/7/2020 9:28 AM
27	Nausea- anti nauseants	12/7/2020 8:37 AM
28	hydromorphone	12/7/2020 8:02 AM
29	Mouth Sores - used mouth wash (didn't help) Anemia - nothing was prescribed. Feeling week - vitamin C (did help). Vitamins and minerals.	12/6/2020 11:53 PM
30	Lomotil Emend	12/6/2020 7:38 PM
31	Nausea meds, dilaudid.	12/6/2020 7:37 PM
32	Neupogen for low white cell count	12/6/2020 7:06 PM
33	creams and antibiotics for skin rash.	12/6/2020 6:08 PM
34	Dexamethasone - inability to sleep	12/6/2020 5:55 PM
35	anti-emetics	12/4/2020 9:52 AM

Q20 If you answered yes to the question above, did you incur out of pocket expenses to help pay for those medications?

Answered: 48 Skipped: 37

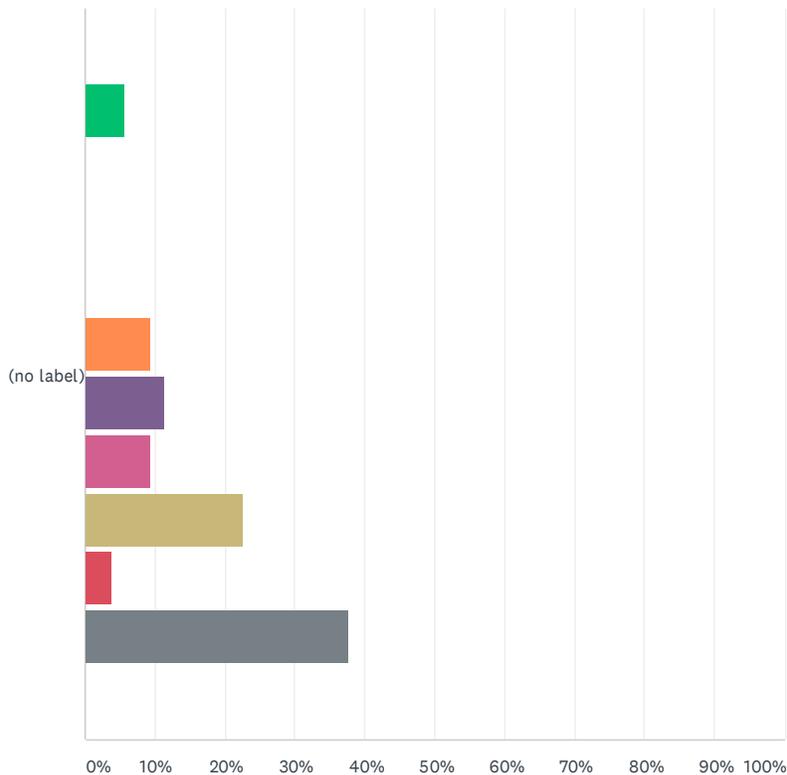


ANSWER CHOICES	RESPONSES
Yes	39.58% 19
No	45.83% 22
N/A	14.58% 7
TOTAL	48

#	IF YES, APPROXIMATELY HOW MUCH DID YOU PAY FOR THOSE MEDICATIONS?	DATE
1	\$68.00	12/23/2020 12:12 PM
2	\$300.00	12/18/2020 12:03 PM
3	Can't remember	12/15/2020 4:22 PM
4	\$25 every 2 weeks	12/15/2020 4:03 PM
5	hundreds not thousands	12/10/2020 10:51 AM
6	Only a small amount out of pocket as we got medical insurance that covered the neupogen and most of the drugs. (The hospital helped us set this up which was fantastic.)	12/9/2020 10:45 PM
7	Total, \$200	12/9/2020 4:44 PM
8	\$100	12/9/2020 2:18 PM
9	Lapelga - Pegfilgrastim \$2100 x 2 = \$4200 Eliquis- Blood clot \$25x5=\$125	12/8/2020 1:07 PM
10	don't remember	12/7/2020 5:05 PM
11	Cannot remember	12/7/2020 5:05 PM
12	\$100 / month	12/7/2020 9:28 AM
13	co-payment	12/7/2020 8:02 AM
14	\$ 20,000 over 4 years.	12/6/2020 11:53 PM
15	\$100	12/6/2020 7:38 PM
16	10% of cost.	12/6/2020 7:37 PM
17	Very little	12/6/2020 5:55 PM

Q21 On a scale of 1-10, with 1 being “not important” and 10 being “very important,” if you had a choice of drugs to treat your cancer, how important was it for you to make that choice based upon each different drug’s known side effects?

Answered: 53 Skipped: 32

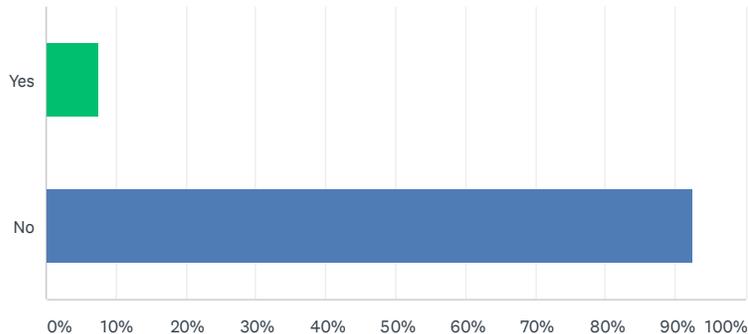


■ 1 (Not important)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Very important)

	1 (NOT IMPORTANT)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT)	TOTAL	WEIGHTED AVERAGE
(no label)	5.66%	0.00%	0.00%	0.00%	9.43%	11.32%	9.43%	22.64%	3.77%	37.74%	53	7.79
	3	0	0	0	5	6	5	12	2	20		

Q22 Have you (or your oncologist) experienced any difficulties in accessing drugs for your colorectal cancer?

Answered: 53 Skipped: 32

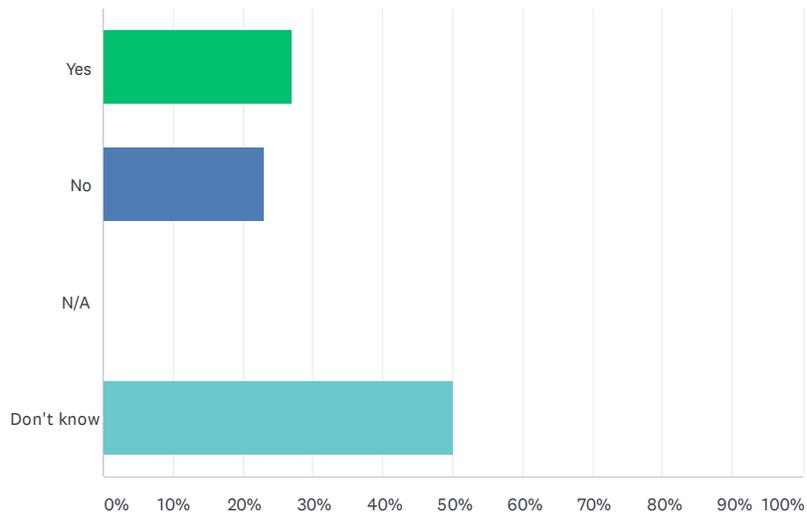


ANSWER CHOICES	RESPONSES	
Yes	7.55%	4
No	92.45%	49
TOTAL		53

#	IF YES, PLEASE DESCRIBE BELOW.	DATE
1	Oncologist had to do some work to get me on encorafenib and cetuximab	12/14/2020 11:26 AM
2	MVASI as second line. I had to use private health insurance.	12/9/2020 11:13 AM
3	We had to wait 3 months for an immunotherapy therapy trial to open up. Started on Chemo that did not help my disease and caused side effects.	12/8/2020 1:07 PM
4	Cetuximab and Encorafenib.	12/6/2020 7:37 PM
5	Not yet but this may happen if surgeries are not on the table. Currently waiting for next step.	12/6/2020 6:13 PM

Q23 Were any of your treatments recommended solely based on what was publicly funded in your province?

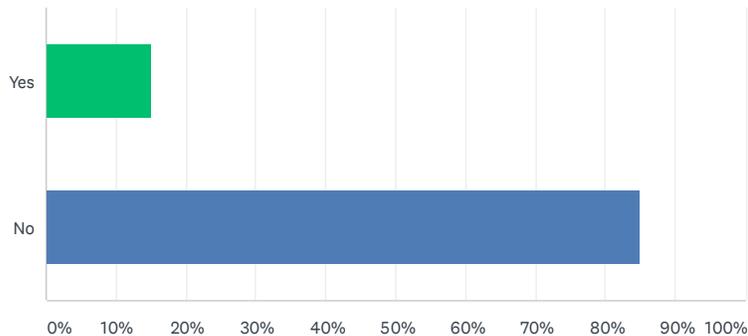
Answered: 52 Skipped: 33



ANSWER CHOICES	RESPONSES	
Yes	26.92%	14
No	23.08%	12
N/A	0.00%	0
Don't know	50.00%	26
TOTAL		52

Q24 Have you had to pay out of pocket for any of your drug therapies?

Answered: 53 Skipped: 32

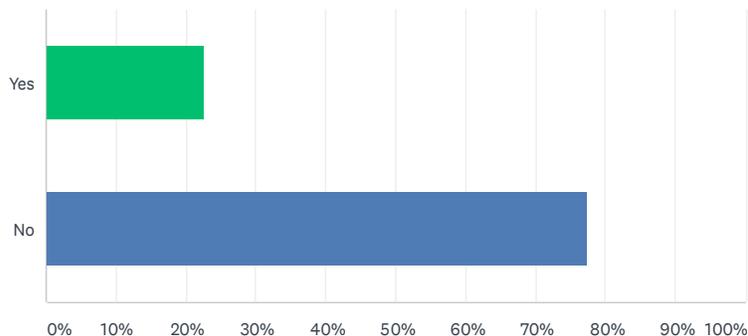


ANSWER CHOICES	RESPONSES	
Yes	15.09%	8
No	84.91%	45
TOTAL		53

#	IF YES, FOR WHICH THERAPIES AND WHAT WAS THE TOTAL COST TO YOU?	DATE
1	all went to Mayo Clinic for all therapy & surgeries	12/10/2020 10:51 AM
2	All	12/9/2020 4:44 PM
3	\$3000 upfront and had to wait for reimbursement	12/9/2020 2:18 PM
4	\$900 biweekly. Ended up having it covered by my drug plan after paying out of pocket.	12/9/2020 10:15 AM
5	Fertility (egg harvest) - \$5,000 to date Colonoscopy prep kits - \$200 Parking - \$500	12/8/2020 10:40 PM
6	Medications to relief nauseau. Injections for low blood count Accupunture for neuropathy	12/8/2020 9:25 PM

Q25 Did you receive any financial assistance from a pharmaceutical/biotech company assistance program or any other assistance program for therapies accessed?

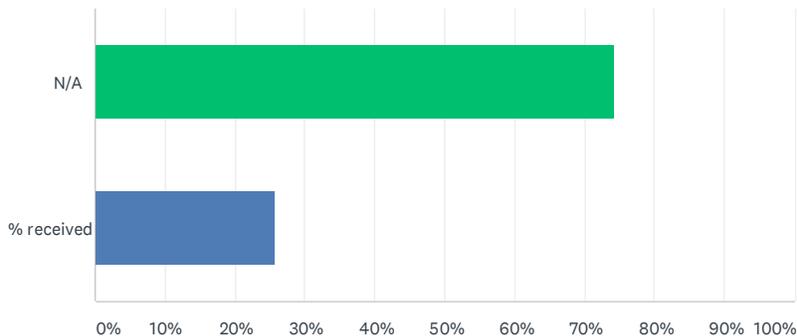
Answered: 53 Skipped: 32



ANSWER CHOICES	RESPONSES	
Yes	22.64%	12
No	77.36%	41
TOTAL		53

Q26 If you did receive financial assistance, what percentage of the total cost of the treatment was covered? Please indicate below.

Answered: 39 Skipped: 46

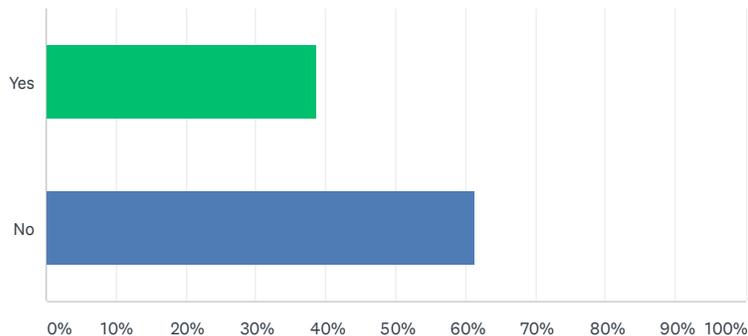


ANSWER CHOICES	RESPONSES
N/A	74.36% 29
% received	25.64% 10
TOTAL	39

#	% RECEIVED	DATE
1	100	12/18/2020 12:03 PM
2	80% private insurance, 20% drug company support	12/14/2020 11:26 AM
3	90	12/9/2020 10:45 PM
4	40%	12/9/2020 4:44 PM
5	10%	12/9/2020 2:18 PM
6	95+	12/9/2020 10:43 AM
7	75%	12/8/2020 10:40 PM
8	100%	12/8/2020 7:44 PM
9	100% for the Immunotherapy Trial	12/8/2020 1:07 PM
10	50	12/7/2020 12:26 PM

Q27 In addition to the drug cost, were there other costs incurred by you in accessing the drugs, such as travel costs, drug administration, etc.?

Answered: 49 Skipped: 36

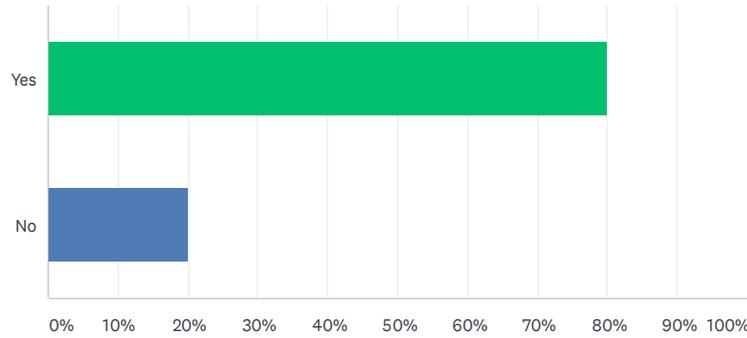


ANSWER CHOICES	RESPONSES	
Yes	38.78%	19
No	61.22%	30
TOTAL		49

#	IF YES, PLEASE LIST THEM BELOW.	DATE
1	Gas 152 km round trip, parking	12/23/2020 12:12 PM
2	Travel costs, parking	12/20/2020 3:37 PM
3	Parking costs, travel costs, some drug fees	12/15/2020 4:22 PM
4	travel accommodation medication surgery professional - time with physician and paid for all tests - scans MRI etc.	12/10/2020 10:51 AM
5	I believe we paid the administrative drug costs.	12/9/2020 10:45 PM
6	Parking, \$300	12/9/2020 4:44 PM
7	Travel 65kilos every week for 6.yrs	12/9/2020 2:18 PM
8	Travel costs	12/9/2020 11:13 AM
9	Taxis service and parking fees	12/8/2020 1:07 PM
10	Parking costs	12/8/2020 11:32 AM
11	Travel	12/7/2020 5:05 PM
12	do not know but did cause serious financial harm, part due to my health plan from work (I was retired) and of course a very big thanks to OHIP	12/7/2020 4:53 PM
13	Stoma products and parking	12/7/2020 4:28 PM
14	parking, some devices,bidet,external creams	12/7/2020 3:20 PM
15	parking	12/7/2020 8:02 AM
16	Hospital	12/6/2020 9:44 PM
17	Hospital parking	12/6/2020 7:06 PM
18	550km round trip for treatment, scans, surgeries etc.	12/6/2020 5:55 PM

Q28 Would you be willing to pay out of pocket to access new drug therapies for the treatment of your stage IV colorectal cancer through a private clinic?

Answered: 50 Skipped: 35



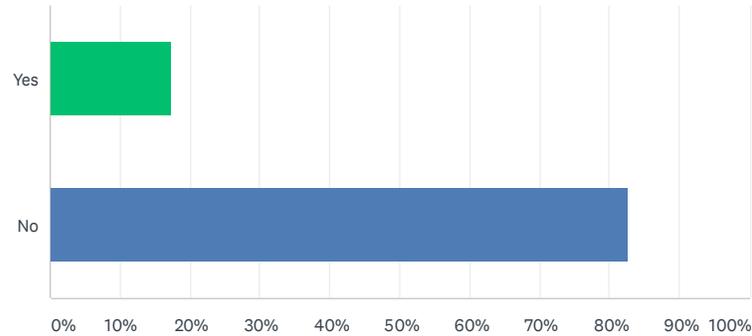
ANSWER CHOICES	RESPONSES	
Yes	80.00%	40
No	20.00%	10
TOTAL		50

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	WHY OR WHY NOT? PLEASE DESCRIBE BELOW.	DATE
1	Decision could be based on cost, efficacy/effectiveness of drugs, quality of life.	12/23/2020 12:12 PM
2	I don't wish to spend all the money I have and then die anyway at my age. Many people do that and leave their loved ones penniless .	12/20/2020 3:37 PM
3	Not financially feasible. I have a young family, mortgage, owner/operator (self employed).	12/18/2020 12:03 PM
4	It seems unfair that those who can pay will get priority access.	12/15/2020 4:22 PM
5	Yes, to a certain extent as far as how much per month. I don't want to put my family in financial jeopardy.	12/14/2020 11:26 AM
6	paying saved my life If I had stayed in Ontario I would have died	12/10/2020 10:51 AM
7	This is a difficult question. I think if I had no other option, I would, but if I could get it cheaper through a regular clinic, then I would go there.	12/9/2020 10:45 PM
8	But only if my insurance will cover it. Also I will pay depending on amount and whether it can be managed as an expense	12/9/2020 11:13 AM
9	I only have one life. If a drug therapy will give me the best health outcome but is not covered, I would do everything in my power to find a way to pay for it.	12/9/2020 10:43 AM
10	At stage IV I would be willing to try anything	12/8/2020 10:40 PM
11	Depends on the cost and if I can afford it but I want access to best and most effective treatment with the minimum side affects	12/8/2020 9:25 PM
12	Canada needs Private health care!	12/8/2020 9:15 PM
13	Will consider it if it will increase life span	12/8/2020 7:35 PM
14	Yes - I want to live a long life and I would do anything to stay alive. If that means accessing drugs in a clinic, then yes, I will pay out of pocket.	12/8/2020 6:46 PM
15	Yes, if it was the only way to treat my disease or/and to extend my life.	12/8/2020 1:07 PM
16	To get the best treatment available	12/8/2020 9:04 AM
17	If they are known to work	12/7/2020 6:10 PM
18	Not enough income	12/7/2020 5:05 PM
19	I feel that our government should have measures in place for this	12/7/2020 3:20 PM
20	Depends on how much it costs and how likely the treatment is to work.	12/7/2020 12:26 PM
21	yes, i fi can afford and it's not covered. but i would prefer if it was covered	12/7/2020 10:49 AM
22	I am willing to do a lot to save my life	12/7/2020 9:28 AM
23	I am willing to pay for the best treatments available.	12/7/2020 8:37 AM
24	I'm 38 years old and I am willing to do anything to live a full life. I am fortunate that I have family that will also pay for any treatment options for me.	12/7/2020 1:38 AM
25	New therapies are very expensive, only rich people can pay for them.	12/6/2020 11:53 PM
26	If it would help you survive you would pay	12/6/2020 9:44 PM
27	Because I want to save my life	12/6/2020 7:38 PM
28	To save my life	12/6/2020 7:10 PM
29	I am hoping that as a senior it would be part of my pension plan.	12/6/2020 7:06 PM
30	I would pending on drugs and cost. If its available through public funding, no. If its only available via private and have a good chance, yes.	12/6/2020 6:13 PM
31	I don't know how I would afford it. But if it enabled me to have a longer or better quality of life I don't feel like I would have a choice to say no.	12/6/2020 5:55 PM
32	because i would do anything to access a therapy that would regress my disease. it's a difficult choice to make but what other choice to i have.	12/4/2020 9:52 AM

Q29 Did you incur additional costs such as access to tumour genomic profiling (Next Generation Sequencing Testing) either within or outside of Canada?

Answered: 52 Skipped: 33

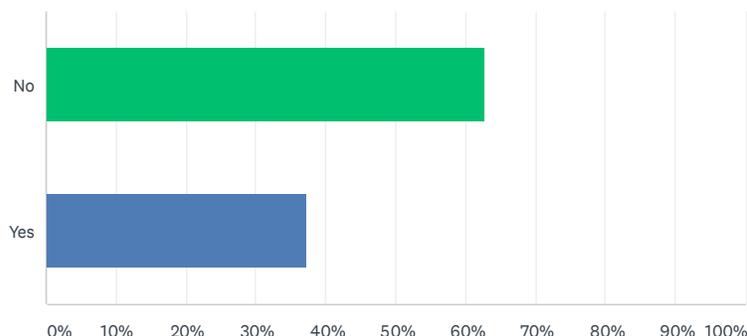


ANSWER CHOICES	RESPONSES	
Yes	17.31%	9
No	82.69%	43
TOTAL		52

#	IF YES, WHAT WAS THE COST INCURRED?	DATE
1	I don't remember the amount.	12/14/2020 11:26 AM
2	don't know my total bill at Mayo was about \$250.0K	12/10/2020 10:51 AM
3	Cost was \$4000, but I did not yet choose to follow through.	12/9/2020 11:13 AM
4	Genetic testing	12/8/2020 9:25 PM
5	8k	12/8/2020 9:15 PM
6	\$2625.00	12/8/2020 7:44 PM
7	\$3500	12/8/2020 6:46 PM
8	\$3,098.62	12/6/2020 6:13 PM
9	\$8200 foundation one in the U.S.	12/4/2020 9:52 AM

Q30 Do you believe that some of your needs are not being met by the current drugs accessible to treat your colorectal cancer? If so, what are these needs?

Answered: 51 Skipped: 34

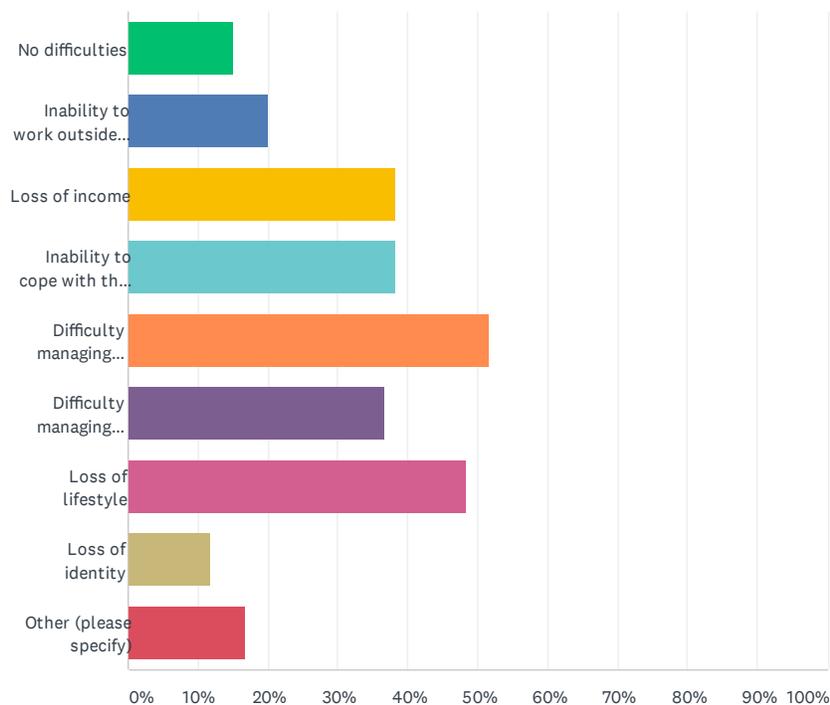


ANSWER CHOICES	RESPONSES	
No	62.75%	32
Yes	37.25%	19
TOTAL		51

#	IF YES, PLEASE LIST THESE NEEDS.	DATE
1	Keytruda (Pembro) has shrunk 4 of my tumors 50% or more (MSI - High) and if I didn't get on this clinical trial I likely would have only received Chemo (palliative chemotherapy) which would have done nothing for me but prolong the inevitable and cause me pain and discomfort. I can not afford to have this treatment (which works) due to the financial strains it would put on me and my family. I would not be able to endure another year of chemotherapy due to the financial, physical and emotional burden it put on me and my family.	12/18/2020 12:03 PM
2	Fulfox and fulfiri were not working for me so we had to get access to encorafenib and cetuximab.	12/14/2020 11:26 AM
3	I am unsure about the scope of availability.	12/9/2020 11:13 AM
4	Colorectal patients undergo a lot of issues going through chemo and side effects and there should be more treatments available	12/8/2020 9:25 PM
5	The drugs, treatments and whole approach to cancer in Canada is heartbreaking.	12/8/2020 9:15 PM
6	I was fortunate that the trial had opened up six months after I was first diagnosed. I might have had a negative outcome if the trial was not made available to me. We must have Immunotherapy available as standard care. Lapelga - Pegfilgrastim - low white Blood count- Should be covered	12/8/2020 1:07 PM
7	I would like more access to preventative measures for lynch syndrome	12/7/2020 2:28 PM
8	i wish there was a drug that would remove all cancer without having to go through surgery	12/7/2020 10:49 AM
9	access to other treatments/drugs that may help that are currently not available here	12/7/2020 8:02 AM
10	1. Need in imune therapy drugs to treat my condition. 2. Vitamins and minerals. 3. Avastin should be funded for second line treatment as well.	12/6/2020 11:53 PM
11	There is always new treatments and Canada seems way behind the US	12/6/2020 10:54 PM
12	Too many to list here.	12/6/2020 7:37 PM
13	I feel that there's more to offer but our oncologists hvsve their hands tied as they must adhere to BCCA guidelines.	12/6/2020 6:13 PM
14	My largest concern comes to the point in the future of possibly rechallenging a previous treatment and not having it be covered.	12/6/2020 5:55 PM
15	We need to address MSS disease that currently has no therapeutic options once standard of care therapies have been exhausted. what do patients do then?	12/4/2020 9:52 AM

Q31 About your family or caregiver’s experience with colorectal cancer treatments: What difficulties do caregivers face in caring for patients with colorectal cancer? Please select your top 3 difficulties from the list below.

Answered: 60 Skipped: 25



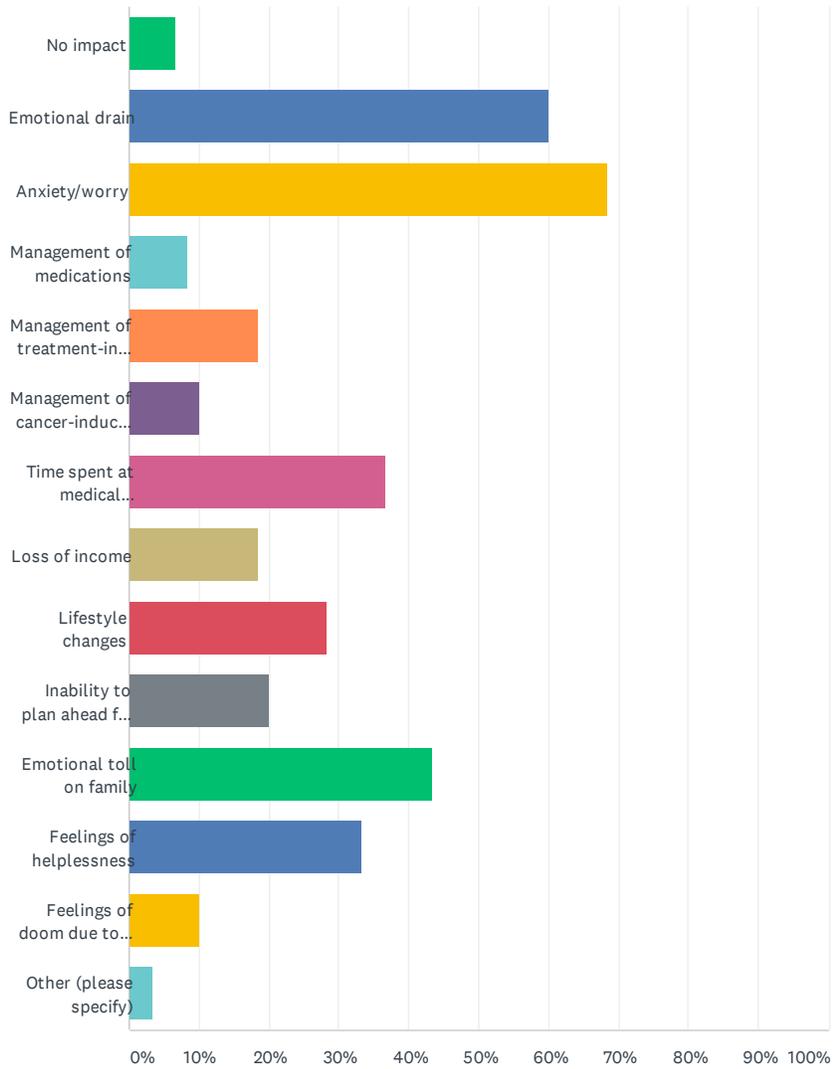
ANSWER CHOICES	RESPONSES	
No difficulties	15.00%	9
Inability to work outside of the home	20.00%	12
Loss of income	38.33%	23
Inability to cope with the diagnosis	38.33%	23
Difficulty managing treatment-induced side effects	51.67%	31
Difficulty managing cancer-induced symptoms	36.67%	22
Loss of lifestyle	48.33%	29
Loss of identity	11.67%	7
Other (please specify)	16.67%	10
Total Respondents: 60		

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	OTHER (PLEASE SPECIFY)	DATE
1	Challenge working and looking after family.	12/14/2020 11:26 AM
2	life is on hold difficult to carry on emotionally	12/10/2020 10:53 AM
3	Dietary changes, dealing with diagnosis given no family history of it.	12/9/2020 11:49 AM
4	Dealing with vivid restrictions	12/9/2020 10:35 AM
5	Dealing with uncertainty waiting for surgery dates. Fear of what the future holds.	12/9/2020 10:17 AM
6	Rarely had caregiver help	12/7/2020 5:11 PM
7	Lets face it caregiving is big inconvenience, and of course caregiver can not work outside the home as usual , loss of income	12/7/2020 5:03 PM
8	Planning to be a single parent.	12/7/2020 1:40 AM
9	Stress and having to cover off my home and business duties for me	12/6/2020 11:00 PM
10	Wondering if my son will survive. Watching him being so sick is unbelievably hard to watch and desk with 24/7.	12/6/2020 8:37 PM

Q32 How have treatments impacted the caregiver’s daily routine or lifestyle? Please select your top 3 from the list below.

Answered: 60 Skipped: 25



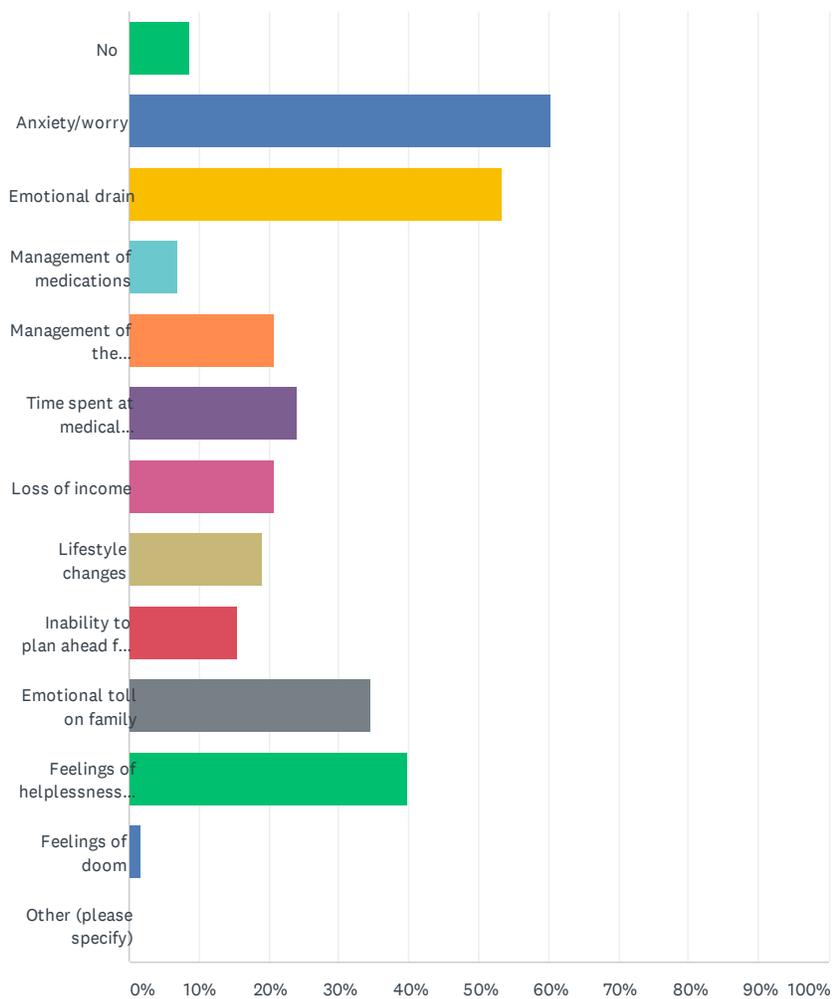
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

ANSWER CHOICES	RESPONSES
No impact	6.67% 4
Emotional drain	60.00% 36
Anxiety/worry	68.33% 41
Management of medications	8.33% 5
Management of treatment-induced side effects	18.33% 11
Management of cancer-induced symptoms	10.00% 6
Time spent at medical appointments	36.67% 22
Loss of income	18.33% 11
Lifestyle changes	28.33% 17
Inability to plan ahead for future	20.00% 12
Emotional toll on family	43.33% 26
Feelings of helplessness	33.33% 20
Feelings of doom due to challenging prognosis	10.00% 6
Other (please specify)	3.33% 2
Total Respondents: 60	

#	OTHER (PLEASE SPECIFY)	DATE
1	Only when I was hospitalized with an infection and chemo side effects were there feelings of helplessness for my husband.	12/9/2020 10:57 PM
2	Coping with dietary changes	12/9/2020 11:49 AM

Q33 Are there challenges for the caregiver in dealing with treatment-induced side effects? If yes, please select from the list below (maximum of 3).

Answered: 58 Skipped: 27



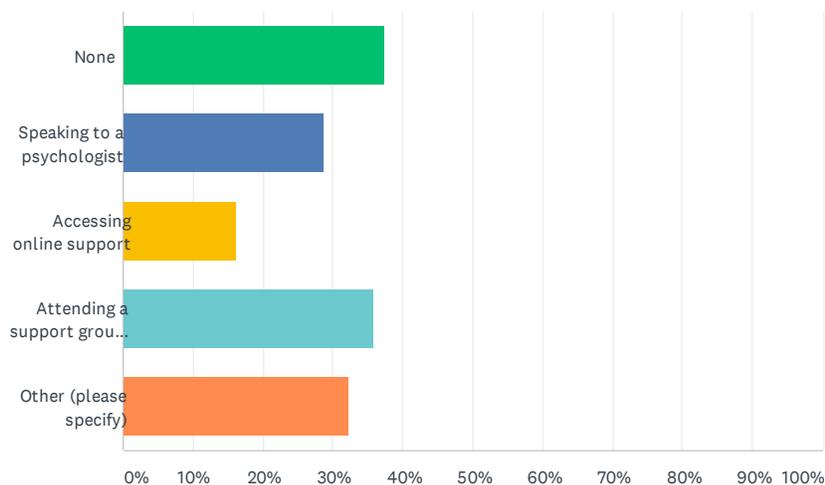
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

ANSWER CHOICES	RESPONSES	
No	8.62%	5
Anxiety/worry	60.34%	35
Emotional drain	53.45%	31
Management of medications	6.90%	4
Management of the treatment-induced side effects	20.69%	12
Time spent at medical appointments	24.14%	14
Loss of income	20.69%	12
Lifestyle changes	18.97%	11
Inability to plan ahead for future	15.52%	9
Emotional toll on family	34.48%	20
Feelings of helplessness because I cannot help my loved one feel better	39.66%	23
Feelings of doom	1.72%	1
Other (please specify)	0.00%	0
Total Respondents: 58		

#	OTHER (PLEASE SPECIFY)	DATE
	There are no responses.	

Q34 If the caregiver does face challenges in dealing with treatment-induced side effects, what resources were accessed to help deal with those challenges? Please select all that apply from the list below.

Answered: 56 Skipped: 29

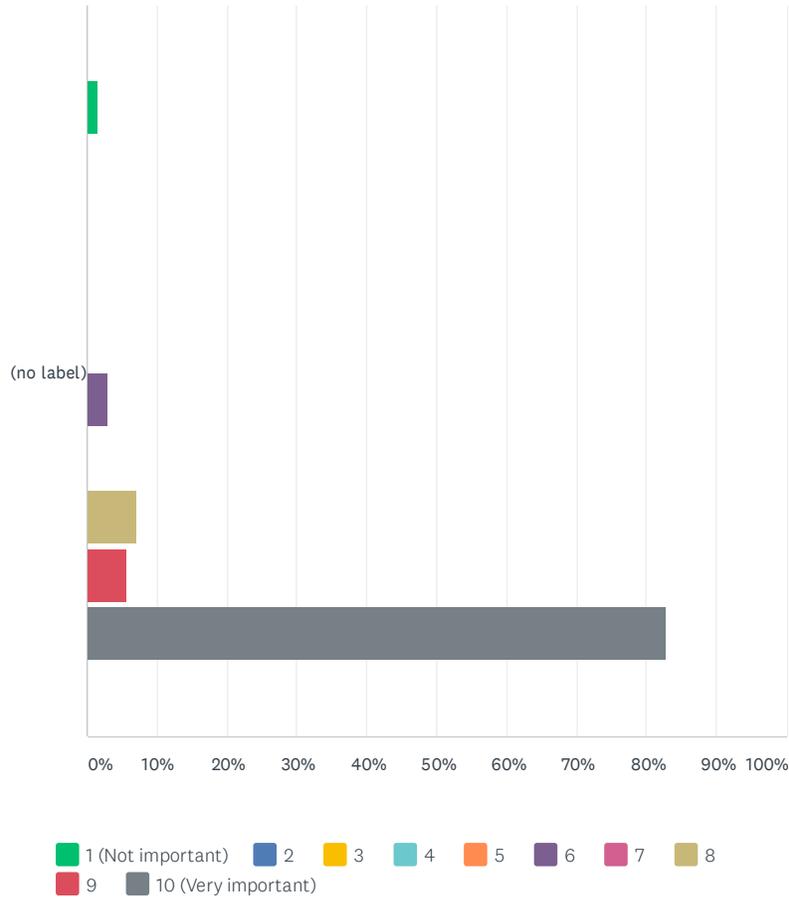


ANSWER CHOICES	RESPONSES
None	37.50% 21
Speaking to a psychologist	28.57% 16
Accessing online support	16.07% 9
Attending a support group (please specify which group below)	35.71% 20
Other (please specify)	32.14% 18
Total Respondents: 56	

#	OTHER (PLEASE SPECIFY)	DATE
1	CCRAN	12/15/2020 4:23 PM
2	Collaborated with specialists (oncologist and palliative care physician)	12/14/2020 11:26 AM
3	praying	12/11/2020 1:50 PM
4	N/A	12/10/2020 8:52 PM
5	family & friends	12/10/2020 10:53 AM
6	CCAC meetings	12/9/2020 10:57 PM
7	CCRAN	12/9/2020 10:45 AM
8	Especially with care of young children we had no support	12/8/2020 9:28 PM
9	Colorectal Cancer Resource & Action Network	12/8/2020 8:57 PM
10	Researching alternative and conventional therapies to help minimize or control the ever changing treatment induced side effects.	12/8/2020 8:08 PM
11	CCRAN	12/8/2020 7:57 PM
12	CCRAN.	12/8/2020 7:37 PM
13	Ottawa Colorectal Cancer Support Group	12/8/2020 11:16 AM
14	ccran	12/7/2020 9:37 AM
15	CCRAN	12/7/2020 9:31 AM
16	Meditation	12/6/2020 11:56 PM
17	Family support with several health and mental health specialists in family	12/6/2020 11:00 PM
18	Colorectal Cancer Resource & Action Network was very helpful	12/4/2020 9:55 AM

Q35 On a scale of 1-10, with 1 being “not important” and 10 being “very important,” if you were to consider taking a new therapy for your cancer, how important is it for you that new therapies bring about improvement in your physical condition? For example: Tumour shrinkage, tumour stability, reduction of pain, improved breathing?

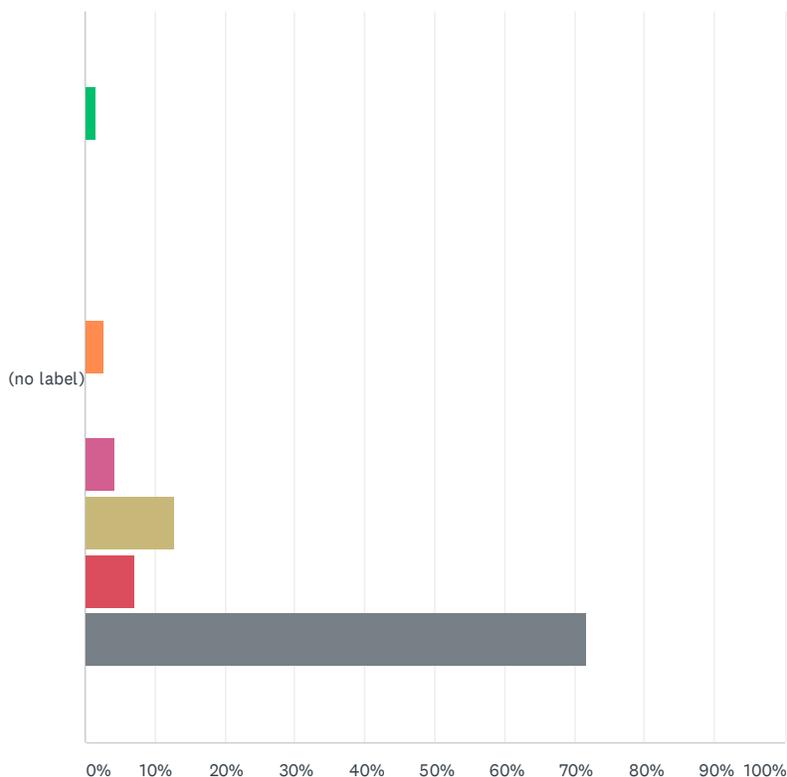
Answered: 70 Skipped: 15



	1 (NOT IMPORTANT)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT)	TOTAL	WEIGHTED AVERAGE
(no label)	1.43%	0.00%	0.00%	0.00%	0.00%	2.86%	0.00%	7.14%	5.71%	82.86%	70	9.56
	1	0	0	0	0	2	0	5	4	58		

Q36 On a scale of 1-10, with 1 being “not important” and 10 being “very important,” if you were to consider taking a new therapy for your cancer, how important is it for you that new therapies bring about improvement in your quality of life? For example: Improved mobility, sense of wellness, relief from side effects?

Answered: 71 Skipped: 14

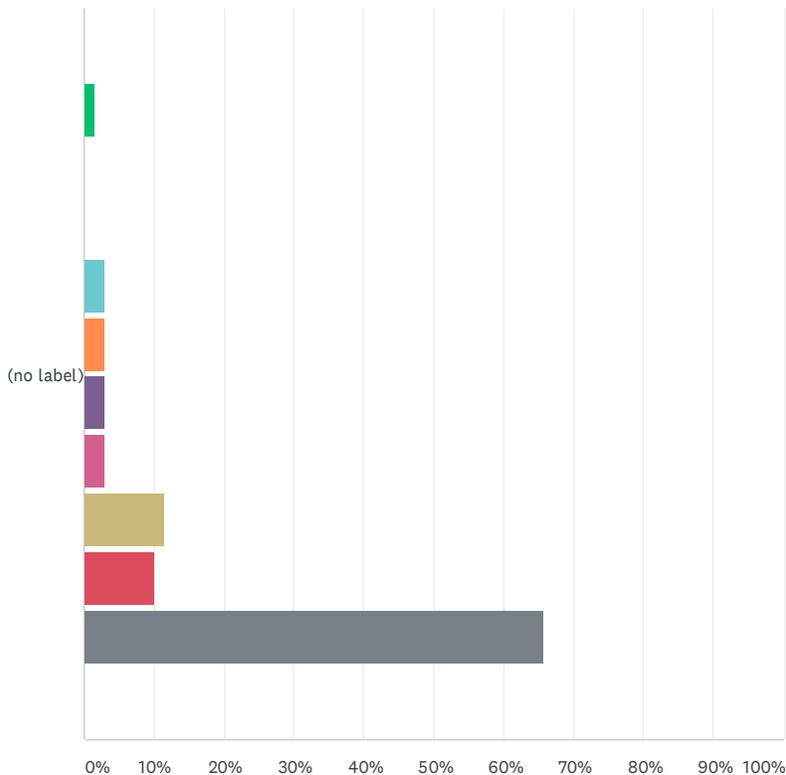


■ 1 (Not important)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Very important)

	1 (NOT IMPORTANT)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT)	TOTAL	WEIGHTED AVERAGE
(no label)	1.41%	0.00%	0.00%	0.00%	2.82%	0.00%	4.23%	12.68%	7.04%	71.83%	71	9.28
	1	0	0	0	2	0	3	9	5	51		

Q37 On a scale of 1-10, with 1 being “not important” and 10 being “very important,” if you were to consider taking a new therapy for your cancer, how important is it for you that you understand the average (or median) period of expected benefit from that new therapy? For example: Would you want to know the progression free survival period (time it takes before the disease gets worse) and overall survival benefit?

Answered: 70 Skipped: 15

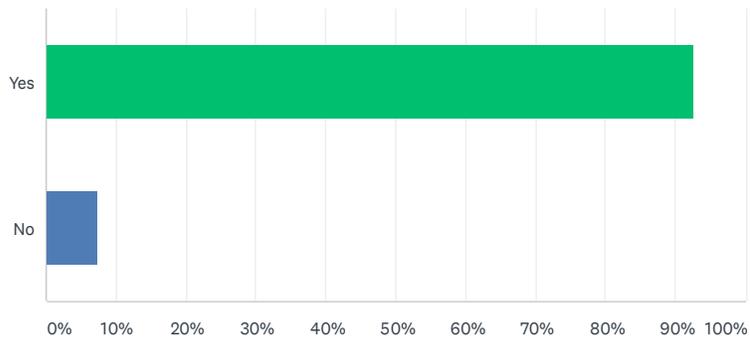


■ 1 (Not important)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Very important)

	1 (NOT IMPORTANT)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT)	TOTAL	WEIGHTED AVERAGE
(no label)	1.43%	0.00%	0.00%	2.86%	2.86%	2.86%	2.86%	11.43%	10.00%	65.71%	70	9.03
	1	0	0	2	2	2	2	8	7	46		

Q38 Would you take a drug that has been proven to provide better quality of life during your lifetime even if it does not extend survival?

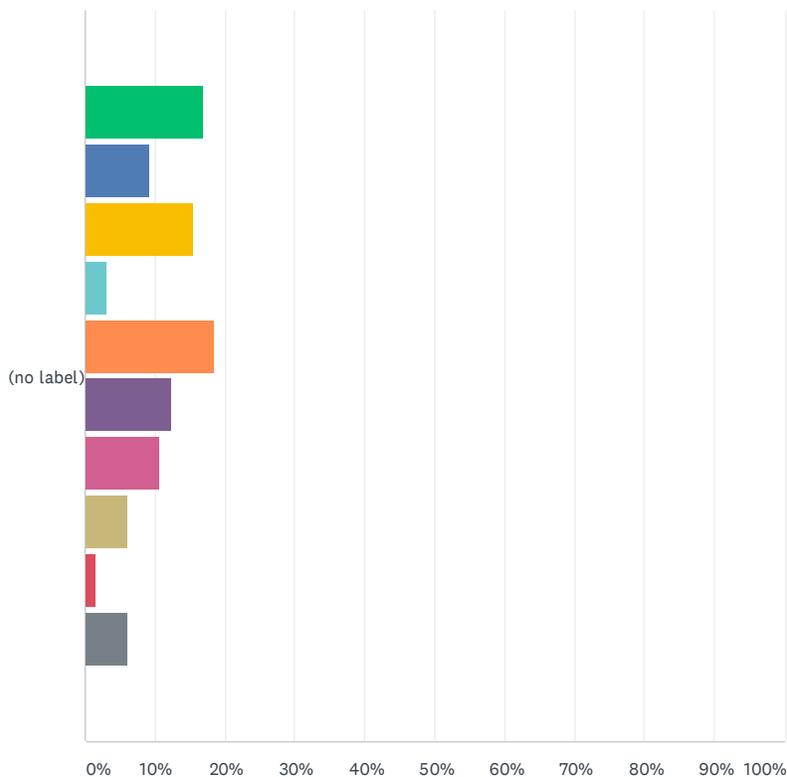
Answered: 69 Skipped: 16



ANSWER CHOICES	RESPONSES	
Yes	92.75%	64
No	7.25%	5
TOTAL		69

Q39 On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects,” if you were to consider taking a new therapy for your metastatic (stage IV) cancer in 3rd or 4th line therapy, what severity of side effects would you be willing to tolerate in order to extend survival by 2 months, after having been told there is no other available treatment? For example, side effects such as nausea, fatigue, vomiting, diarrhea.

Answered: 65 Skipped: 20

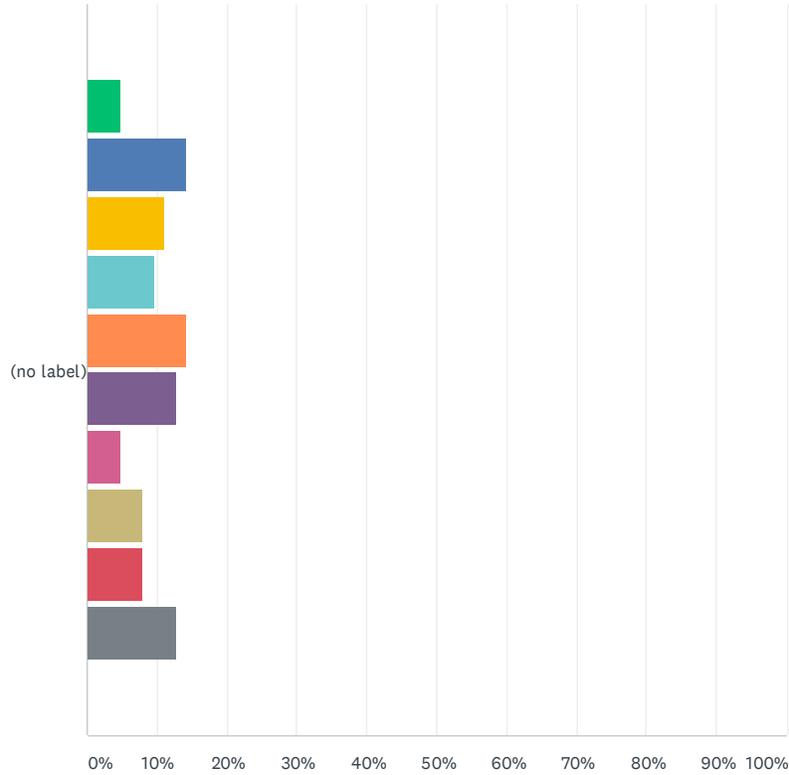


■ 1 (No side effects)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Significant side effects)

	1 (NO SIDE EFFECTS)	2	3	4	5	6	7	8	9	10 (SIGNIFICANT SIDE EFFECTS)	TOTAL	WEIGHTED AVERAGE
(no label)	16.92% 11	9.23% 6	15.38% 10	3.08% 2	18.46% 12	12.31% 8	10.77% 7	6.15% 4	1.54% 1	6.15% 4	65	4.60

Q40 On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects,” if you were to consider taking a new therapy for your metastatic (stage IV) cancer in 3rd or 4th line therapy, what severity of side effects would you be willing to tolerate in order to extend survival by 6 months, after having been told there is no other available treatment? For example, side effects such as nausea, fatigue, vomiting, diarrhea.

Answered: 63 Skipped: 22

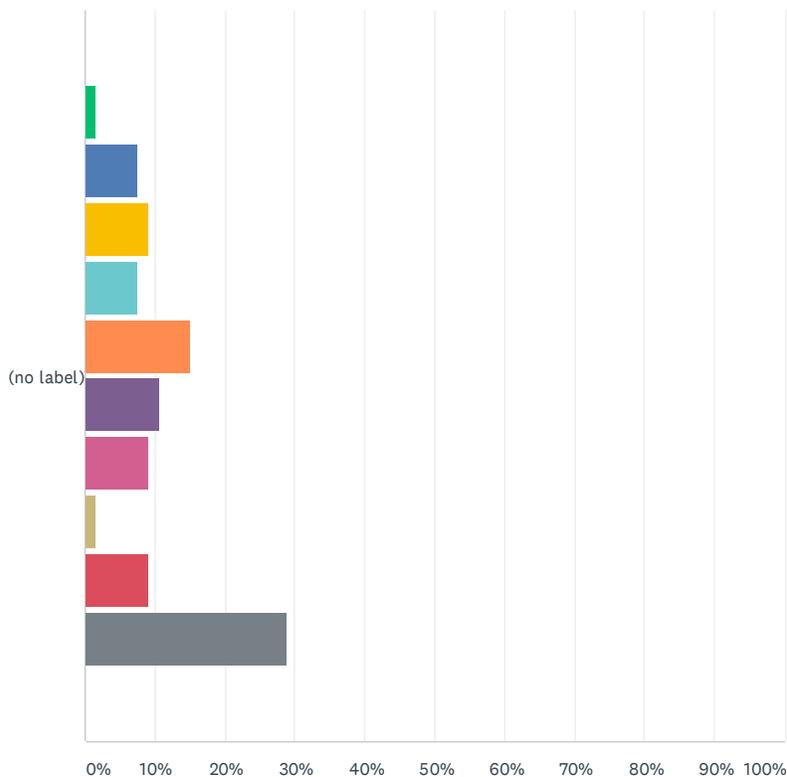


■ 1 (No side effects)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Significant side effects)

	1 (NO SIDE EFFECTS)	2	3	4	5	6	7	8	9	10 (SIGNIFICANT SIDE EFFECTS)	TOTAL	WEIGHTED AVERAGE
(no label)	4.76% 3	14.29% 9	11.11% 7	9.52% 6	14.29% 9	12.70% 8	4.76% 3	7.94% 5	7.94% 5	12.70% 8	63	5.48

Q41 On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects,” if you were to consider taking a new therapy for your metastatic (stage IV) cancer, what severity of side effects would you be willing to tolerate in order to extend survival by 1 year, after having been told there is no other available treatment? For example, side effects such as nausea, fatigue, vomiting, diarrhea.

Answered: 66 Skipped: 19

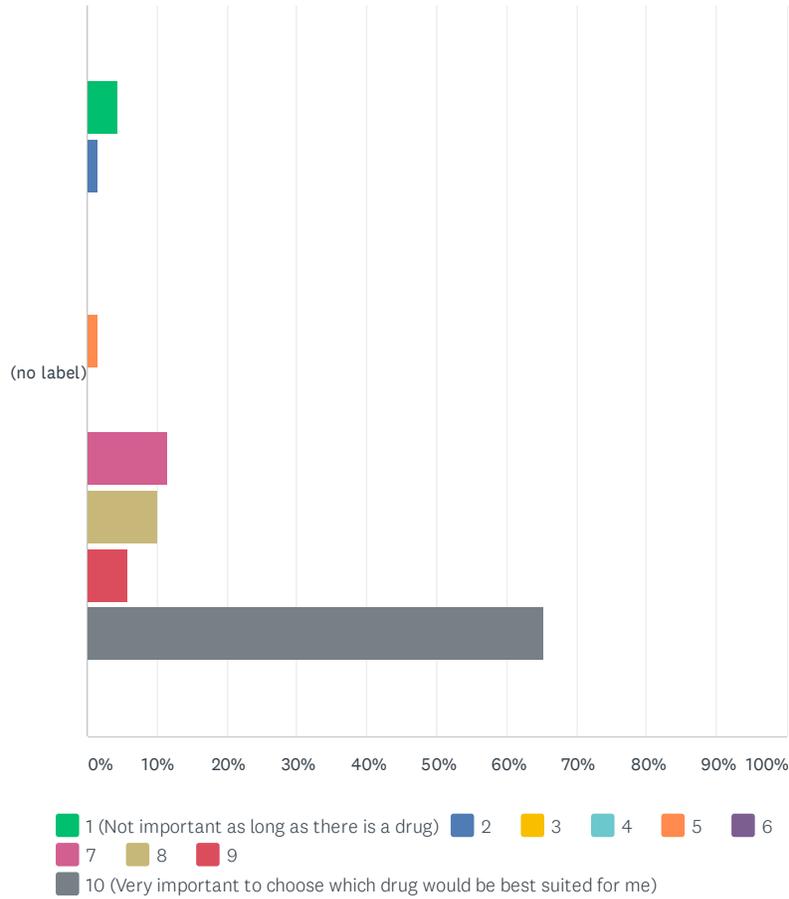


■ 1 (No side effects)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Significant side effects)

	1 (NO SIDE EFFECTS)	2	3	4	5	6	7	8	9	10 (SIGNIFICANT SIDE EFFECTS)	TOTAL	WEIGHTED AVERAGE
(no label)	1.52%	7.58%	9.09%	7.58%	15.15%	10.61%	9.09%	1.52%	9.09%	28.79%	66	6.59
	1	5	6	5	10	7	6	1	6	19		

Q42 On a scale of 1-10, with 1 being “not important as long as there is a drug” and 10 being “very important to choose which drug would be best suited for me,” if you were to consider taking a new therapy for your cancer, how important would it be for you and your physician to have a choice in deciding which drug to take?

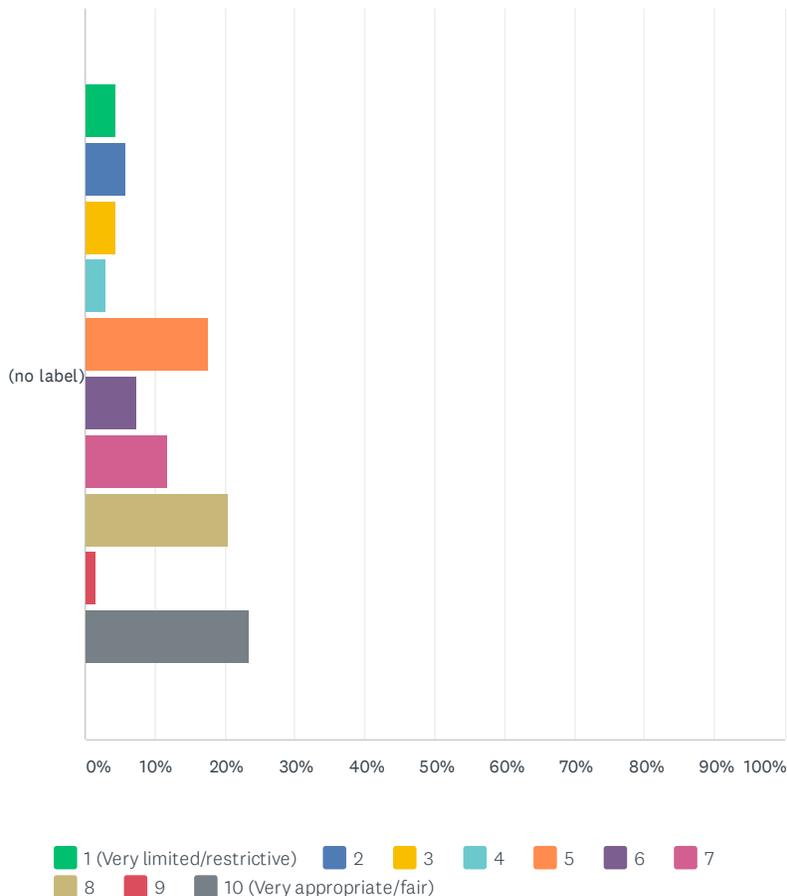
Answered: 69 Skipped: 16



	1 (NOT IMPORTANT AS LONG AS THERE IS A DRUG)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT TO CHOOSE WHICH DRUG WOULD BE BEST SUITED FOR ME)	TOTAL	WEIGHTED AVERAGE
(no label)	4.35%	1.45%	0.00%	0.00%	1.45%	0.00%	11.59%	10.14%	5.80%	65.22%	69	8.81
	3	1	0	0	1	0	8	7	4	45		

Q43 On a scale of 1-10, with 1 being “very limited/restrictive” and 10 being “very appropriate/fair,” to ensure the best outcome for your cancer, would you say that access to relevant drug therapies in your province (state)/country is limited/restrictive or is it appropriate/fair?

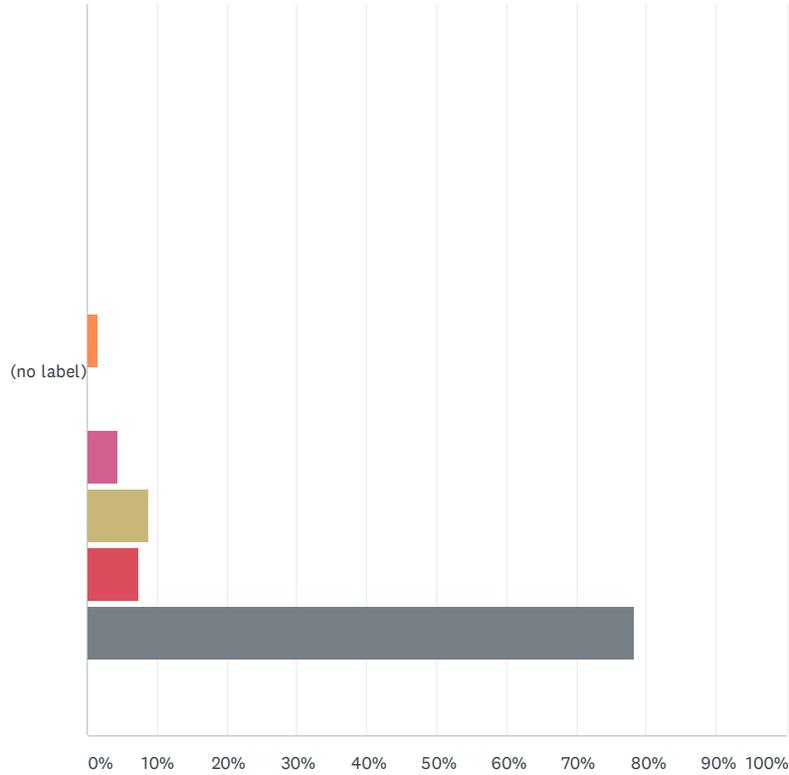
Answered: 68 Skipped: 17



	1 (VERY LIMITED/RESTRICTIVE)	2	3	4	5	6	7	8	9	10 (VERY APPROPRIATE/FAIR)	TOTAL
(no label)	4.41%	5.88%	4.41%	2.94%	17.65%	7.35%	11.76%	20.59%	1.47%	23.53%	
	3	4	3	2	12	5	8	14	1	16	68

Q44 On a scale of 1-10, with 1 being “not important” and 10 being “very important,” if your government or funder (such as insurance company, hospital or other funder) was to fund a minimum of two therapies for the treatment of your colorectal cancer, how important would it be for you that your oncologist have flexibility in deciding which of those therapies to choose?

Answered: 69 Skipped: 16

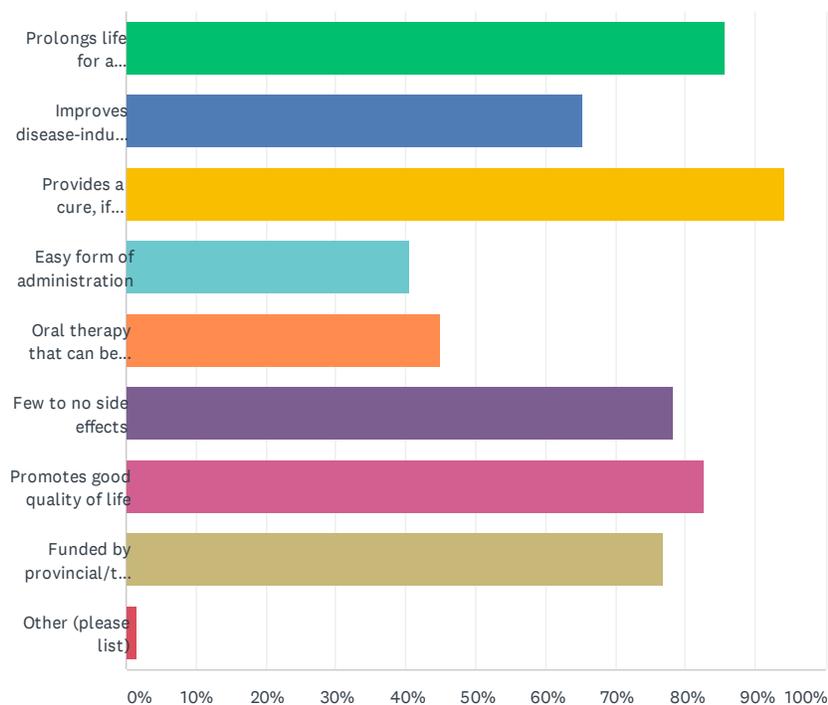


■ 1 (Not important)
 ■ 2
 ■ 3
 ■ 4
 ■ 5
 ■ 6
 ■ 7
 ■ 8
 ■ 9
 ■ 10 (Very important)

	1 (NOT IMPORTANT)	2	3	4	5	6	7	8	9	10 (VERY IMPORTANT)	TOTAL	WEIGHTED AVERAGE
(no label)	0.00%	0.00%	0.00%	0.00%	1.45%	0.00%	4.35%	8.70%	7.25%	78.26%	69	9.55
	0	0	0	0	1	0	3	6	5	54		

Q45 What improvements would you like to see overall in a drug therapy that are not available currently in other therapies for the treatment of metastatic colorectal cancer? Please select all that apply.

Answered: 69 Skipped: 16

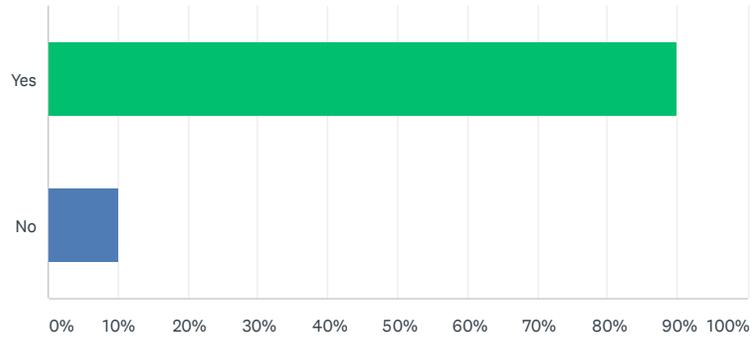


ANSWER CHOICES	RESPONSES	
Prolongs life for a substantial amount of time	85.51%	59
Improves disease-induced symptoms	65.22%	45
Provides a cure, if possible	94.20%	65
Easy form of administration	40.58%	28
Oral therapy that can be taken at home	44.93%	31
Few to no side effects	78.26%	54
Promotes good quality of life	82.61%	57
Funded by provincial/territorial health care plan	76.81%	53
Other (please list)	1.45%	1
Total Respondents: 69		

#	OTHER (PLEASE LIST)	DATE
1	Manageable side effects	12/11/2020 12:36 PM

Q46 Did you seek out information on colorectal cancer?

Answered: 69 Skipped: 16



ANSWER CHOICES	RESPONSES	
Yes	89.86%	62
No	10.14%	7
TOTAL		69

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	IF SO, FROM WHERE?	DATE
1	CCRAN, websites CCC, American ie Hospitals, Mayo clinic	12/23/2020 12:36 PM
2	Physicians	12/20/2020 3:52 PM
3	CCRAN CCC	12/18/2020 12:36 PM
4	Online, associations	12/15/2020 4:26 PM
5	Google, ccca	12/15/2020 4:10 PM
6	everywhere	12/11/2020 1:55 PM
7	Doctors, various websites in Canada and the US	12/11/2020 12:43 PM
8	from the Cancer Institute and on line	12/10/2020 8:58 PM
9	Colorectal Cancer Ass Internet Physician	12/10/2020 10:58 AM
10	CCRAN,	12/9/2020 11:23 PM
11	Hospital and online resources. Patient support groups	12/9/2020 11:59 AM
12	CCRAN, Canadian Cancer Society	12/9/2020 10:52 AM
13	The internet and various online groups	12/8/2020 10:50 PM
14	Internet	12/8/2020 9:34 PM
15	Internet and CCRAN	12/8/2020 9:22 PM
16	CCRAN, internet, doctors, hospital, friends, books, naturopath,	12/8/2020 9:05 PM
17	Internet	12/8/2020 8:13 PM
18	CCRAN	12/8/2020 8:06 PM
19	CCRAN and Wellspring	12/8/2020 8:03 PM
20	Internet.	12/8/2020 7:43 PM
21	Yes and I was directed to CCRAN. It made a world of difference in my journey. PRICELESS support and information.	12/8/2020 1:45 PM
22	Online groups and organizations	12/8/2020 12:30 PM
23	Internet	12/8/2020 11:39 AM
24	Ottawa Colorectal Cancer Support Group	12/8/2020 11:26 AM
25	Hospital, internet	12/8/2020 9:14 AM
26	Support groups Internet	12/7/2020 5:19 PM
27	Medical journals	12/7/2020 5:11 PM
28	Doctors, nurses fellow cancer survivors	12/7/2020 5:05 PM
29	Books, libraries , support groups	12/7/2020 4:37 PM
30	Everywhere I could read.	12/7/2020 2:32 PM
31	websites, cancer society, wellspring, gilda's club, ccran	12/7/2020 10:52 AM
32	CCRAN	12/7/2020 9:35 AM
33	Internet	12/7/2020 8:43 AM
34	Internet before dignosis. CCRAN after diagnosis and more internet	12/7/2020 8:19 AM
35	CCRAN	12/7/2020 8:10 AM
36	Colontown, BC cancer	12/7/2020 1:49 AM
37	Internet	12/7/2020 12:17 AM
38	Online	12/6/2020 11:05 PM
39	canadian cancer society.....and ccran	12/6/2020 9:51 PM
40	CCRAN	12/6/2020 9:49 PM
41	Support groups Research papers Crc conferences and webinars	12/6/2020 9:38 PM
42	Colontown Google	12/6/2020 7:49 PM
43	Ccc and ccran. Facebook groups as well.	12/6/2020 7:41 PM
44	Reputable internet sources, support group	12/6/2020 7:19 PM
45	Google My oncologist/surgeon Facebook support groups	12/6/2020 6:29 PM
46	Internet, CCRAN.	12/6/2020 6:18 PM

Patient & Caregiver Perspective Survey - Colorectal Cancer Resource & Action Network (CCRAN)

47	From CCRAN	12/6/2020 5:56 PM
48	CCRAN	12/4/2020 10:00 AM

Q47 Would you like to tell us why it is important to you that Pembrolizumab or Encorafenib + Cetuximab be funded for metastatic colorectal cancer patients?

Answered: 43 Skipped: 42

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	RESPONSES	DATE
1	Feel all patients should have available to them any drug approved that would benefit overall health & quality of life	12/23/2020 12:36 PM
2	Any drug that helps with living longer with cancer I support.	12/20/2020 3:52 PM
3	I am LIVING proof that Pembro works. My cancer does not respond to chemotherapy and that is a fact. My results, like many, are the answers to questions that need not be answered anymore. If I had access to this therapy as my first choice it would have been a no contest Chemotherapy was the worst time of my life, and Keytruda has been a walk in the park in comparison. What bothers me is that this was available when I was diagnosed and I had no knowledge of it. Now i advocate for this therapy and hope it gets funded for the young and old alike that are diagnosed with MSI High Colorectal Cancer.	12/18/2020 12:36 PM
4	I am not familiar	12/15/2020 4:26 PM
5	Because it has been a huge improvement in life. On the encorafenib and cetuximab I don't have any days that I feel 'bad'. When taking fulfox and fulfiri I would be feeling bad for a week, and then another few days to feel in good health, which only allowed me a few days every 2 weeks to do what I love with my family.	12/14/2020 11:26 AM
6	If these interventions help this group of patients, e.g., offering potential cure , extending life, improving quality of life, then these drugs ought to be available to patients and funded by the government.	12/11/2020 12:43 PM
7	to reduce financial burden	12/10/2020 8:58 PM
8	anything that can help is important	12/10/2020 10:58 AM
9	Any treatment that can help with the treatment of cancer and not overwhelm financially would be a blessing.	12/9/2020 11:23 PM
10	Prolong better quality of life	12/9/2020 2:26 PM
11	With all that is going on, I don't want to have to worry about funding	12/9/2020 11:59 AM
12	All effective drug therapies should Be funded so physicians can tailor drug selection to an individual patient's situation.	12/9/2020 10:52 AM
13	N/a	12/9/2020 10:44 AM
14	To have options	12/8/2020 9:34 PM
15	Because it's the right thing to do	12/8/2020 9:20 PM
16	For those of us who's cancer is "wild type" our options for lines of treatment are severely limited.	12/8/2020 8:05 PM
17	To save on out of pocket expenses especially for retirees.	12/8/2020 8:03 PM
18	If this will improve the quality of life, it will be worth to try.	12/8/2020 7:40 PM
19	To provide patients with additional treatment to prolong survival	12/8/2020 6:51 PM
20	Pembrolizumab SAVED MY LIFE! I want this drug to be made available to all candidates are no cost.	12/8/2020 1:45 PM
21	It has proven to have excellent efficacy in treating my wife's disease	12/8/2020 12:30 PM
22	So everyone get the best treatment regardless of income	12/8/2020 9:14 AM
23	It is the best known treatment for now.	12/7/2020 5:11 PM
24	any option that may extend life for the patient is worth it	12/7/2020 3:29 PM
25	I do not know anything about these medications	12/7/2020 10:52 AM
26	We need all of the options available to treat metastatic colon cancer	12/7/2020 9:35 AM
27	It is important that we have more choices of therapies.	12/7/2020 8:43 AM
28	n/a	12/7/2020 8:19 AM
29	Help prolong life	12/7/2020 8:10 AM
30	These drugs exist and have helped patients. They should be available in Canada.	12/7/2020 1:49 AM
31	Because, there was only chemotherapy available for decades with very limited success and a lot of side effects and now with immune therapies we get new hope!! Also it is very sad to see oncologist with very few drugs available to them with which they are trying to treat all the colorectal cancer patients. Not being able to be a full fledged professionals.	12/7/2020 12:17 AM
32	It provides choices and options	12/6/2020 11:05 PM
33	it should be funded.....access should be universal...to all in need	12/6/2020 9:51 PM
34	Keytruda has been extremely effective in stage 4 crc patients. Providing access to these new medications give hope to individuals who may be running out of options.	12/6/2020 9:38 PM
35	We are poor and I can't work either due to age and a disability	12/6/2020 8:43 PM

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

36	Better options for survival	12/6/2020 7:49 PM
37	No one should have to face burden of cost.	12/6/2020 7:41 PM
38	not sure ,would have to see the research.	12/6/2020 7:29 PM
39	Any new and effective treatment should be made available to all colorectal cancer patients regardless of income.	12/6/2020 7:19 PM
40	I think none of us should have to pay for any treatments as its not our fault we were diagnosed with cancer. Most of us may be financially strapped as it is prior to treatments due to not being able to work etc	12/6/2020 6:29 PM
41	It provides alternatives of treatment for patients and less financial burden.	12/6/2020 6:18 PM
42	Since already heaving it I could get it again. If so the drug is not always affordable for many especially those retired.	12/6/2020 5:56 PM
43	These are patients who need these therapies in order to regress their disease. without it, they will not fare well. please fund these therapies for patients who will not otherwise respond to other therapies.	12/4/2020 10:00 AM

Q48 Can you tell us about your personal story and why access to future therapies is so important to you?

Answered: 42 Skipped: 43

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

#	RESPONSES	DATE
1	I am a healthy cancer patient who loves life, my husband, family, and friends. So much more to do & enjoy.	12/23/2020 12:36 PM
2	I am 31 now I was diagnosed at 29 years old, 2 months after getting married. I have 2 beautiful girls, a dog, a small business and everything I need in life. I've spent most of my days wondering how much time is left since my cancer returned. When I found out all that "they" could do for me was give me palliative chemotherapy I refused to put my family through everything we just battled through, and the hardest thing to do is to accept the inevitability of death at this point in my life. I decided to advocate for myself and contact research centres through the world (during COVID) when I found out about keytruda. It was not an option here as I could not afford to have this therapy in Ontario due to the fact that I had a cancer that was not funded for the treatment. Seemed a little ridiculous that cancer had a different budget throughout the body or else I would have told it to move somewhere else. After a month of phone calls/interviews and emails Throughout the world my Oncologist found me a study that was being conducted at a local hospital (after being told from another local World renowned cancer hospital that they couldn't help me) and I got in on the last day of submissions! If I didn't get the chance that day I would likely be looking at planing my own funeral on a Zoom meeting. I've made it 7 more months with little side effects and over 50% shrinkage of all tumors. The trial has costed me very little in comparison to what chemotherapy would have and I'm back at work contribution to the economy and my country because of it. These therapies may not cure me but it's looking pretty good right now from where I'm standing, and I can honestly say I'm alive in part because of this treatment and when the trial ends I hope to be cancer free.	12/18/2020 12:36 PM
3	I am a colorectal cancer survivor, and I don't wish that experience on anyone else. Access to future therapies is paramount so that others will be able to cope much better than I did.	12/15/2020 4:26 PM
4	I have had two rounds of chemo therapy,, fulfox and fulfiri, and my oncologist decided that they weren't working for me any longer. That brought us to encorafenib and cetuximab, which has improved my quality of life a massive amount, to the point where I am hoping to go back to work in 2021.	12/14/2020 11:26 AM
5	I was at Stage III when diagnosed. I am now Stage IV (limited); thankfully the spots that have shown up are resectable. My biggest fear is further reoccurrence, and even greater than that is not having the best options available to treat me by offering a further potential cure, or treatment that would prolong my life while maintaining a good quality of life.	12/11/2020 12:43 PM
6	N/A	12/10/2020 8:58 PM
7	I am living a fairly normal life if it comes back I want to know there is hope	12/10/2020 10:58 AM
8	I had stage 3 colon cancer treated with a right hemicolectomy and folfox chemo. I had several side effects but managed 10/12 chemo treatments. I now have suspected lung metastasis. My future holds lung resection. If there were therapies that would help stop metastasis, then continue the research and provide the therapies.	12/9/2020 11:23 PM
9	I had been diagnosed with stage 3 colorectal cancer. I had surgery and had a total resection. I was on xeloda for 1 1/2 days and had a heart attack, drug related. The Drs were afraid to give me anything after that. I was given 16 colonoscopy's 24 cat scans and many scopes and tests for 3 years. This is why there needs to be more options	12/9/2020 2:26 PM
10	I'm a scientist by background and have been working in areas of future technologies. The old way of therapy is archaic and with advances in genetics and push towards personalized medicine I would want to have access to the most cutting edge approaches. E.g. I would love a CAR-T type therapy for colorectal cancer.	12/9/2020 11:59 AM
11	Publicly available and funded medical resources saved my life. I count on the health care system being there for me, as do all Canadians. Best in class therapies should always be available in an advanced medical system such as ours.	12/9/2020 10:52 AM
12	I would like to live for a few years.	12/9/2020 10:44 AM
13	To be able to have options especially when your disease is stage Iv	12/8/2020 9:34 PM
14	My sister's cancer is spreading even with existing Chemo.	12/8/2020 9:22 PM
15	I was diagnosed with stage 4 colon cancer at the age of 42. My disease is currently not visible on scans. I was treated with surgery (sigmoidectomy) and CEPOX. I did not tolerate the oxaliplatin and was pulled off it after 4/8 rounds. The xeloda caused chronic neutropenia so I was pulled off that after 7/8 rounds. I'm scared that if my cancer comes back, my options for effective therapies will be limited. My cancer is currently wild type so I would not qualify for immunotherapy.	12/8/2020 8:05 PM
16	I would like to be totally cancer free and will do anything to prevent recurrence of colorectal cancer.	12/8/2020 8:03 PM
17	I have heard that icing helps reduce the neuropathy. Oncologist should be able to suggest this to be used during infusion.	12/8/2020 7:40 PM
18	This is the second time cancer has entered my life. And I have been successful as beating both. I don't know what the future holds but I want to life a long life and want therapies available to me if I have to go through this a third and fourth time!	12/8/2020 1:45 PM
19	My wife has stage 4 CRC. After trying traditional methods of treatment like chemotherapy, the	12/8/2020 12:30 PM

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

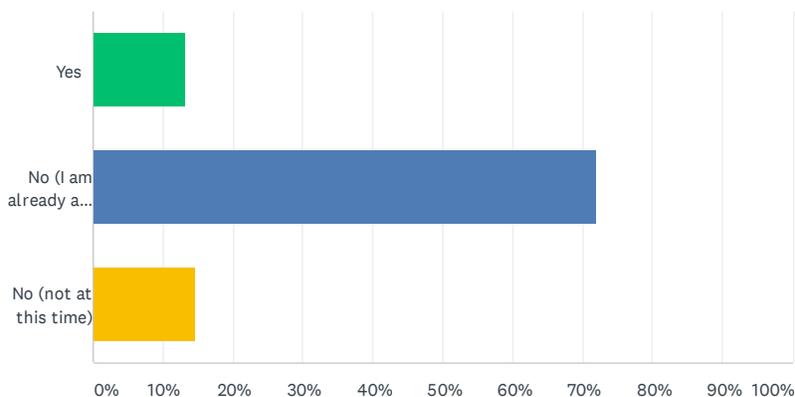
	immunotherapy clinical trial gave us the results we were desperately waiting for.	
20	My cancer is in remission for 2 1/2 years now, I am hoping for a cure.... any access to further therapies will be more than welcome to treat this terrible disease affecting millions of Canadians each year	12/8/2020 9:14 AM
21	Improve quality of life.	12/7/2020 5:11 PM
22	I was diagnosed when I was 59 years old and had cancerous polyp. I had to have an ileostomy and removal of my rectum. I had a reversal and doing ok now. My sister 7 years younger only had colonoscopy because of me, but also had cancer. She had the same thing done as me. I think maybe if we had access to therapies that didn't involve getting you rectum removed that would have been great. I am happy I am alive still but this surgery has definitely changed my life.	12/7/2020 3:29 PM
23	I have a rare form of lynch syndrome, which I did not get diagnosed with until a year after treatment. I would be incredibly interested in preventative measures to help lower reoccurrence risks	12/7/2020 2:32 PM
24	I have 2 kids that still need my help	12/7/2020 9:35 AM
25	I am stage 4 and inoperable, so new lines of treatments may give me more time.	12/7/2020 8:43 AM
26	I can but I am not sure my story that is only at the very shallow end of the pool will be of much help to anyone. I was diagnosed with stage 2. Within 10 days I had successful surgery. That was 10 months ago and that is my whole story,	12/7/2020 8:19 AM
27	Would not be here today	12/7/2020 8:10 AM
28	I was diagnosed with stage 4 cancer during my first colonoscopy at age 37. My symptoms were ignored and dismissed by no less than 5 doctors in BC. I'm at the point where chemotherapy is my only option and knowing there are other drug treatments available should my first two lines of therapy fail, would be nice.	12/7/2020 1:49 AM
29	When almost 5 years ago I was diagnosed with stage 4 colorectal cancer. I heard a lot of promising things from doctors about new treatments that are coming, like immune therapies. But till now I am given same old chemotherapy, and all this new treatments seems as far away as they were 5 years ago!	12/7/2020 12:17 AM
30	5 years of treatments and operations and if i become sick again i wish to have a cure	12/6/2020 11:05 PM
31	therapy must be accessible....you never know when YOU MAY be in need.....recurrence can happen	12/6/2020 9:51 PM
32	Really don't want anyone to go through what I went through	12/6/2020 9:49 PM
33	I was diagnosed before I turned 30, stage 4, no family history. I have 2 young children. Being diagnosed inoperable with advanced disease, the dreams I had for my family shattered. I went from imaging my children grow up, having careers and families of their own, to hoping to be alive long enough to hear my daughter say mama, take her first steps, and hopefully remember me. Thanks to advances in available medication after first line of treatment failed (Panitumumab and FOLFIRI were successful for me) I eventually made it to liver resection. Now my hopes are extended to see my son enter kindergarten next year, maybe my daughter 2 years later. I don't have long term goals anymore. I don't even want to sign a 2 year phone contract. I understand the severity of my diagnosis, but if there was a medication, or surgical technique that would give me more time with my babies, I would do it. Even if it was just one more day.	12/6/2020 9:38 PM
34	██████ is only 36 and has suffered so much in his short life. He deserves a better quality of life. I currently take care of him but, all family members died of cancer at a relatively young age. I don't know how long I got.	12/6/2020 8:43 PM
35	Diagnosed with young onset CRC after bloody stools for a decade being brushed off by doctors as hemorrhoids. Access to future therapies important to extend my life to be here for my kids.	12/6/2020 7:49 PM
36	N/a	12/6/2020 7:41 PM
37	my personal story is one of remission for the past 11 years , I do keep up with research through CCRAN updates.	12/6/2020 7:29 PM
38	Am currently 3.5 years with no evidence of disease but there is always a fear that it could return.	12/6/2020 7:19 PM
39	I am Stage 4 with 3 mets in my lungs and 2 mets in my liver. Was diagnosed in Nov. 2018. Had Coloresection and liver resection. Also had emergency hysterectomy due to kunkerberg tumor that has burst and surgeon found another one along with both ovaries full of cancer cells. I begged the surgeon to do complete hysterectomy regardless what he has found. Thsnk goodness I did as he originally was going to check prior to next step. I would nit e here today if I haven't begged! Already did 2 lines of drug therapies with no success. Currently waiting for surgeons to decide to do surgeries (to remove mets on my lungs and liver), if not, will apply for CAPTUR trial, if not my oncologist will apply for funding and approval for a drug(didn't catch the name of the drug). Already told me that I have 1 in 20 chances of that happening!!! This is where its not fair when our options are running out and feel fine. I can't help but think if others who were denied when chances could happen to make it work!! I also believe we should have same access to trials happening in US like ovanterib (sp?)	12/6/2020 6:29 PM

Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

40	I'm a young mCRC patient and have a young family. Having access to future therapies allow me to spend more valuable time with family and friends.	12/6/2020 6:18 PM
41	I am completely cured but would like to know that there are therapies should it happen again.	12/6/2020 5:56 PM
42	My loved one has stage IV disease and is MSS. He is now exhausting therapies and proceeding to a clinical trial which does not offer a MSS targeted therapy. we need to do more for these patients in Canada.	12/4/2020 10:00 AM

Q49 Would you like to become a member of Colorectal Cancer Resource & Action Network (CCRAN) and receive additional information on colorectal cancer?

Answered: 68 Skipped: 17



ANSWER CHOICES	RESPONSES	
Yes	13.24%	9
No (I am already a member)	72.06%	49
No (not at this time)	14.71%	10
TOTAL		68

#	IF YES, PLEASE PROVIDE YOUR NAME AND EMAIL ADDRESS BELOW OR GO TO WWW.CCRAN.ORG TO REGISTER TO BECOME A MEMBER.	DATE
1	[REDACTED]	12/14/2020 11:26 AM
2	[REDACTED]	12/10/2020 10:58 AM
3	[REDACTED]	12/9/2020 2:26 PM
4	[REDACTED]	12/7/2020 2:32 PM
5	[REDACTED]	12/6/2020 8:43 PM
6	Already a member	12/6/2020 7:49 PM
7	[REDACTED]	12/6/2020 7:29 PM
8	[REDACTED]	12/6/2020 5:56 PM