

## CADTH REIMBURSEMENT REVIEW

# Patient Input

**ENCORAFENIB (Braftovi)**  
(Pfizer Canada ULC)

**Indication:** In combination with cetuximab, for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation, after prior therapy.

**CADTH received patient input from:**

Colorectal Cancer Canada

Colorectal Cancer Resource & Action Network

**January 15, 2021**

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## Patient Input Template for CADTH CDR and pCODR Programs

Name of the Drug and Indication	Encorafenib in combination with cetuximab, for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation, after prior therapy.
Name of the Patient Group	Colorectal Cancer Canada
Author of the Submission	[REDACTED]
Name of the Primary Contact for This Submission	[REDACTED]
Email	[REDACTED]
Telephone Number	[REDACTED]

### 1. About Your Patient Group

Colorectal Cancer Canada is registered with CADTH.

[www.colorectalcancercanada.com](http://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 December 23, 2020 of which two patients and four caregivers (Patient 1-2, Caregiver 1-4) responded. Data was gathered from patients across the United States, Canada, United Kingdom and Turkey. The survey was posted on the social media platforms of CCC as well as international colorectal cancer organizations. CCC's patient support specialist also reached out to patients currently taking the drug under review. As a result of this outreach, two patients and four 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 and Caregivers – Information Gathering

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>Connection to Cancer</b>	Caregiver on behalf of patient undergoing treatment	Caregiver on behalf of patient previously treated	Patient undergoing treatment	Caregiver on behalf of patient undergoing treatment	Caregiver on behalf of patient previously treated	Patient undergoing treatment
<b>Country and Region</b>	United Kingdom	United States - California	United States - Texas	Turkey	United States - Colorado	Canada – Ontario
<b>A. Gender</b> <b>B. Age at Dx</b>	A. Female B. 30-39 years	A. Male B. 30-39 years	A. Female B. 30-39 years	A. Female B. 70-79 years	A. Male B. 30-39 years	A. Female B. 40-49 years
<b>Date of Dx</b>	04/2017	01/04/2018	16/07/2020	11/06/2020	15/01/2019	14/07/2020
<b>A. Stage at Dx</b> <b>B. Current Stage</b> <b>C. Metastases</b>	A. Stage IV B. Stage IV C. Liver (Hepatobiliary), Lung, Diaphragm	A. Stage IV B. Deceased	A. Stage IV B. Stage IV	A. Stage IV B. Stage IV C. Liver (Hepatobiliary), lung, peritoneum	A. Stage I B. Deceased C. Brain/CNS, Liver (Hepatobiliary), Lung, Peritoneum, Bones (spine, hip)	A. Stage I B. Stage IV C. Liver (Hepatobiliary)

### 3. Disease Experience

All patients/caregivers (100%) experienced cancer-induced symptoms prior to diagnosis. Symptoms commonly reported include fatigue, bloody stools, and abdominal cramping. When questioned which symptoms are more important to control than others, most patients/caregivers (83%) mentioned pain as the most important symptom to control. Those patients/caregivers felt that their symptoms affected their work life, social life, and ability to exercise. *“Between the constant nausea, and decreased energy I find it very difficult most days to do even a fraction of what I used to do in a day”* (Patient 1). Additionally, symptoms had a psychological impact on three out of six patients/caregivers (50%): *“I lost 15 lbs, had to be on anti-anxiety drugs”* (Caregiver 2).

Caregivers were uniquely questioned on the difficulties faced while caring for their loved one. All caregivers mentioned the inability to continue work and loss of income as main difficulties. Caregiver 2 also mentioned challenges in dealing with her son’s side effects related to treatments:

*“Sleepless nights comforting my son while he was in pain. Administering his pain medication/fentanyl patches, and oral medications on schedule. Assisting him with bowel issues with his ostomy, helping him to the toilet to vomit, drawing baths to help with pain, rubbing creams on his rashes, the list goes on and on caring for a cancer patient. Wound care from peeling skin on his fingers and toes and bedsores.”*

Caregivers also reported how treatments impacted their daily routine or lifestyle:

*“Everything revolves around what he needs and this varies each day depending on pain levels and energy”* (Caregiver 1)

*“It was a 24/7 job to be his sole caregiver.”* (Caregiver 2)

*“Fear of no positive result with treatment”* (Caregiver 3)

*“Took a leave of absence from job, required help with household tasks and childcare, loss of sleep, increased stressed impacted my own health, spent most days at the hospital for appointments”* (Caregiver 4)

All patients and caregivers rated access to new effective treatments for cancer as very important (10) on a scale of 1-10.

The data on disease experience is summarized and represented in Table 2.

Table 2: Surveyed Patients and Caregivers – Disease Experience

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>Symptoms experienced from cancer prior to Dx</b>	Fatigue, side pain	Bloody stools, fatigue, abdominal cramping, constipation, pencil thin stools	Fatigue, abdominal cramping	abdominal cramping	Fatigue, back pain, weight loss	Bloody stools, fatigue, abdominal cramping, anemia
<b>Which symptoms of cancer were/are more important to control than others?</b>	Fatigue and pain	Pain, mobility, bowel movements	Pain, nausea, fatigue	Pain	Pain, fatigue, nausea	
<b>How symptoms and problems resulting from any symptoms impact or</b>	Can't work, limited social contact	My son went on disability upon DX, he was very ill	I am a housewife and have been for over 10 years, this means that my "job" is running the house. Cooking,	Lack of exercise , lack of social relationship	Work, exercise, family life	

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>limit quality of life</b>			cleaning, shopping, all my job. Between the constant nausea, and decreased energy I find it very difficult most days to do even a fraction of what I used to do in a day.			
<b>Psychological impact as a result of your cancer on you or your family?</b>		I quit work to care for my son, misdiagnosis from his doctors, lack of genomic testing	Cooking. I love to cook, I find being in the kitchen relaxing. Not being able to be on my feet for very long or handle the smells, it has really been hard for me. Realizing that I have to ask for help around the house has also been hard, I hate not being able to do things for myself.		Pain, fatigue	
<b>On a scale of 1-10, how important to you is the access to new effective treatments for cancer, with 1</b>	10	10	10	10	10	10

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>being “not important” and 10 being “very important”?</b>						
<b>Difficulties caregiver faced:</b>	<p>I had to close my business to look after my partner. It's hard to help him manage the side effects of treatment and operations, hard to keep him believing there might be a cure in time for him.</p>	<p>I quit working to care for my 37 year old son, with Stage IV. He was very ill. I had loss of income, we went to counseling sessions (therapy) together to deal with his DX. I lost 15 lbs, had to be on anti-anxiety drugs and traveled far and wide with him getting second and third opinions. I moved into his home to care for him and my granddaughter. He was a single dad. I lost him in 7 months from DX.</p> <p>Sleepless nights comforting my son while he was in pain. Administering his pain medication/fentanyl patches, and oral medications on schedule. Assisting him with bowel issues with his ostomy, helping him to the toilet to vomit, drawing baths to help with pain, rubbing</p>		<p>Loss of income, psychological impact</p>	<p>inability to work, limited sleep, stress impacts on my own health, difficulties finding child care</p>	

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
		creams on his rashes, the list goes on and on caring for a cancer patient. Wound care from peeling skin on his fingers and toes and bedsores.				
<b>How treatments impacted caregivers' daily routine or lifestyle</b>	Everything revolves around what he needs and this varies each day depending on pain levels and energy	He had to get infusions every 2 weeks, blood draws every 1-2 weeks, was hospitalized 4 times, had colostomy surgery for a bowel blockage, weekly doctor's visits. It was a 24/7 job to be his sole caregiver.		Fear of no positive result with treatment	Took a leave of absence from job, required help with household tasks and childcare, loss of sleep, increased stressed impacted my own health, spent most days at the hospital for appointments	

#### 4. Experiences With Currently Available Treatments

Apart from Caregiver 3, all patients/caregivers (100%) accessed previous therapies for the treatment of their colon cancer. Therapies included mostly chemotherapy, and surgery (Caregiver 1). For all patients/caregivers (100%), previous therapies were not able to control their symptoms or the therapies were able to only partially control them (Caregiver 1 and Patient 2). Patients/caregivers were questioned what side effects were most difficult to tolerate from their therapies. Most patients reported similar side effects such as diarrhea, nausea, vomiting, mouth sores, low white blood cell count and fatigue. On a scale of 1-10 of "not important", to "very important", all caregivers rated >7 on the importance of having a choice on which drug to choose based upon each different drug's known side effects; except Patient 1 who rated that as 4.

Patient 2 and Caregiver 1 and 4 experienced difficulties accessing drugs for their cancers. Caregiver 1, 2 and 4 also report that the treatments they were recommended were solely based on what was funded in their region of residence. Caregiver 2 had to pay out of pocket for co-pays on visits, medications and tests. In addition to treatment cost, Caregiver 2 noted travel and ostomy supplies as an additional expense incurred by accessing their treatments. Caregiver 1 and 4 received financial assistance that covered 100% of the total costs for their treatments, and Patient 2 received around 20%.

Caregivers 2-4 and Patient 1-2 are willing to pay out of pocket to access new drug therapies. For Caregiver 1, paying out of pocket to access new drug therapies is dependent on the cost for most patients. Patient 1 expresses her willingness to pay out of pocket as she is *“determined to live as long as possible.”* Similarly, Caregiver 3 will be willing to pay out of pocket as *“This disease is very severe and unfair”*.

Three out of six patients/caregivers (50%) felt that some of their needs are not being met by the current drugs available to treat colorectal cancer:

*“There aren’t many treatment options for CRC other than chemo. My son was BRAFv600e, so the Beacon drugs were vital and gave him 3 months.”* (Caregiver 2).

*“When my late husband was treated for cancer, we both felt that we were limited by what was available.”* (Caregiver 4)

The data on patients’ and caregivers’ experiences with currently available treatments is summarized and represented in Table 3.

Table 3: Surveyed Patients and Caregivers – Experiences With Currently Available Treatments

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>If Encorafenib (BRAFTOVI) is not your first line treatment, what treatments have you received previously?</b>	Chemotherapy, surgery	Chemotherapy	Chemotherapy	No other treatment	Chemotherapy	Chemotherapy
<b>Have these therapies been effective at controlling the symptoms resulting from your colorectal cancer?</b>	Partially	No	No		No	Partially
<b>What side effects have you experienced with your previous treatments?</b>	Diarrhea, nausea, hair loss, vomiting, mouth sores, low white blood cell count, fatigue, pain, skin rash, hand and foot syndrome	Nausea, vomiting, nausea, vomiting, mouth sores, fatigue, pain, hand and foot syndrome	Diarrhea, vomiting, mouth sores, low white blood cell count	.	Diarrhea, nausea, hair loss, vomiting, mouth sores, anemia, low white blood cell count, fatigue, pain	Nausea, hair loss, mouth sores, fatigue, pain, neuropathy
<b>Top two side effects that were</b>	Hand and foot pain and rash	Vomiting and Nausea	Vomiting		Pain, low platelets	Hair loss, neuropathy

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>most difficult to tolerate:</b>						
<b>Have you (or your oncologist) experienced any difficulties in accessing drugs for your colorectal cancer?</b>	Yes	No	No		Late husband's first line of treatment failed (leucovorin, fluorouracil (5-FU), irinotecan, oxaliplatin and Avastin) and he was in liver failure in the hospital. We knew that encorafenib, binimetinib, and cetuximab were the last option for him. Unfortunately at that time his insurance did not cover the enco and bini drugs, so it was a rush against time to get them. We were about to pay \$25,000 to get a supply of them but the hospital was able to get a sample supply for him to start.	Yes, it took 4+ weeks for the drugs to arrive
<b>Were any of your treatments recommended solely based on what was funded in your region of residence?</b>	Yes	Yes	No	.	Yes	I don't know
<b>Have you had to pay out of pocket for any of your previous treatments?</b>	No	Yes, Co-pays on visits, medications and tests	No	.	No	No
<b>Did you receive any financial</b>	Yes	No	No		Yes	Yes

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>assistance from a pharmaceutical/biotech company assistance program or any other assistance program?</b>						
<b>If you did receive financial assistance, what percentage of the total cost of the treatment was provided?</b>	100%				A large portion, almost 100% I believe	20%
<b>In addition to the treatment cost, were there other costs incurred by you in accessing the treatment, such as travel costs, drug administration, etc.?</b>	No	Yes, Travel and hotel costs for second opinions, ostomy supplies	No		No	Yes
<b>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?</b>	Depends on the cost	Yes	Yes, I am determined to live as long as possible.	Yes, This disease is very severe and unfair	Yes	Yes
<b>On a scale of 1-10, with 1 being "not important" and 10 being "very important",</b>	8	10	4	7	9	10

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>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?</b>						
<b>Do you believe that some of your needs are not being met by the current drugs available to treat your colorectal cancer? If so, what are these needs?</b>	Yes	Yes, There aren't many treatment options for CRC other than chemo. My son was BRAFv600e, so the Beacon drugs were vital and gave him 3 months.	No	No	Yes, When my late husband was treated for cancer, we both felt that we were limited by what was available.	No

## 5. Improved Outcomes

All patients and caregivers (100%) expressed a common reaction regarding new therapies stressing the increased importance for new therapies to bring about improvement in their physical condition and quality of life. Trade-offs considered when choosing therapy include both extended overall survival and quality of life. All patients/caregivers (100%) would take a drug that has been proven to provide better QoL during their lifetime even if it does not extend overall survival. They felt the need to be able to carry on social activities without the burden of the therapies side effects that aggravate their quality of life. Caregiver 2 would be willing to tolerate significant side effects in order to extend survival by just 2 months, and Caregiver 2, 3 and 4 would be willing to do so to extend survival by 1 year.

Patient 1 from the United States, Patient 2 from Canada and Caregiver 3 from Turkey reported that access to drug therapies in their respective countries is very appropriate/fair. Whereas, Caregiver 1 from United Kingdom rates access to drug therapies as very limited/restrictive. Caregivers 2 and 4 from the United States rated access as 5 and 7 respectively on a scale of 1-10.

All patient/caregivers (100%) find it very important to have a choice along with their physicians in deciding which drug to take. They also find it very important to understand the average (or median) period of expected benefit from a new therapy.

The data on improved outcomes is summarized and represented in Table 4.

Table 4: Surveyed Patients and Caregivers – Improved Outcomes

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>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:</b>						
<b>New therapies bring about improvement in your physical condition?</b>	10	10	10	10	10	10
<b>New therapies bring about improvement in your quality of life?</b>	9	10	10	10	10	10
<b>You understand the average (or median) period of expected benefit from that new therapy?</b>	10	10	10	10	10	10
<b>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?</b>	Yes	Yes	Yes	Yes	Yes	Yes
<b>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:</b>						
<b>(a) 2 months?</b>	5	10	5	4	8	5
<b>(b) 6 months?</b>	7	10	7	5	9	5
<b>(c) 1 year?</b>	9	10	10	7	10	5
<b>On a scale of 1-10, with 1 being “not important as long as there is a drug” and 10 being “very</b>	10	10	10	10	10	10

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>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 deciding which drug to take?</b>						
<b>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?</b>	1	5	10	10	7	10
<b>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 those therapies to choose?</b>	10	10	10	10	10	10

## 6. Experience With Drug Under Review

As evidenced in Table 5, only Caregiver 3 had the drug under review as first line treatment. Caregiver 2 and 4, and Patient 1 and 2 had the drug under review as second line. Caregiver 1 had the drug under review as fourth line treatment. Patient 1 and 2 changed to the drug under review after results of biomarker testing came in: *“I was BRAF v600E positive and my oncologist immediately made the decision to change my therapy to Encorafenib”* (Patient 1). Caregiver 4 changed to the drug under review because *“first line of treatment failed”*. Caregiver 1 and 3 changed their treatment option to the drug under review after recurrence. All patients/caregivers took the drug under review in combination with other treatments which varied from chemotherapy, other targeted therapy and immunotherapy.

None of the patients/caregivers had access to the drug under review via clinical trials. Instead, they had access to the drug through assistance from pharmaceutical companies and insurance plans. None of the patients/caregivers, except Patient 2, experienced additional financial restrictions related to the drug. However, four out of six patients/caregivers (66.7%) had other issues accessing the drug under review. Caregiver 1 and Patient 1 report that the drug was not available in their cancer centre and Caregiver 1 had no provincial coverage. Similarly, Caregiver 4 reports financial hardship due to the cost, and Patient 2 experienced issues with drug supplies and administration.

All patients were prescribed Encorafenib after being tested positive for BRAF V600E. When asked about a particular gap or unmet patient need with current therapies, patients/caregivers voiced their thoughts about the drug under review:

Patient 1 reiterates that Encorafenib is effective: *“Traditional first line treatment options have been proven to work for patients with BRAF mutation”*.

Caregiver 1 mentioned the importance of Encorafenib as a targeted treatment for BRAF V600E-positive tumours:

*“This is the only proven therapy for BRAF V600E so it is imperative it is issued as a treatment”*.

Caregiver 2 mentioned the importance of having a knowledgeable clinician when it comes to treatment choice. She emphasizes that:

*“Patients that are BRAFv600e should be informed about BRAFTOVI by their oncologist and not have to seek 2nd opinions to learn about it. They should be treated by a CRC specialist, not an oncologist that treats all cancers.”*

Patients and caregivers rated side effects' impact on daily living differently (1-7) on a scale from 1-10. Common side effects experienced include fatigue, joint pain, muscle weakness, headache, rash, dry skin, itching, nausea, hair loss and fever. Some patients and caregivers noted these side effects as somewhat tolerable and relatively minor. Of those side effects, patients/caregivers report that some symptoms were managed better with Encorafenib compared to existing therapies – those symptoms include fatigue, shortness of breath, diarrhea, constipation, liver function and platelet levels.

When questioned about the most difficult aspects of the drug, patients/caregivers commonly reported the emotional drain and fatigue it causes along with the management of medications:

*"I do find the capsules hard to swallow, they get stuck in my throat and I need to eat something to help push them down. Not fun when I'm already nauseous."* (Patient 1).

Patients and caregivers were also questioned on what they expect, or hope, that Encorafenib will have on the cancer and their prognoses, most patients and caregivers (66.7%) hope it can "increase overall survival" and 66.7% also hope it "maintains and improves quality of life". Patient 2 hopes Encorafenib can "shrink my cancer so I can have surgery". Patients/caregivers rated their quality of life differently, varying from 2 (Caregiver 3) to 9 (Caregiver 2) on a scale of 1-10 with 10 being high quality of life.

Most patients appreciated that Encorafenib provided them additional survival time and improved quality of life which was certainly clinically meaningful:

*"My son was BRAFv600e, so the Beacon drugs were vital and gave him 3 months."* (Caregiver 2)

*"On day two of the new targeted treatment his liver values began to improve. His quality of life improved significantly! Ultimately these drugs bought him 8 more weeks with us before he passed away. His quality of life was greatly improved, which was such a blessing for him, myself and our 6 year old son."* (Caregiver 4).

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 and normal activities and improve their prognosis:

*"My son was able to walk more freely, his pain subsided from his intact sigmoid/rectal tumor. He was able to travel, ride his motorcycle and eat well."* (Caregiver 2)

*"Live. I don't know that I would have made it this far without the current drug combination. I was in the hospital in liver failure before my treatment was changed. After the first two weeks my liver functions started falling back into the normal range and at my two month scan my mets had shrunk considerably."* (Patient 1)

*"Yes! My late husband was able to travel to NYC for a vacation with me and our son to make lasting memories!"* (Caregiver 4)

Two out of six patients/caregivers (33%) following treatment had their tumour completely gone, shrunk or controlled, and two out of six (33%) had it partially shrunk. Patients and caregivers were also asked if they believe the drug under review will change their long-term health and well-being for the better. All patients responded positively:

*"Yes, My son was in the hospital with early signs of liver failure. This drug got him out of the hospital and gave him 3 months of a good QOL."* (Caregiver 1)

*"Yes, Encorafenib provided my late husband with a better quality of life in his last 8 weeks. While ultimately he died because the cancer was so advanced, he was able to experience better QOL his last months."* (Caregiver 4).

Apart from Patient 1, all caregivers report that the patients appreciate the easily administered oral therapy. All patients/caregivers (100%) find it simple to integrate in their daily routine. Compared to other treatments, most patients/caregivers (80%) rated their overall experience with the drug under review as >7 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. Caregiver 4 emphasizes that treatment choice should not be restricted based on what is covered/funded in the country.

*“Yes, Cancer patient and their caregivers should be given a choice between treatments and be able to choose with their oncologists help which is best for them. They should not be restricted based on what is covered/funded. In the US, at the time when my late husband needed this targeted therapy, his insurance would not cover it (this has now changed) so we had to appeal and also go through the hoops of getting help from the drug company's assistance program. When someone has such an aggressive form of cancer, every moment counts and time spent waiting to get coverage allow the cancer to spread. Thankfully the hospital provided my late husband with the drugs for free for the first month to give us time to get coverage for them.”* (Caregiver 4).

*“Yes, Without it I doubt I'd be alive right now. Every patient should have access to the drugs that their doctors believe will give them the best outcome.”* (Patient 1)

*“Yes, if it is proven to work, why not make it accessible?”* (Patient 2).

The data on the experience with drug under review is summarized and represented in Table 5.

**Table 5: Surveyed Patients and Caregivers – Experience with Drug under Review**

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>At the start of your discussion with your oncologist, were you informed of Encorafenib (BRAFTOVI) by your oncologist as a potential treatment option for you?</b>	No	No	No	Yes	No	No
<b>Why were you prescribed Encorafenib (BRAFTOVI)?</b>	I found out about the beacon trial after it had closed (UK) so I went about finding specialists who still had access but we managed to get compassionate use from the	We obtained a 2nd opinion from a UCSF	I was started on a different line of therapy (folfox) before the results from the genetic testing were in. After only two treatments I was getting worse and ended up in the hospital in liver failure. While there,	Colorectal cancer stage 4 with braf gene	First line of treatment failed	Due to BRAF V600e mutation

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
	drug company. Our oncologist didn't know it could be accessed. It's down to us as patient/caregiver.		the results of my testing came back and showed that I was BRAF+ and my oncologist immediately made the decision to change my therapy to Encorafenib + binimetinib and cetuximab.			
<b>In what line of therapy were you prescribed/given Encorafenib (BRAFTOVI) for the treatment of your metastatic colorectal cancer?</b>	Fourth Line	Second Line	Second Line	First Line	Second Line	Second line
<b>Did you participate in a clinical trial in connection to this drug? If yes, please specify clinical trial name and location:</b>	No	No	No	No	No	No
<b>Have you taken Encorafenib (BRAFTOVI) in combination with another treatment? If so, which one?</b>	Chemotherapy	Targeted therapy	Immunotherapy	Chemotherapy	Targeted therapy	Chemotherapy, Cetuximab
<b>How long have you been taking Encorafenib (BRAFTOVI)?</b>	6 weeks	3 months	3 months	3 months	8 weeks	3 weeks
<b>If applicable, did you change your treatment option to Encorafenib (BRAFTOVI) after recurrence?</b>	Yes, Plural lining recurrence and end of treatment options	N/A	N/A	yes, Failure after 3 months	N/A	N/A

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>In your opinion, is there a particular gap or unmet patient need with current therapies that Encorafenib (BRAFTOVI) will help alleviate?</b>	Yes, This is the only proven therapy for BRAF V600E so it is imperative it is issued as a treatment	Yes, Patients that are BRAFv600e should be informed about BRAFTOVI by their oncologist and not have to seek 2nd opinions to learn about it. They should be treated by a CRC specialist, not an oncologist that treats all cancers.	Yes, Traditional first line treatment options have been proven to work for patients with BRAF mutation	No	Yes	No
<b>What effect do you expect (or hope) that Encorafenib (BRAFTOVI) will have on the cancer and your prognosis?</b>	Increase overall survival, Reduce side effects from current medications or treatments	Maintain or improve quality of life, Increase overall survival, Delay onset of symptoms, Reduce side effects from current medications or treatments, Ease of use	Maintain or improve quality of life, Increase overall survival	Maintain or improve quality of life, Increase overall survival	Maintain or improve quality of life	Shrink my cancer so I can have surgery
<b>Which symptoms does Encorafenib (BRAFTOVI) manage better than the existing therapies?</b>		Fatigue, shortness of breath	Diarrhea, constipation	Fatigue	Fatigue, Diarrhea, Liver function, platelet levels	
<b>Which symptoms does Encorafenib (BRAFTOVI) manage less effectively than the existing therapies?</b>	Fatigue					

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>Was Encorafenib (BRAFTOVI) able to shrink/control your colorectal cancer and/or spread of the disease to other organs (metastases)?</b>	Partially	Yes	Yes	Partially	I Don't know	I don't know
<b>What side effects have you experienced while on Encorafenib (BRAFTOVI)?</b>	Fatigue, Joint pain", headache	Rash, dry skin, itching	Nausea, muscle weakness, rash, dry skin, hair loss, fever		Fatigue	Fatigue, joint pain, muscle weakness, constipation, headache, dry skin, itching
<b>Of the side effects experienced with Encorafenib (BRAFTOVI), which ones were most difficult to tolerate?</b>	Tiredness	Rash	Nausea, rash, hair loss		When my late husband started taking the Encorafenib (plus Cetuximab and Binimetinib) his cancer was extremely advanced. It's difficult to determine if his symptoms were from the targeted therapy or the cancer itself. However, even with the advanced stage of his cancer, he said he felt so much better on the Encorafenib targeted therapy compared to his previous chemo. He had a much	Fatigue, joint pain

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
					better quality of life.	
<b>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 Encorafenib (BRAFTOVI)?</b>	6	3	5	3	2	7
<b>Did you have to stop the Encorafenib (BRAFTOVI) earlier than planned or did you have to skip doses due to side effects?</b>	No	No	No	Yes	No	Yes
<b>As an oral therapy (drug administered through your mouth), has Encorafenib (BRAFTOVI) been easy to administer/receive?</b>	Yes	Yes	No	Yes	Yes	Yes
<b>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 Encorafenib (BRAFTOVI)?</b>	4	9	5	2	5	8
<b>Were you able to continue your daily activities or work while undergoing/after completing Encorafenib (BRAFTOVI)?</b>	No	Yes	Yes	Yes	Yes	No
<b>Do you find Encorafenib (BRAFTOVI) to be easy</b>	Yes	Yes	Yes	Yes	Yes	Yes

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>to integrate in your daily routine?</b>						
<b>What is/are the most difficult aspect(s) of Encorafenib (BRAFTOVI) for you?</b>	Fatigue, emotional drain	Management of medications	Emotional drain, I do find the capsules hard to swallow, they get stuck in my throat and I need to eat something to help push them down. Not fun when I'm already nauseous.	Management of medications, Hours spent in medical appointments	N/A	Social issues, monetary concerns, lifestyle changes, inability to plan ahead, feeling isolated, impact on career, fatigue, emotional drain, anxiety/worrying, feelings of helplessness
<b>Do you believe Encorafenib (BRAFTOVI) will change your long-term health and well-being for the better?</b>	Yes	Yes, My son was in the hospital with early signs of liver failure. This drug got him out of the hospital and gave him 3 months of a good QOL.	Yes, Hope.	Yes	Yes, Encorafenib provided my late husband with a better quality of life in his last 8 weeks. While ultimately he died because the cancer was so advanced, he was able to experience better QOL his last months.	Yes, I am hopeful this drug will shrink my cancer so I can have surgery
<b>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 Encorafenib (BRAFTOVI)</b>	10	10	10	7	10	8

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>compared to other treatments?</b>						
<b>Did accessing Encorafenib (BRAFTOVI) 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.</b>		Yes, my son was able to walk more freely, his pain subsided from his intact sigmoid/rectal tumor. He was able to travel, ride his motorcycle and eat well.	Live. I don't know that I would have made it this far without the current drug combination. I was in the hospital in liver failure before my treatment was changed. After the first two weeks my liver functions started falling back into the normal range and at my two month scan my mets had shrunk considerably.		Yes! My late husband was able to travel to NYC for a vacation with me and our son to make lasting memories!	No
<b>How was Encorafenib (BRAFTOVI) funded for you?</b>	Pharmaceutical company	Insurance Plan	Insurance Plan	We bought it in germany	Hospital provided the first month's dose while we worked with the drug company to get assistance for subsequent doses.	Special Access Program
<b>Do you believe Encorafenib (BRAFTOVI) should be funded where you reside for the treatment of metastatic colorectal cancer? Why or why not.</b>	Yes	Yes	Yes, Without it I doubt I'd be alive right now. Every patient should have access to the drugs that their doctors believe will give them the best outcome.	Yes	Yes, Cancer patient and their caregivers should be given a choice between treatments and be able to choose with their oncologists	Yes, if it is proven to work, why not make it accessible?

Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
				<p>help which is best for them. They should not be restricted based on what is covered/funded. In the US, at the time when my late husband needed this targeted therapy, his insurance would not cover it (this has now changed) so we had to appeal and also go through the hoops of getting help from the drug company's assistance program. When someone has such an aggressive form of cancer, every moment counts and time spent waiting to get coverage allow the cancer to spread. Thankfully the hospital provided my late husband with</p>	

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
					the drugs for free for the first month to give us time to get coverage for them.	
<b>Did you experience any financial constraints due to Encorafenib (BRAFTOVI)?</b>	No	No	No	No	No	Yes
<b>Have you had issues accessing Encorafenib (BRAFTOVI)? If so, what issues have you experienced?</b>	Not available in my cancer center/hospital, Did not have access to a clinical trial, No provincial coverage	I haven't had any issues accessing therapy	I haven't had any issues accessing therapy	Not available in my cancer center/hospital	Financial hardship due to cost	Supplies or issues with administration

## 7. Companion Diagnostic Test

All patients/caregivers (100%) confirmed patients tested positive for the unique biomarker, BRAF V600E. Caregiver 1 and 2 also tested positive for MSI/dMMR. All patients/caregivers (100%) report biomarker testing was done after diagnosis, which emphasizes the need to adopt biomarker testing as a standard practice at time of diagnosis. After biomarker testing was done, Caregivers 1-4 and Patient 2 were treated with chemotherapy, while Patient 1 was first treated with immunotherapy. Caregiver 1 and 2 were also tested for hereditary colorectal cancer syndromes, of which Caregiver 2 was tested positive for Lynch Syndrome.

The data on the companion diagnostic test is summarized and represented in Table 6.

Table 6: Surveyed Patients and Caregivers – Companion Diagnostic Test

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>What methods were used to diagnose the colorectal cancer?</b>	Colonoscopy, CT scan, biopsy	CT scan, biopsy	Colonoscopy, CT scan, reporting of symptoms and/or discomfort, blood work, ultrasound	Colonoscopy, CT scan, biopsy	Colonoscopy, CT scan, biopsy, blood work	Colonoscopy, CT scan, blood work, MRI, PET scan

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>Did you have one or more biopsies to further investigate the make-up of your tumour(s)?</b>	Yes	Yes	Yes	Yes	Yes	Yes
<b>Prior to your diagnosis, were you aware that biomarkers can help to determine a specific treatment option for you?</b>	No	No	No	Yes	No	No
<b>Did your oncologist or any other member of your medical team explain biomarker testing (or tumor profiling) before treatment started?</b>	No	No	Yes	Yes	Yes	No
<b>Do you recall having biomarker testing before or after being diagnosed with colorectal cancer?</b>	After diagnosis	After diagnosis	After diagnosis	After diagnosis	After diagnosis	After diagnosis
<b>If you have you been tested for any other biomarkers, which biomarker did you test positive for?</b>	BRAF V600E, MSI/dMMR	BRAF V600E, MSI/dMMR	BRAF V600E	BRAF V600E	BRAF V600E	BRAF V600E
<b>If you had your biomarkers tested, what treatment did your oncologist first select?</b>	Chemotherapy, surgery	Chemotherapy (FOLFOX)	Immunotherapy	Chemotherapy	Chemotherapy (FOLFOX, Irinotectan, Avastin)	Chemotherapy

	Caregiver 1	Caregiver 2	Patient 1	Caregiver 3	Caregiver 4	Patient 2
<b>Have you been tested for hereditary colorectal cancer syndromes?</b>	Yes	Yes, Lynch Syndrome	No	I don't know		No
<b>Did your family members get tested as well? If yes, were they positive for the syndrome?</b>	N/A	No	N/A	No		N/A

## 8. Biosimilar

N/A

## 9. Anything Else?

The six patients/caregivers provide evidence that the drug under review improves prognosis, improves quality of life, and majorly reduces their cancer symptoms with manageable side effects from the drug. The drug under review, Encorafenib, provides positive evidence of the effectiveness of drugs that are based on tumour biomarkers (specifically BRAF V600E) rather than tissue-specific status.

Patients and caregivers provided compelling comments on the importance of having access to information about the right targeted treatment:

*“It took me several months to get this drug, and the only way I was able to obtain was to go outside my health care system of doctors to get a second opinion with a leading cancer teaching hospital, UCSF to learn about targeted therapy for BRAF” (Caregiver 4).*

Patient 1 also provided comments on why they believe effective targeted treatments such as the drug under review should be easily accessible to patients:

*“As I've already stated, I was in the hospital in liver failure. My first line treatment wasn't working and I was getting worse. When I was switched to my current therapy, that includes encorafenib, I started rebounding almost immediately. Everyone diagnosed with this terrible disease should have access to whatever treatment will give them the best chance.” (Patient 1).*

Most significantly, Caregiver 4 stresses the importance of access to high-quality essential treatments and the patient's choice in the treatment options.

*“On day two of the new targeted treatment his liver values began to improve. His quality of life improved significantly! Ultimately these drugs bought him 8 more weeks with us before he passed away. His quality of life was greatly improved, which was such a blessing for him, myself and our 6 year old son. My late husband and I are so thankful we lived in the USA where we had the option to get the cancer drugs we did. As Canadians, had we still lived in Canada he would not have survived as long. I believe the patient should have a say in their treatment options and that it is not up to the government, insurance or other 3rd parties to make these decisions for us.” (Caregiver 4).*

Based on the objective research carried out as represented herein, Colorectal Cancer Canada strongly urges that a positive funding recommendation be issued for Encorafenib for the treatment of patients with BRAF V600E. 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 related to funding. 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.

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

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

Name of the Drug and Indication	Encorafenib (Braftovi®) in combination with Cetuximab for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation, after prior therapy.
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. 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](http://www.ccran.org)

**2. Information Gathering**

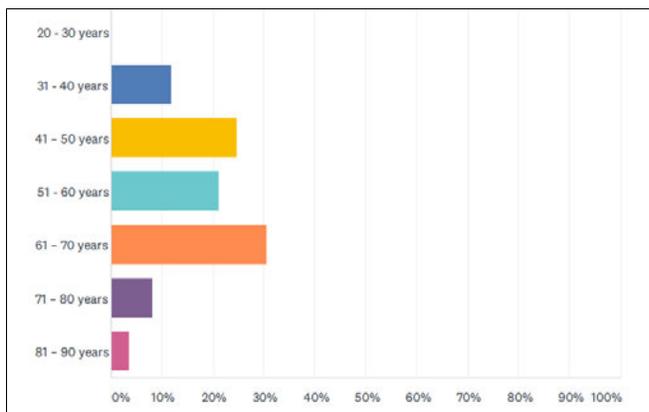
To help capture the critically important patient and caregiver perspective on the colorectal cancer journey and drug therapy under review, CCRAN issued a national online survey from **December 6<sup>th</sup> – December 30<sup>th</sup>, 2020** surveying colorectal cancer patients and caregivers residing 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 1 patient who cites their experience with the therapy under review in addition to the 3 interviewed patients)

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 national colorectal cancer information/support group meeting. Seven (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 20<sup>th</sup>, 2020** to help identify patients who would be willing to provide details of their experience with **Encorafenib in combination with Cetuximab (Encorafenib + Cetuximab)** by participating in a telephone interview. CCRAN also reached out to **members of its Medical Advisory Board** on **December 10 – December 30, 2020** to respectfully request their patients who are currently undergoing treatment with Encorafenib + Cetuximab contact CCRAN if interested in providing their experience with the therapy. A plea was also made through an online colorectal cancer support group (Colon Town), requesting patients who were currently undergoing treatment with the therapy under review contact CCRAN to provide their perspective and experience with the therapy. Three patient perspectives were secured with these outreach methods and the 3 telephone interviews were conducted between **December 16, 2020 and January 18, 2021**. Patients provided first hand, compelling, relevant and high quality input through the telephone interviews in the following treatment settings:

- **Patient A (Clinician Outreach):** Second Line Therapy – Accessed Encorafenib + Cetuximab through the Special Access Program.
- **Patient B (CCRAN Member):** Second Line Therapy – Accessed Encorafenib + Cetuximab through the Special Access Program.
- **Patient C (Colon Town Outreach):** First Line Therapy – Accessed Encorafenib + Cetuximab through the Compassionate Use Program.

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%)

Patients thoughtfully commented:

*“Unable to always predict how your bowels are going to react that day and will it impact daily activities.”  
“Just tired and did not do as much physically. Couldn’t eat as well either.”*

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 20-30% of colorectal diagnoses occur at a late stage of the disease when upfront surgery is no longer possible. A larger proportion of metastatic colorectal cancer diagnoses include patients who have developed metachronous metastases after curative radical surgery (Roviello et al, 2020). This highlights 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
- CAPECITABINE
- BEVACIZUMAB / MVASI
- CETUXIMAB / PANITUMUMAB
- REGORAFENIB
- TRIFLURIDINE + TIPIRACIL
- LAROTRECTINIB
- PEMBROLIZUMAB
- **ENCORAFENIB**

Close to 100% of surveyed patients accessed combination chemotherapies, such as FOLFOX (72%) / FOLFIRI (34%), whose side effects were deemed to be toxic and at times intolerable (Q16); 40% accessed Capecitabine and 21% 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. 2% accessed the therapy under review and 6% accessed Pembrolizumab. 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).

The response of BRAF V600E-mutated colorectal cancer to standard chemotherapy regimens is limited. The response rate is extremely low and the duration of the response is short. The disease tends to be aggressive and patients are less likely to tolerate subsequent lines of therapy. The standard first line chemotherapy regimens used for patients with BRAF V600E tumours usually consist of cytotoxic combinations such as FOLFIRI or FOLFOX, with or without Bevacizumab/MVASI. This may result in only a modest benefit in the first line setting which reflects the aggressive nature of the disease.

According to the first 2 telephone interviews conducted, first line therapy for **Patients A and B** consisted of **12 cycles** of FOLFIRI and **4 cycles** of FOLFOX respectively. Both patients reported a diminished quality of life (QoL) on those therapies which significantly failed to control their cancers for their metastatic colorectal cancer progressed after 6 and 2 months respectively.

**Patient A** commented:

*"The FOLFOX and the FOLFIRI gave me pretty much similar side effects: they knocked me off my feet and on my ass for a week before I was able to even think about doing anything!! I would have 3-4 days out of 2 weeks wherein I would be up to feeling ok to doing anything. And then the cycle would start again! I felt horrible fatigue, a mushy head, not right in the head, constipation and with folfox I felt numbness in my hands and feet that prevented me from doing simple things like buttoning my shirt or tying my shoelaces. My quality of life was truly impaired."*

And **Patient B** commented:

*"Oh, gosh, it was horrible. I had terrible neuropathy, and nausea was horrible. Neither were kind to me. I was not able to keep up with my young kids. For the first 5 days, I was in bed and unable to do anything and constantly debilitated. I found it painful to touch anything. And the smells, oh the smells they made me so ill. They made me nauseous. And I couldn't eat or drink. Even the smell of soaps did the same thing. They nauseated me. It was very bizarre."*

The third interviewed patient (**Patient C**) accessed CAPOX in the adjuvant setting for the treatment of her MSS Sigmoid Colon Cancer. The patient's metastatic disease was detected 1 month post completion of CAPOX therapy. The patient maintains the adjuvant treatment was totally ineffective and, in actuality, her disease progressed while on the CAPOX treatment. While on the CAPOX, she endured debilitating side effects that disengaged her from her life and prevented her from caring for her 2 young children (ages 1.5 and 3 years). She needlessly endured toxic, traumatic and debilitating

therapy which supplied no therapeutic benefit or value whatsoever for her type of colon cancer. When asked to describe her quality of life while on those previous therapies, she states:

*“... The first week was really tough, because I was so nauseated, really tired and I felt I didn’t participate in the world at all. I felt I was sitting on the chair and not there at all because of the fog I was in. My mind was a blank, a blur so to speak. I had terrible neuropathy in my fingers and even in my throat too. My throat closed up and I would choke. I couldn’t drink or eat anything remotely cold. Everything had to be heated in the microwave. Even my desserts had to be heated like ice cream. The second week would be a bit better. The fatigue and fog would lift a bit but then it would start all over again once I received the oxaliplatin again. The Xeloda wasn’t too bad but the oxaliplatin was terrible. There was nervousness I experienced and dread before each round because I knew what was coming. It’s always in your mind. So, my quality of life was very poor. Not good at all. I was not myself and never engaged. How could I be? I couldn’t care for my two little ones who are my life and mean the world to me. I was lost and so sick and frightened. Why was this happening to me. I wasn’t their mother anymore.”*

Patient C’s experience confirms that her disease was chemotherapy-insensitive and was very much in need of a superior and more effective therapy to target her unique subtype of metastatic colorectal 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 provided the following input: They prefer a therapy that is designed to **cure** a patient’s cancer. If a therapy cannot provide a cure, it should indeed provide **significant extension in survival with minimal to no side effects**. And while the therapy is destroying the cancer, it should not be destroying the balance of the body’s healthy tissues. Hence, 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. 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 B and C** replied as follows respectively:

*“Of course, it would. I wouldn’t find myself in the position I am today. My disease would not have progressed, I wouldn’t have undergone a toxic and useless treatment and I likely would have qualified for surgery. That’s how different my life would have been today. And who knows, maybe I would have been cured.....”*

*“For sure it would have been different. It might have killed my cancer and I wouldn’t have lasting effects like I do today – such as the neuropathy in my feet and hands. And I feel that I didn’t experience time with my kids during CAPOX – I missed a lot of months even though it was only 4 cycles of CAPOX that I had.”*

All three interviewed patients (Patients A, B and C) **believe Encorafenib + Cetuximab therapy has the desired improvements of which they spoke**. According to the patients, it is capable of 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 (as with Patient C), spend time with their family and friends and according to **Patient A**:

*“...it’s a great therapy. It’s easy to use, gives me great quality of life. One of the drugs is oral so I get to take it at home. The other one is infused at the hospital but it’s a quick infusion and the side effects are nowhere near as toxic as the other therapies I have had. I feel really lucky.”*

## 6. Experience With Drug Under Review

**TABLE 1** in **APPENDIX 1** captured the demographics and treatment-related experiences for three adult patients who are currently undergoing the therapy under review. Two of the three patients (**Patients A and B**) accessed the therapy through the Special Access Program in Second Line therapy. And **Patient C** accessed the therapy through Compassionate Use in the first line setting. All three patients tested positive for the BRAF V600E mutation which qualified them for the therapy. Patients were not aware of how their BRAF status had been determined. The technology utilized to determine their BRAF status was unbeknown to the 3 interviewed patients. They were, however, informed that a sample of their primary tumour had been accessed for testing purposes. Patients whose colorectal cancers are confirmed to harbor a BRAF V600E mutation through **Immunohistochemistry (IHC) testing** (which is quite typically performed at cancer centres throughout Canada) or through **Next Generation Sequencing Testing**, are eligible for the therapy under review. Patients must also be identified to be RAS Wild Type to support use of the Cetuximab therapy. Together, Encorafenib and Cetuximab have an antitumour effect greater than either drug alone.

**Patient A** is a 49 year old male who is a husband and father of a teen age daughter. After having endured debilitating toxicities from adjuvant FOLFOX, and failing first line FOLFIRI, **Patient A** proceeded to access the therapy under review on October 6, 2020 for his BRAF V600E Mutant Sigmoid Colon Cancer that had metastasized to his pelvis, abdomen, spinal column and neck. He has received **11 cycles** to date and in comparison to previously accessed colorectal cancer therapies, he rates his quality of life as **excellent (10/10)** and has experienced only minor side effects: upper gastrointestinal problems such as gas and initially some fatigue on the day of the infusion. He comments: *“In comparison to my other treatments, this therapy is so much better. On the day of the infusion, I am actually able to do stuff. I can work in my shed, do things around the house and able to go out. I couldn’t do that with folfox or folfiri.”* Before starting the therapy under review, **Patient A** was experiencing cancer induced symptoms (abdominal and back pain) for which he was prescribed pain medication (Dilaudid) as well as Lyrica. He was delighted to have been able to wean himself off both medications after starting the Encorafenib + Cetuximab for he had no further use for either medication. The therapy under review was able to resolve the cancer induced symptoms which had become quite debilitating and had caused much emotional upheaval: He was not able to function due to the pain, for it had imposed considerable limitations and challenges in his life. But the therapy helped to resolve the pain completely. Furthermore, his first CT scan findings revealed a **33% reduction** in his tumours which brought great satisfaction and relief to him and his family. He relays:

*“After my December 7<sup>th</sup> CT Scan, my oncologist called me to relay the results and they were really good. In that big tumour which was 3 cm, there was a 33% reduction and all the other tumours shrank as well. I was really happy with the results. This was my first CT scan.”*

And save for a couple of days due to GI issues, the patient has never had to stop the therapy. The patient believes the therapy has been of great value and well worth accessing. It permitted him to renovate his cottage because his quality of life was high and he was in a position to be able to complete such a demanding task. He is active physically, riding his bike and in his own words, **“living again”**. He also maintains:

*“Yes, of course it has [been worth accessing]. Definitely because of the quality-of-life factor. I am now at the point where I am debating going back to work and being a productive member of society again instead of a burden. And that’s all because of this therapy. That should be the largest indicator of how worthy it was to access this therapy – the fact that I am well enough to consider returning to work.”*

What is important to note from this patient is the fact that he *is indeed responding to the therapy under review in the **second line setting*** – a response that historically would not have been achievable or quite so durable or been associated with a high quality of life in this subset of the patient population. Historically, patients whose tumours harbor a BRAF V600E mutation have a limited response to standard chemotherapy regimens in first line treatment. And when they do respond, the response rate is low and the duration of the response is short. Since the disease is aggressive, patients are less likely to tolerate subsequent lines of therapy and if they do, **response is minimal and short lived, unlike the response observed in Patient A**. The therapy inspires hope for this underserved population in so far as it has been observed to extend progression free survival and overall survival, while maintaining a patient’s quality of life in a meaningful way.

**Patient B** is a 41 year old female who is a wife and mother of two young children. She was diagnosed with BRAF V600E Transverse Colon Cancer in August 2020 with metastatic disease to the liver. After receiving 4 cycles of FOLFOX, the patient’s disease (liver metastases) progressed while on the FOLFOX therapy. She then was recommended she commence the therapy under review, which she did on December 17, 2020 as part of second line therapy. The side effect which has been noted to be of concern for the patient is the extreme fatigue resulting from the Cetuximab, which she experiences for approximately 5 days post infusion. She sleeps for approximately 18 hours every day for 5 days after the infusion. Additional side effects experienced are: constipation, itching, burning sensation, freckles, and new moles. She rated her quality of life a 5/10 simply because she experiences the extreme fatigue but when compared to the previously accessed therapies, such as the FOLFOX, she maintains this therapy is much improved in comparison. Additionally, she has only received a couple of cycles and believes most of the side effects will likely dissipate/resolve. She states:

*“I am assigning a 5 because of the horrible fatigue which keeps me in bed for 18 hours a day after the Cetuximab infusion which means I cannot do anything at all. Although, I have only had two cycles, so it may very well improve in time.”*

The patient was experiencing cancer induced symptoms prior to starting the therapy under review. She had extreme pain in her upper right part of her abdomen. She believes it is due to the primary tumour that is located in the hepatic flexure of the transverse colon. It is quite large and pressing on the liver. She finds it difficult to sleep at night or to assume a comfortable position. However, upon receiving her first dose of the therapy, the pain resolved completely. In her words:

*“When I had my first cycle of Encorafenib + Cetuximab, for the first 7 days after the therapy, I had zero pain in my upper right abdomen. It mysteriously disappeared. I felt nothing for the first 7 days after that first cycle. It was amazing. My digestive system was finally on track. The therapy had finally resolved my pain. But the constipation set in due to this therapy and the sensation/discomfort returned. It is quite annoying when I turn or try to lie on my side.”*

**Patient B** has not been assessed for treatment efficacy yet but believes she is responding. She is pleased with the therapy in terms of how easy the therapy is in its use compared to previous therapies. She has not experienced any neuropathy, she is able to eat and drink, has an appetite, no nausea, no “baby bottle” to bring home with her for 46 hours, and she claims she does:

*“not feel ill or as ‘crappy’ as she did on the folfox therapy. You feel really terrible on folfox. And I like the pills, it’s easy. I have a better quality of life on this treatment than previously accessed treatments, that’s why it’s been easier to use.”*

The patient was quite articulate when relaying what she has been able to accomplish while on the therapy under review and kindly bear in mind that she has just recently accessed the therapy (2 cycles):

*“I am now able to walk my kids to the bus stop in the morning, get them ready for school, able to pick them up from school, I can do grocery shopping again, I can now drive again, which I wasn’t able to do while on folfox because my balance was off. I can now walk my dog, I get to cook for my family which I couldn’t do before because of the smells that I couldn’t tolerate, I am able to eat and drink and one of the greatest privileges is being able to play with my kids now with so much love and joy in my heart – I feel as though my heart will explode. Folfox was a nightmare and I wouldn’t wish it on my worst enemy. My hair has started to grow back, and I love it for it has improved my self-esteem. My husband and I get to enjoy each other’s company as well. These are the simple but precious moments that I was robbed of before but now able to enjoy because of this therapy.”*

**Patient C** is a 32 year old female and single mother of two toddlers. She was diagnosed with MSS BRAF V600E Sigmoid Colon Cancer with peritoneal metastases on September 2, 2020 after having discovered that her adjuvant CAPOX had failed. She was devastated to learn that her disease progressed while undergoing CAPOX adjuvant therapy because she tolerated significant treatment-induced toxicities which compromised her quality of life while on the therapy. She was advised to start the therapy under review. Hence, on October 2, 2020, she accessed her first cycle of Encorafenib + Cetuximab and has had 15 cycles to date to which she has responded quite well in the first line setting. According to the patient, side effects have been relatively minor: an acne type rash, facial hair growth, hair loss on her legs and arm pits, and splitting skin on the tips of her fingers. Overall, she has been quite pleased with the side effects which are quite tolerable and almost non-existent according to her. She rates her quality of life a **9/10** because she is able to function almost normally. The cancer induced symptoms she experienced prior to starting the therapy under review (ascites, abdominal pain and bowel sounds/agitation) **resolved completely** upon starting the therapy. In her words:

*“Yes, the therapy helped to resolve all of them! I don’t have any of them anymore. The ascites was so bad. Like I said, I felt as though I was 5 months pregnant with all that fluid in my belly. But after just one week it started to dissipate and then was gone completely. And it was the same with the other cancer symptoms. I was so relieved. I was so grateful for this therapy. It accomplished what the chemotherapy could not do.”*

**Patient C** was so very pleased to learn that she was responding to the therapy based on the first CT scan findings but not surprised for she had seen remarkable cancer symptom resolution. Her CEA levels were plummeting, her abdominal ascites had resolved, pain had completely resolved as well and she was now able to resume her former life, including her employment. She did have to stop therapy for one week initially due to arrhythmia but that too resolved and she has never experienced a treatment interruption again. In terms of how easy the therapy has been to use, the patient cites the following: *“The Cetuximab IV doesn’t hurt like the other chemotherapy I used to receive. And the side effects are so minimal. Pills are easy to use and I don’t forget to take these pills like I did the other chemo pills. I am not forgetful at all. That’s a good thing. And the IV takes only 50 minutes and that’s it. So convenient.”*

**Patient C** maintains that it was well worth accessing the therapy under review because of the life expectancy she was delivered back in September 2020. At that time, she was advised that she would live no longer than 6 months but thanks to the therapy, she is alive and well and looking forward to many more days with an excellent quality of life. Additionally, the therapy has permitted **Patient C** to rejoin the workforce. She maintains that if she were still on chemotherapy, she would not have been able to resume any employment opportunities. Being gainfully employed permits her to take good care of her two toddlers who rely on their mother completely for care. Furthermore, if she had not accessed Encorafenib + Cetuximab, in her words:

*“I would have died. I am doing so much because of this treatment and I likely would be doing more if it weren’t for COVID. I am exercising because of this therapy. I train with a physiotherapist and do a lot of different things like cycling, volleyball, I walk a lot around my neighborhood to stay fit. But most importantly, I get to keep up with the kids, who are so young and active, because of this medication. I am tired not due to the medicine, but because of the kids. My body feels like my old self again (colostomy notwithstanding). It is the best feeling ever.”*

## 7. Companion Diagnostic Test

BRAF mutations are estimated to occur in approximately 10% of people with metastatic colorectal cancer. The BRAF V600E mutation is the most common BRAF mutation, accounting for approximately 90% of all BRAF mutations. CCRAN has observed an area of **high unmet need** in this patient population as there are currently no approved therapies specifically indicated for people with BRAF V600E mutant metastatic colorectal cancer.

The presence of a BRAF V600E mutation in colorectal tumour specimens must be confirmed prior to initiating Encorafenib + Cetuximab treatment. Clinicians are requesting BRAF testing together with expanded RAS testing after a diagnosis of metastatic colorectal cancer has been confirmed. Patients whose colorectal cancers are confirmed to harbor a BRAF V600E mutation through **Immunohistochemistry (IHC) Testing** or through **Next Generation Sequencing Testing**, are eligible for the therapy under review. Patients must also be identified to be RAS Wild Type to support use of the Cetuximab therapy. Given the aggressive biology seen in this patient population, including a rapid decline in performance status in the setting of disease progression, **early testing** for BRAF mutations is important to identify optimal treatments and appropriately establish expectations for these patients and their caregivers. Tumours that are BRAF V600E mutant are typically associated with RAS Wild Type Status and would support accessing the combination therapy under review.

All interviewed patients (**Patients A, B, C**) confirmed they tested positive for the BRAF V600E mutation which allowed them to access the therapy under review. Additionally, one survey respondent also tested positive for the unique biomarker which permitted access. Interviewed Patients were not aware of how their BRAF status had been determined. The technology utilized to determine their BRAF status was unbeknown to the 3 interviewed patients. They were, however, informed that a sample of their primary tumour had been accessed for testing purposes. Testing ultimately altered the course of their disease, however. They are alive today because of the combination therapy. All three interviewed patients maintain their BRAF V600E status identification allowed them to gain access to a highly targeted combination therapy that has improved their quality of life as well as their survival compared with standard chemotherapy.

The three interviewed patients did not wait very long for test results to be generated because their BRAF Status had been determined through upfront testing. Nor did they pay out of pocket for the testing and the testing, which identified their cancer as BRAF V600E mutant, was easily accessible through their local treatment Centers. Patients were grateful to have accessed the test, despite the fact that it was unbeknown to them. It allowed them to qualify and experience a life-prolonging therapy based on the identification of a unique biomarker. This underscores the need to conduct upfront testing in the metastatic colorectal cancer population. While only a small subset of the metastatic colorectal cancer population harbor BRAF V600E mutations in their tumours, (approximately 9%), testing early on to identify the patients who qualify for the combination therapy will ultimately change the treatment paradigm. It will help guide treatment decisions which will undeniably be life altering for these patients and their families. It may certainly help to improve patient outcomes in a patient population who has in the past experienced especially poor outcomes and limited available targeted therapies for the BRAF V600E mutation.

The therapy under review delivers on the promise of precision medicine guiding treatment decisions: the identification of biomarkers defining the treatment approach for a colorectal cancer patient's disease. A BRAF Inhibitor alone has been found to have limited benefit for patients with BRAF-mutant colorectal cancer. However, combining the targeted therapy Cetuximab with the BRAF inhibitor Encorafenib, to simultaneously block components of the BRAF signaling pathway helps to improve outcomes in patients with metastatic BRAF-mutant colorectal cancer. Identifying patients whose cancers harbor the BRAF V600E mutation early on through technologies such as IHC testing or ideally through Next Generation Sequencing Testing will provide these patients with an effective, rationally designed regimen that attacks multiple points in the pathway that drives the patient's cancer growth and proliferation. According to our interviewed patients, BRAF V600E is now a target for a treatment that provides acceptable toxicity and an extension in progression free survival and overall survival. A ray of hope shines through for these patients.

## 8. Anything Else?

Subsets of the colorectal cancer population continue to face poor disease prognoses due to molecular subtypes driving their colorectal cancer. Consequently, many patients present with metastatic colorectal cancer, which often limits options and shifts treatment focus away from their highly sought-after curative therapies. BRAF V600E mutations are present in approximately 9% of metastatic colorectal tumours and are associated with uninhibited cell proliferation and resistance to standard therapeutic options. Patients whose tumours are BRAF V600E mutant will experience decreased overall survival and poor treatment responses relative to their wild type BRAF counterparts. This patient population is desperately in need of new therapeutic strategies that are relevant and will target their unique tumour biology. Our interviewed patients have articulately expressed the limitations and debilitating effects experienced on the standard cytotoxic therapies accessed to help treat their BRAF V600E mutant disease, resulting in little to no benefit in either the adjuvant or first line setting. These chemotherapeutic combinations caused significant and debilitating toxicities as relayed by our interviewed patients. Of noteworthy importance: **The standard of care therapies also have a limited, if any, benefit in the second line and beyond setting as well.** To have observed the magnitude and duration of response to the therapy under review in our interviewed patients (specifically **Patients A and C**), who have undergone 11 and 15 cycles

respectively, brings a glimmer of hope for this difficult to treat patient population who has historically experienced poor outcomes due to limited and ineffective treatment options.

There are no approved therapies currently indicated specifically for BRAF V600E mutant metastatic colorectal cancer. This creates an **unmet need** for this patient population. The therapy under review would address this unmet need: It would make a meaningful impact on the lives of those patients living with BRAF V600E mutant metastatic colorectal cancer for it would be the first chemotherapy-free, targeted regimen for this patient population capable of improving progression free and overall survival and quality of life. As the first targeted regimen for people with BRAF V600E mutant metastatic colorectal who have received prior therapy, Encorafenib in combination with Cetuximab would be a much needed new treatment option for these patients. Encorafenib + Cetuximab would certainly help to address an identified unmet need in a population who is desperately in need of a precision therapy.

Patients who were interviewed provided thoughtful and compelling examples of why the combination therapy was worth accessing. Their values and preferences were captured in **TABLE 1** within **APPENDIX 1** and highlighted throughout this submission. Essentially, the therapy represents a beacon of hope and a significant advancement for these patients. They recognize that in the absence of this therapy, they likely would not be here today. This precision therapy targets their difficult to treat BRAF V600E mutation and has clearly expanded treatment options for this poor prognosis group of patients. They would have been lost without access to this life prolonging therapy that has provided excellent quality of life and few to no side effects.

**Patients A and C** both made a plea in their last remarks reflective of the values and preferences captured throughout **TABLE 1** of **APPENDIX 1**:

*“For me, it all comes back to quality of life which this therapy is able to provide. I am able to do things on this treatment that I wasn’t able to do on the others and everyone who qualifies for this therapy should have the chance to do the same. Caregivers have an easy time on it too because it’s easy to take, easy to care for the patient due to minimal side effects. It’s a win-win situation.”*

*“I think I have pretty much said it all but since quality of life is so much higher on this therapy than regular chemo, this therapy should be made available to all who qualify. It is so much easier to use than regular chemo. There are few to little side effects and we don’t know for sure but it works very well for me. Maybe it gives one hope which can’t be measured, and for some, you can be cured, and for others it buys you time. It’s a therapy that is now keeping us alive where previously there was none available. It needs to be made available for people like me. I would strongly recommend it be funded.”*

**Patient B** also commented:

*“This therapy serves as a hope for patients like me. It should be funded and available for patients who qualify.”*

The online survey respondent who accessed the therapy under review provided the following reason as to why the therapy should be made available (**Q47**):

*“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 folfox 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.”*

Other survey respondents provided the following input as to why the therapy should be made available to patients(**Q47**):

*“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.”*

And,

*“All effective drug therapies should be funded so physicians can tailor drug selection to an individual patient’s situation.”*

Based on the qualitative data supplied, Encorafenib + Cetuximab has the potential to change the treatment paradigm for patients with metastatic BRAF V600E positive colorectal cancer. Patients’ input clearly demonstrate the therapy’s superior progression free survival compared to standard of care chemotherapy (either FOLFIRI or FOLFOX, with or without a biologic therapy). Second line treatment responses lasted longer than what has historically been observed among those treated with combination chemotherapy, responses lasting a median of 2 months. The qualitative data shows that **Patient A** and **Patient C** have each been responding to the therapy for 4 months. Patients whose tumours harbor BRAF V600E mutations have historically faced poor outcomes. Typically, chemotherapy-containing regimens were the only approved treatment options until now. The approval of Encorafenib + Cetuximab 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. Patients are being provided with hope. Robbing them of that hope would be unconscionable according to our interviewed patients.

If publicly funded, Encorafenib in combination with Cetuximab would be an extremely important therapeutic option for patients whose tumours test positive for BRAF V600E, after prior therapy. 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 Encorafenib + Cetuximab for the treatment of metastatic BRAF V600E colorectal cancer. We believe the therapy aligns well with the

identified patient need for an effective, quickly administered (Cetuximab), oral (Encorafenib), 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 after having received prior treatment for patients with BRAF V600E metastatic colorectal cancer, with fewer treatment-related toxicities reported 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	
Pfizer			X	
Merck			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 29, 2021

## APPENDIX 1

### TABLE 1: ENCORAFENIB + CETUXIMAB SUBMISSION: PATIENT INTERVIEW QUALITATIVE DATA

INTERVIEW QUESTION	PATIENT A	PATIENT B	PATIENT C
<b>PART A: DEMOGRAPHICS/INFORMATION GATHERING</b>			
<b>1. INTERVIEW DATE, TIME &amp; METHOD</b>	December 16, 2020 11:00-12:00 p.m. Telephone	January 11, 2021 10:00 – 11:30 a.m. Telephone	January 18, 2021 1:30 – 3:00 p.m. Telephone
<b>2. PATIENT'S AGE OF DIAGNOSIS, CURRENT AGE AND GENDER (M, F, NON-BINARY)</b>	-47 years -49 years -Male	-40 years -41 years -Female	-31 years -32 years - Female
<b>3. CITY &amp; PROVINCE/STATE</b>	██████ Ontario	██████ Ontario	██████, Netherlands
<b>4. A. MARITAL STATUS (S/M/D)</b>	A. Married	Married	Single
<b>B. CHILDREN?</b>	B. Yes, 14-year daughter	Yes, 7-year-old girl, 6-year-old boy	Yes, 3-year boy and 1 and a half year old girl
<b>5. OUTREACH METHOD? - CCRAN MEMBER - COLONTOWN - CANADIAN CLINICIAN - OTHER?</b>	Canadian Clinician	CCRAN Member	ColonTown Support Group
<b>6. TREATMENT CENTRE</b>	██████████	██████████	Local Hospital in ██████, Netherlands
<b>PART B: DISEASE EXPERIENCE &amp; EXPERIENCE WITH CURRENTLY AVAILABLE THERAPIES</b>			
<b>7. A. TYPE OF PRIMARY CANCER?</b>	A. Adenocarcinoma, Sigmoid Colon Cancer, BRAFV600E Mutation	BRAF V600E Mutant Transverse Colon Cancer, (Hepatic Flexure)	MSS, BRAF V600E Mutant Sigmoid Colon Cancer
<b>B. DATE OF FIRST DIAGNOSIS?</b>	B. October 15, 2018	July 14, 2020	April 21, 2020
<b>C. DATE OF METASTATIC DIAGNOSIS</b>	C. January 15, 2020	August 30, 2020	September 2, 2020
<b>8. A. THERAPIES RECEIVED BEFORE ENCORAFENIB + CETUXIMAB?</b>	A. "In November 2018 I had surgical resection of my sigmoid colon due to a micro perforation that had been identified. I then underwent 12cycles of FOLFOX that started in January 2019 that went on till approximately July 2019. In January 2020, I suffered a recurrence, so I started FOLFIRI which went on till approximately August 2020 (12 cycles). I also had radiation for a lymph node in my neck (March 2020) and lymph node in my abdomen (September 2020)."	"While I was deemed to be a stage I patient in July of 2020, in August of 2020, after multiple testing, I was finally told that I was a stage IV patient because of lesions discovered in my liver. So, on September 25, I started Folfox treatment not only for the 7 liver metastases but for the primary tumour that they discovered in my hepatic flexure. I received 4 cycles of folfox therapy, that's it and then my disease progressed. My last treatment was on November 13, 2020. My liver lesions went from 7 or 8 to 12 spots in that time."	"I had emergency sigmoid colon cancer surgery on April 22, 2020 and then started CAPOX on May 22, 2020 I believe. I had 4 cycles of CAPOX because the studies showed that only 4 cycles instead of 8 were sufficient to effectively treat any microscopic disease after surgery. I also ended up with a permanent colostomy."
<b>B. DID THOSE TREATMENTS CONTROL YOUR CANCER? Y/N (PLEASE EXPLAIN)</b>	B. "No, not really. The FOLFOX was totally ineffective because the disease progressed immediately after I stopped the FOLFOX (approximately 5 months later) and the FOLFIRI didn't really do much in terms of stopping the cancer from progressing."	"NO! The CT scan results confirmed further growth and that the Folfox was not working. I had more lesions in my liver and they were growing significantly. But the primary tumour was the same size. I had to undergo the folfox to essentially confirm that it was a therapy that could not address my BRAFV600E mutant disease."	"Oh, I think not! Because halfway through it (my treatment) I had an appointment with my oncologist and the bloodwork was apparently fine but a week later my belly started swelling badly and quickly. I went back to my surgeon and he told me that the ascites and weight gain was due to disease progression while I was actually on the CAPOX! So, no I don't think the treatment I was on was effective at all."
<b>C. DESCRIBE QOL ON THOSE TREATMENTS?</b>	C. "The FOLFOX and the FOLFIRI gave me pretty much similar side effects: they knocked me off my feet and on my ass for a week before I was able to even think about doing anything!! I would have 3-4 days out of 2 weeks wherein I would be up to feeling ok to doing anything. And then the cycle would start again! I felt horrible fatigue, a mushy head, not right in the head, constipation and with folfox I felt numbness in my hands and feet that prevented me from doing simple things like buttoning my shirt or tying shoelaces. My quality of life was truly impaired."	"Oh, gosh, it was horrible. I had terrible neuropathy, and nausea was horrible. Neither were kind to me. I was not able to keep up with my young kids. For the first 5 days, I was in bed and unable to do anything and constantly debilitated. I found it painful to touch anything. And the smells, oh the smells they made me so ill. They made me nauseous. And I couldn't eat or drink. Even the smell of soaps did the same thing. They nauseated me. It was very bizarre. Everything that had a scent was nauseating. Anything that was too hot or cold was too painful for me to swallow so I couldn't eat, and I lost so much weight. My diet was really limited. I informed my oncologist after each treatment, but I just kept going. My neuropathy lasted 10 days after each treatment to the point where I couldn't hold my sandwich at all so they dialed down my oxaliplatin by 20%. I couldn't take care of my	"I guess it would depend on when in the cycle of the treatment I was. The first week was really tough, because I was so nauseated, really tired and I felt I didn't participate in the world at all. I felt I was sitting on the chair and not there at all because of the fog I was in. My mind was a blank, a blur so to speak. I had terrible neuropathy in my fingers and even in my throat too. My throat closed up and I would choke. I couldn't drink or eat anything remotely cold. Everything had to be heated in the microwave. Even my desserts had to be heated like ice cream. The second week would be a bit better. The fatigue and fog would lift a bit but then it would start all over again once I received the oxaliplatin again. The Xeloda wasn't too bad but the oxaliplatin was terrible. There was nervousness I experienced and dread before each round because I knew what

<p><b>D. APPROXIMATELY HOW LONG DID IT TAKE BEFORE YOU PROGRESSED ON THOSE PREVIOUS THERAPIES?</b></p>		<p>children. That's what hurt the most from the folfox – NOT BEING ABLE TO CARE FOR MY KIDS. Then I had an allergic reaction to the folfox after the 3<sup>rd</sup> cycle. But I still managed to have a 4<sup>th</sup> cycle with steroids. I have to say I was so debilitated from that therapy. I hated it. My quality of life was the worst. I even lost my hair!! How horrible."</p>	<p>was coming. It's always in your mind. So, my quality of life was very poor. Not good at all. I was not myself and never engaged. How could I be? I couldn't care for my two little ones who are my life and mean the world to me. I was lost and so sick and frightened. Why was this happening to me. I wasn't their mother anymore. "</p>
<p><b>9. WAS THERE ANY PARTICULAR ASPECT OF THE DISEASE THAT WAS DIFFICULT TO CONTROL WHILE ON THOSE TREATMENTS?</b></p>	<p>D. "It didn't take very long. It took about 5 months for the disease to progress on the Folfox and the folfiri never really did anything at all. I was on the FOLFIRI for about 6-7 months, a total of 12 cycles."</p>	<p>"It took 2 months (4 cycles later), from September 25 to November 13, 2020 for my disease to get worse and it got worse in a fury. My liver metastases got larger and increased in number so quickly."</p>	<p>"The disease was detected one month after my last chemotherapy. But my doctors think it grew while I was actually on the chemotherapy CAPOX."</p>
<p><b>PART C: EXPERIENCE WITH ENCORAFENIB + CETUXIMAB</b></p>			
<p><b>10. LOCATION OF YOUR METASTATIC DISEASE?</b></p>	<p>-Abdomen/Pelvis -Spinal Column -Neck</p>	<p>-Liver</p>	<p>"Peritoneal lining and cavity."</p>
<p><b>11. A. WHERE WERE YOU TESTED FOR ENCORAFENIB + CETUXIMAB CANDIDACY?</b></p>	<p>A. ██████████</p>	<p>"May have been done at ██████████ ██████████"</p>	<p>"At my local hospital."</p>
<p><b>B. WAS IT DIFFERENT THAN YOUR TREATMENT CENTRE?</b></p>	<p>B. No</p>	<p>Perhaps</p>	<p>"No, it was not."</p>
<p><b>C. HOW WERE YOU TESTED FOR ENCORAFENIB + CETUXIMAB CANDIDACY? THROUGH WHAT TECHNOLOGY?</b></p>	<p>C. "Not really sure. All I know is that I was supposed to pay for it but I never saw a bill."</p>	<p>"I don't really know. I was told about my BRAFV600E mutation status after my first folfox treatment. It likely came from a liver metastasis biopsy, but I can't be certain. With COVID-19 restrictions in place, I have had only 2 in person meetings with doctors. I have only met with my oncologist once. And I have only met with my liver surgeon once. So, the information hasn't flowed all that readily. So, if they took a sample from my liver for the purpose of testing mutations, I was never really informed of that. The follow of information was segmented and scattered. I have never had a physical examination by anyone."</p>	<p>"The doctors tested a sample of the primary tumour that was removed in April 2020. I don't really know the technology that was used though."</p>
<p><b>D. DID YOU HAVE TO TRAVEL TO GET TESTED?</b></p>	<p>D. No</p>	<p>"I don't know how to answer that. I wasn't aware I was being tested at the time. But no, it was local."</p>	<p>"No, I did not have to travel."</p>
<p><b>E. DID YOU HAVE TO PAY OUT OF POCKET TO GET TESTED?</b></p>	<p>E. No</p>	<p>"No, not at all."</p>	<p>"No, I did not."</p>
<p><b>F. DID YOU HAVE TO WAIT LONG FOR THE TEST RESULTS?</b></p>	<p>F. "I can't recall. It was done while I was on FOLFIRI."</p>	<p>"No, I wasn't aware of anything at the time."</p>	<p>"No, I think it was about 4 days."</p>
<p><b>G. DID YOU EXPERIENCE ANY ANXIETY WAITING FOR THE RESULTS?</b></p>	<p>G. No.</p>	<p>"No, because again, I wasn't aware of anything."</p>	<p>"No, reason being I didn't even know they were testing for my BRAF status until they presented me with the results."</p>
<p><b>12. HOW WERE YOU ABLE TO ACCESS ENCORAFENIB + CETUXIMAB? IE CLINICAL TRIAL?</b></p>	<p>"My oncologist recommended I go on it. I believe it's through the Special Access Program as well as through my private</p>	<p>"I accessed it through the special access program. My oncologist helped me."</p>	<p>"It was through compassionate use. The Board had to approve it and then the pharmaceutical company pays for it."</p>

PRIVATE INSURANCE? SPECIAL ACCESS? SELF PAY?	insurance and Eli Lilly is covering the rest for Cetuximab.”		
13. A. WHEN DID YOU RECEIVE ENCORAFENIB + CETUXIMAB (DATE)?	A. “My first dose was on October 6, 2020.”	“My first dose was December 17, 2020.”	“My first round was October 2, 2020.”
B. AND IN WHAT LINE OF THERAPY?	B. Second line therapy.	Second line therapy	“It was in first line therapy”
C. HOW MANY CYCLES DID YOU RECEIVE?	C. “I have received <b>11 cycles</b> . I receive Encorafenib daily through a pill. And I receive Cetuximab weekly through an infusion, though my oncologist says she will be switching my to biweekly infusions starting next week.”	“I have received <b>2 cycles</b> already. My second cycle was December 30 <sup>th</sup> , 2020 and my next cycle is scheduled for January 14 <sup>th</sup> , 2021.”	“I have had <b>15 cycles</b> so far and I am doing really well.”
15.A. HAVE YOU EXPERIENCED ANY SIDE EFFECTS WHILE ON ENCORAFENIB + CETUXIMAB? Y/N	A. “Yes. I have but just some minor ones.”	“Yes, I have.”	“Yes, I have but they have been nothing to really speak of.”
B. IF SO, WHAT ARE THOSE SIDE EFFECTS?	B. “I have had some upper gastrointestinal problems. Mostly some gas in my stomach. It has happened approximately 5 times or so. And my bowels feel funny. In the beginning, I have felt tired on the infusion day.”	“I take the Encorafenib pills once a day every day. And I have infusions of Cetuximab every 2 weeks for 2 hours but then I am monitored for 1.5 hours for cardiac arrest. As for the <b>side effects</b> I have experienced, I believe I can identify which are due to Encorafenib and which are due to the cetuximab. I’ve experienced some <b>pretty extreme fatigue</b> due to the cetuximab because for 5 days after the infusion, I’m sleeping for 18 hours after it. I have been experiencing ongoing constipation every day. I have had itching, burning sensation on my skin that comes and goes like a match that comes and goes that lasts a minute or two due to what I believe is due to the pills (Encorafenib). I have freckles popping up over my body, like sunspots, odd, shaped sunspots and new moles over my body. I ask myself, are they permanent, or will they go away?”	“1. I have had an acne type rash from the Cetuximab which was pretty bad right at the beginning because I had welts and itching but it got so much better. 2. I have had hair growth – a bit of a mustache – I think the hair color changes and I have sideburns too. I think this is from the Encorafenib. 3. I have experienced hair loss in my arm pits and legs which in my opinion has been very good. I think this has been from the Encorafenib. 4. and the skin on the tips of my fingers has been splitting, like small paper cuts. I am not certain what this is due to.  Overall, I have been very pleased with the side effects which are quite tolerable and almost nonexistent. In comparison to chemotherapy, this therapy is wonderful and allows me to live again and be engaged. It is not toxic at all.”
16. ON A SCALE OF 1-10, HOW WOULD YOU RATE YOUR QOL WHILE ON ENCORAFENIB + CETUXIMAB? 1 REPRESENTING VERY POOR AND 10 REPRESENTING VERY GOOD QUALITY OF LIFE.	<b>10</b> “In comparison to my other treatments, this therapy is so much better. On the day of the infusion, I am actually able to do stuff. I can work in my shed, do things around the house and able to go out. I couldn’t do that with folfox or folfiri.”	<b>5</b> “I am assigning a 5 because of the horrible fatigue which keeps me in bed for 18 hours a day after the Cetuximab infusion which means I cannot do anything at all. Although, I have only had two cycles, so it may very well improve in time.”	<b>9</b> “I would rate it very high because there are so few side effects and so small side effects. The acne is nothing compared to the disease. And the rest of the side effects are nothing compared to chemotherapy. The doctors gave me a list of potential side effects but they’re not happening to me. So, I am really happy about that.”
17. DID YOU HAVE ANY CANCER SYMPTOMS BEFORE STARTING ENCORAFENIB + CETUXIMAB? IF SO, WHAT WERE THEY?	“Yes, I had terrible abdominal and back pain. I was on 21 mg of dilaudid and 50 mg Lyrica daily “	“Yes, I had extreme pain in my upper right part of my abdomen that I kept complaining about before and especially during folfox treatment. It has been so painful. This has been likely due to the primary tumour that is located in the hepatic flexure of the transverse colon. It is quite large and pressing on the liver. I haven’t been able to sleep at night or get into any comfortable position.”	“Yes. I had ascites in my belly, and felt as though I was 5 months pregnant; I had pain low down in my belly, in my pelvis. It was a stabbing pain. I felt agitation in my belly, as though something was not right. There were bowels sounds that were happening all the time too.”
18. IF YOU DID HAVE CANCER SYMPTOMS BEFORE STARTING ENCORAFENIB + CETUXIMAB, DID LAROTRCTINIB HELP RESOLVE THOSE CANCER SYMPTOMS? IF SO, WHICH ONES? PLEASE EXPLAIN.	“Yes, I have no more pain. I have weaned myself off of the pain meds and Lyrica.”	“When I had my first cycle of Encorafenib + Cetuximab, for the first 7 days after the therapy, I had zero pain in my upper right abdomen. It mysteriously disappeared. I felt nothing for the first 7 days after that first cycle. It was amazing. My digestive system was finally on track. The therapy had finally resolved my pain. But the constipation set in due to this therapy and the sensation/discomfort returned. It is quite annoying when I turn or try to lie on my side.”	“Yes, the therapy helped to resolve all of them! I don’t have any of them anymore. The ascites was so bad. Like I said, I felt as though I was 5 months pregnant with all that fluid in my belly. But after just one week it started to dissipate and then was gone completely. And it was the same with the other cancer symptoms. I was so relieved. I was so grateful for this therapy. <b>It accomplished what the chemotherapy could not do.</b> ”
19. A. HOW WAS RESPONSE CONFIRMED TO ENCORAFENIB + CETUXIMAB: CLINICALLY (SYMPTOMS RESOLVED), BIOCHEMICALLY, OR RADIOGRAPHICALLY (SUCH AS CT, MRI)?	A. “I have had a CT Scan.”	“Since I just started the therapy last month, I haven’t had any imaging yet and I haven’t had any tumour markers ordered yet either. But I will. But I know how I feel and when my disease gets worse, I feel it. I don’t think that’s the case for me right now.”	“First of all, I knew I was responding because I was feeling better and looking better. My belly was flat again. The CEA went down and the CT scan results showed that I was responding.”

<p><b>B. WHAT WAS YOUR RESPONSE TO ENCORAFENIB + CETUXIMAB?</b></p>	<p>B. "After my December 7<sup>th</sup> CT Scan, my oncologist called me to relay the results and they were really good. In that big tumour which was 3 cm, there was a 33% reduction and all the other tumours shrank as well. I was really happy with the results. This was my first CT scan."</p>	<p>"As per above..."</p>	<p>"My CT scan results showed a great response according to my oncologist. I have another CT scan scheduled for next week. I am anxious about that one. I can't wait."</p>
<p><b>20. DID YOU HAVE TO STOP ENCORAFENIB + CETUXIMAB? IF SO WHY?</b></p>	<p>"I never had to stop the Cetuximab, but I did have to stop the Encorafenib for a couple of days because of my stomach issues."</p>	<p>"No, not at all. I hope I never do. "</p>	<p>"Yes, there was a bit of a hiccup since at the beginning with my heart rate because it went into overdrive. When I had my first dose on the Friday, I had to go into the hospital on the Saturday because of my heartrate so they stopped the therapy for a week. But it was just a one-time disturbance. I am on a beta-blocker now and I haven't had any other problems."</p>
<p><b>21. HAS ENCORAFENIB + CETUXIMAB BEEN EASIER TO USE THAN PREVIOUS THERAPIES? WHY OR WHY NOT?</b></p>	<p>"Yes. It has never knocked me off my feet. My quality of life has been great and always maintained. It's been really easy to take the pills every day the infusion is quick even though it's weekly. Though, my oncologist has now advised me that it will be delivered every two weeks so that will be so much better now. "</p>	<p>"Oh, yes. First of all, I don't have any neuropathy that results from the treatment, I am able to eat and drink and therefore hungry. Previously, the thought of food make me nauseous because of the folfox. And the smell of food and beverages was horrible. There is no pump to bring home for 46 hours so that is so convenient. I do not feel ill or as crappy as I did on folfox. You feel really terrible on folfox. And I like the pills, it's easy. I have a better quality of life on this treatment than previously accessed treatments, that's why it's been easier to use."</p>	<p>"Yes, definitely. The Cetuximab IV doesn't hurt like the other chemotherapy I used to receive. And the side effects are so minimal. Pills are easy to use and I don't forget to take these pills like I did the other chemo pills. I am not forgetful at all. That's a good thing. And the IV takes only 50 minutes and that's it. So convenient. "</p>
<p><b>22. WAS IT WORTH ACCESSING ENCORAFENIB + CETUXIMAB? WHY OR WHY NOT?</b></p>	<p>"Yes, of course it has. Definitely because of the quality-of-life factor. I am now at the point where I am debating going back to work and being a productive member of society again instead of a burden. And that's all because of this therapy. That should be the largest indicator of how worthy it was to access this therapy – the fact that I am well enough to consider returning to work."</p>	<p>"Oh, yes, absolutely, especially when you have been told that first line won't work for you because of a mutation that your tumour contains. You shouldn't have to go through a useless first line therapy to prove that it will not work to access a second line treatment designed to target your particular cancer and your genetic mutation. I was essentially told be prepared for first line to not work and then you'll be able to access something that will work and be easier on your body! That's just wrong and unconscionable. I just couldn't understand that and on top of that, to wait for the treatment to 6 weeks, to fight for it to get here in 4 weeks and was yes grateful to know people who helped get it here sooner is again unconscionable and should be that way for people who are fighting for their life, who have my mutation, an aggressive form of cancer!! So overall, <b>YES, IT WAS SURELY WORTH ACCESSING THE TREATMENT.</b>"</p>	<p>"Oh my goodness, definitely. Because of life expectancy, they gave me 6 months to live back in September so I would have been at the end of my life by now. But I am still here. And the treatment worked for the ascites which was so agonizing for me. And it improved my quality of life so much. I don't feel sick any more. At the moment, I am fine and looking forward to life and doing more. I know I am sick but I don't feel it which is the most important thing of all. It's a stable situation every week which I will gladly take. With chemo, you go up and own. But not with this therapy. You have stability and well being."</p>
<p><b>23. DID ACCESSING ENCORAFENIB 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? IF YES, PLEASE EXPLAIN.</b></p>	<p>"It actually allowed me to renovate our cottage – what does that tell you? And again, the quality of life is huge, I am able to do things I just could not do on the other therapies. I am active, I can ride my bike again which I could not do before. I can live."</p>	<p>"Were there any milestones, I don't think so, other than just getting through therapy. BUT, I am now able to walk my kids to the bus stop in the morning get them ready for school, able to pick them up from school, I can do grocery shopping, I can now drive again, which I wasn't able to do while on folfox because my balance was off. I can now walk my dog, I get to cook for my family which I couldn't do before because of the smells that I couldn't tolerate, I am able to eat and drink and one of the greatest privileges is being able to play with my kids now with so much love and joy in my heart – I feel as though my heart will explode. Folfox was a nightmare and I wouldn't wish it on my worst enemy. My hair has started to grow back, and I love it for it has improved my self-esteem. My husband and I get to enjoy each other's company as well. These are the simple but precious moments that I was robbed of before but now able to enjoy because of this therapy."</p>	<p>"Well, I think so, I am working again which I wouldn't have been able to do if I was on chemo, that's for sure. And if I hadn't gone on this treatment, I would have died. I am doing so much because of this treatment and I likely would be doing more if it weren't for Covid. I am exercising because of this therapy. I train with a physiotherapist and do a lot of different things like cycling, volleyball, I walk a lot around my neighborhood to stay fit. But most importantly, I get to keep up with the kids who are so young and active because of this medication. I am tired not due to the medicine, but because of the kids. My body feels like my old self again (colostomy notwithstanding). It is the best feeling ever."</p>
<p><b>24. WHAT IMPROVEMENTS WOULD YOU LIKE TO SEE OVERALL IN A DRUG THERAPY THAT ARE NOT AVAILABLE CURRENTLY IN OTHER THERAPIES?</b></p>	<p>"Obviously I would like to see better survival rate and side effect profile but improved quality of life is key for me."</p>	<p>"A treatment should provide no side effects but that may be far-fetched. It should provide good quality of life, a cure if possible, and extend survival."</p>	<p>"Wow, if I had my choice I would have a treatment that gives you no side effects, extends your life for a very, very long time and gives you a wonderful quality of life with no toxicities from that medication. And if you can have a medication that you can take at home through a pill, that would be a bonus."</p>

25. WOULD YOUR LIFE BE ANY DIFFERENT IF THE DRUG THERAPIES HAD THOSE DESIRED IMPROVEMENTS?	"It sure would. The past year and half would have been so very different for me. It would have been a lot easier on me. It would not have been so grueling or toxic and challenging."	"Of course, it would. I wouldn't find myself in the position I am today. My disease would not have progressed, I wouldn't have undergone a toxic and useless treatment and I likely would have qualified for surgery. That's how different my life would have been today. And who knows, maybe I would have been cured...."	"For sure it would have been different. It might have killed my cancer and I wouldn't have lasting effects like I do today – such as the neuropathy in my feet and hands. And I feel that I didn't experience time with my kids during CAPOX – I missed a lot of months even though it was only 4 cycles of CAPOX that I had."
26. DO YOU BELIEVE ENCORAFENIB + CETUXIMAB HAS THOSE DESIRED IMPROVEMENTS? WHY OR WHY NOT?	"Yes. It's a great therapy. It's easy to use, gives me great quality of life. One of the drugs is oral so I get to take it at home. The other one is infused at the hospital but it's a quick infusion and the side effects are no where near as toxic as the other therapies I have had. I feel really lucky."	"I want to believe that it does have some or all those improvements."	"Yes, I think so. I think the therapy has all those wonderful things. But I wish it could cure me. I think that's the only downside."
27. DO YOU WISH TO ADD ANYTHING ABOUT WHY ACCESSING ENCORAFENIB + CETUXIMAB IS SO IMPORTANT TO PATIENTS CAREGIVERS?	"For me, it all comes back to quality of life which this therapy is able to provide. I am able to do things on this treatment that I wasn't able to do on the others and everyone who qualifies for this therapy should have the chance to do the same. Caregivers have an easy time on it too because it's easy to take, easy to care for the patient due to minimal side effects. It's a win-win situation."	"Ummmmm....If this therapy has been proven to extend survival and give better quality of life, I don't understand why it is not available to people such as myself who quality based on a genetic marker. Why do patients have to prove first line therapy doesn't work? Why do I have to undergo a toxic treatment like folfox and allow my disease to progress? Why do I have to go through something so horrible and allow me to suffer needlessly? Why go through this needlessly? We should have put through the paperwork immediately in the beginning for the therapy. Other countries do it. Why can't we? Other patients in the U.S. with liver mets are getting surgery and I am just sitting here because I have so many tumours in my liver and therefore inoperable, so I have to suffer for a second line of treatment to see if it works and potentially a surgical candidate. There is no reason why I can't have surgery in Canada. I should be a candidate. I have indicated to numerous docs of my pain from the primary and still I received no surgery. So many issues with so few remedies. This therapy serves as a hope for patients like me. It should be funded and available for patients who quality."	"I think I have pretty much said it all but since quality of life is so much higher on this therapy than regular chemo, this therapy should be made available to all who qualify. It is so much easier to use than regular chemo. There are few to little side effects and we don't know for sure but it works very well for me. Maybe it gives one hope which can't be measured, and for some that you can be cured, and for others it buys you time. <b><i>It's a therapy that is now keeping us alive where previously there was none available. It needs to be made available for people like me. I would strongly recommend it be funded.</i></b> "

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

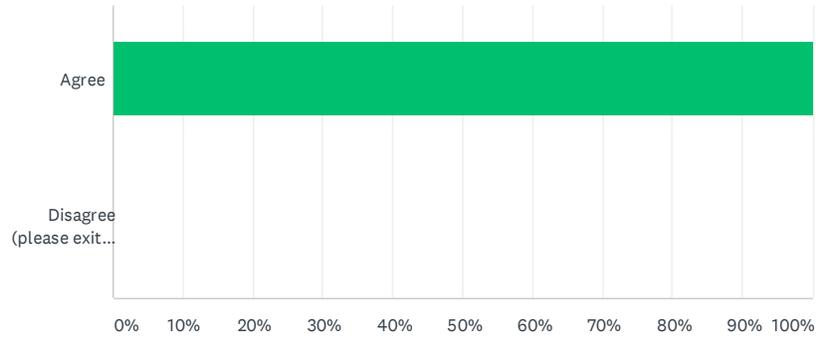
**QUESTION: "WHAT SYMPTOMS, IF ANY, DID YOU EXPERIENCE FROM YOUR METASTATIC COLORECTAL CANCER?"**

<b>PATIENT D, 39-Year-Old Female,</b> ██████, BC 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."
<b>PATIENT E, 60-Year-Old Male</b> ██████ ON 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."
<b>PATIENT F, 47-Year-Old Female,</b> ██████, ON 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. "

<p><b>PATIENT G, 59-Year-Old Female,</b> [REDACTED], NS  Diagnosed March 2017  Rectal Cancer, RAS WT, BRAF-WT  Pelvic Disease (Anterior to vagina, attached to urethra, in levator muscle, pelvic floor)</p>	<p>“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 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><b>PATIENT H, 52-Year-Old Male</b>  [REDACTED], On  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><b>PATIENT I, 70 Years Old Female,</b> [REDACTED], On  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><b>PATIENT J, 58-Year-Old Female,</b> [REDACTED] NS  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.”

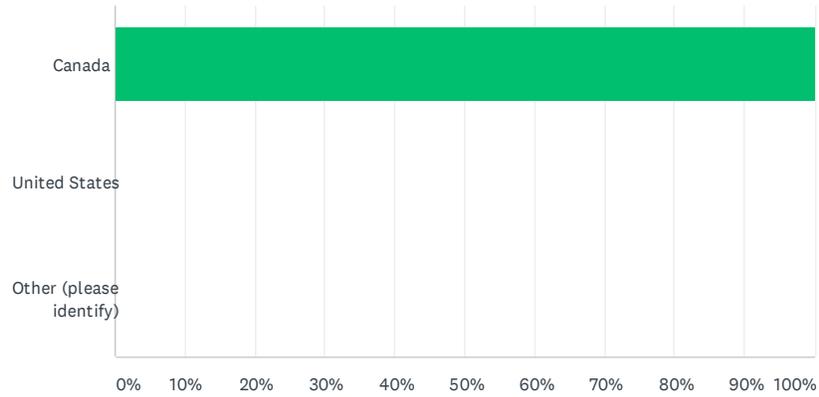
Answered: 85 Skipped: 0



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

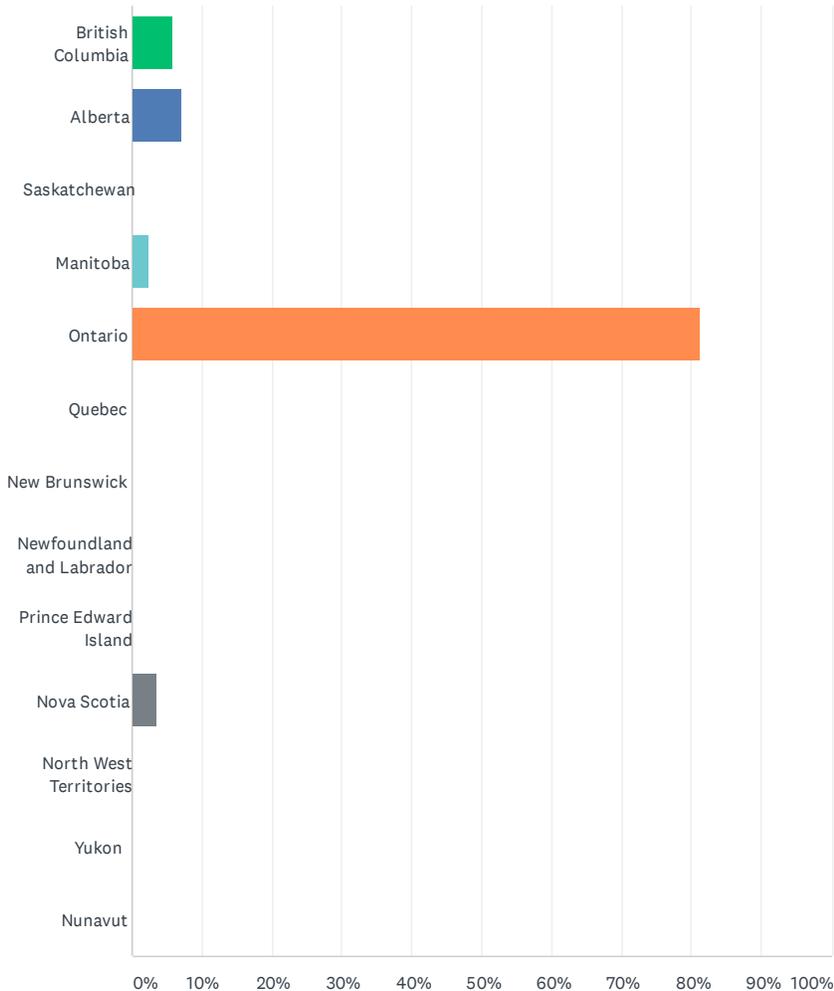


ANSWER CHOICES	RESPONSES
Canada	100.00% 85
United States	0.00% 0
Other (please identify)	0.00% 0
<b>TOTAL</b>	<b>85</b>

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

### Q3 If Canada, please indicate your province or territory:

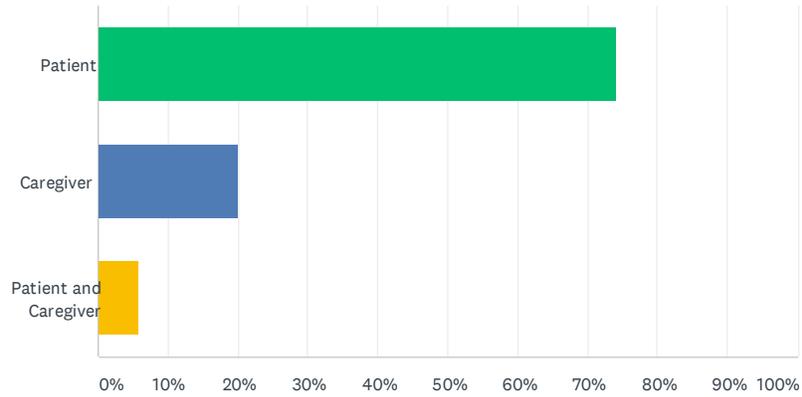
Answered: 85 Skipped: 0



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
<b>TOTAL</b>		<b>85</b>

### Q4 Are you a:

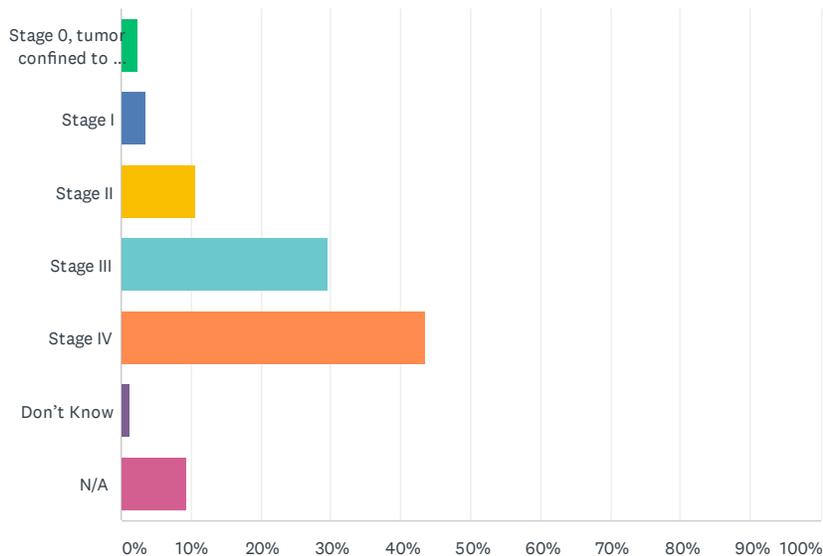
Answered: 85 Skipped: 0



ANSWER CHOICES	RESPONSES	
Patient	74.12%	63
Caregiver	20.00%	17
Patient and Caregiver	5.88%	5
<b>TOTAL</b>		<b>85</b>

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

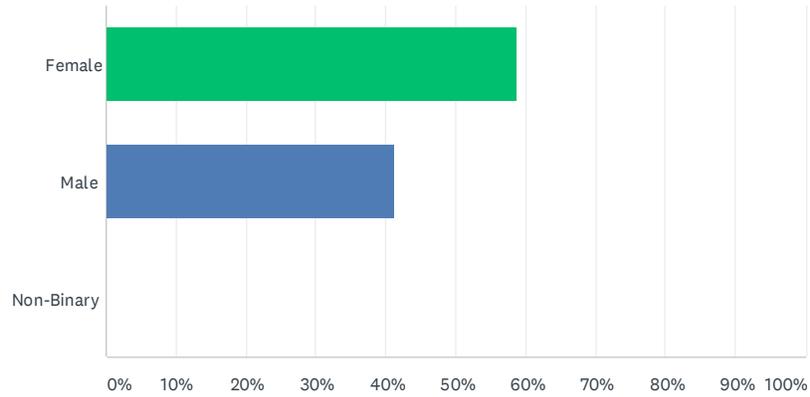
Answered: 85 Skipped: 0



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
<b>TOTAL</b>		<b>85</b>

### Q6 Are you:

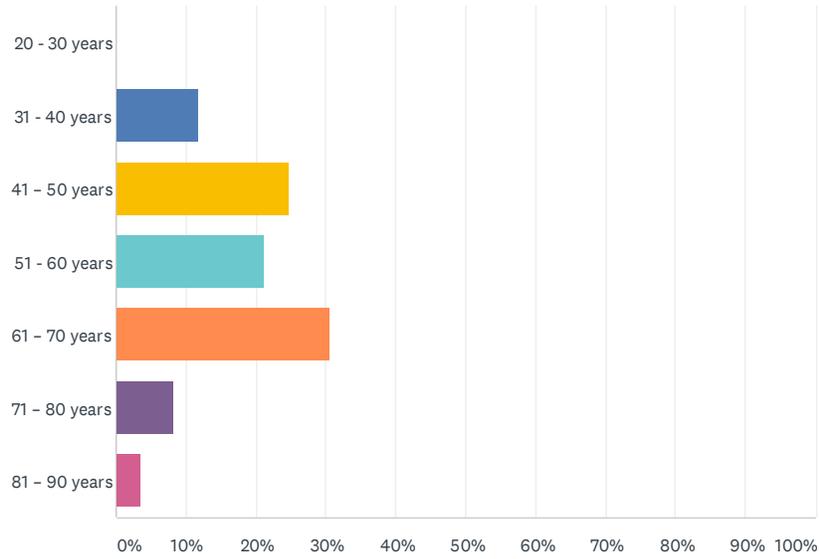
Answered: 85 Skipped: 0



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

### Q7 How old are you:

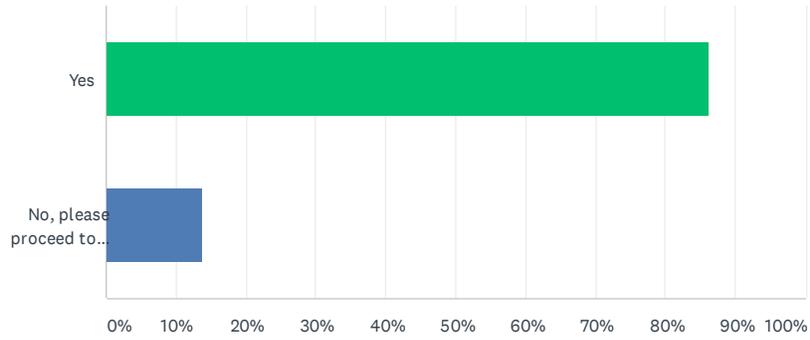
Answered: 85 Skipped: 0



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
<b>TOTAL</b>		<b>85</b>

### Q8 Have you experienced any symptoms from colorectal cancer?

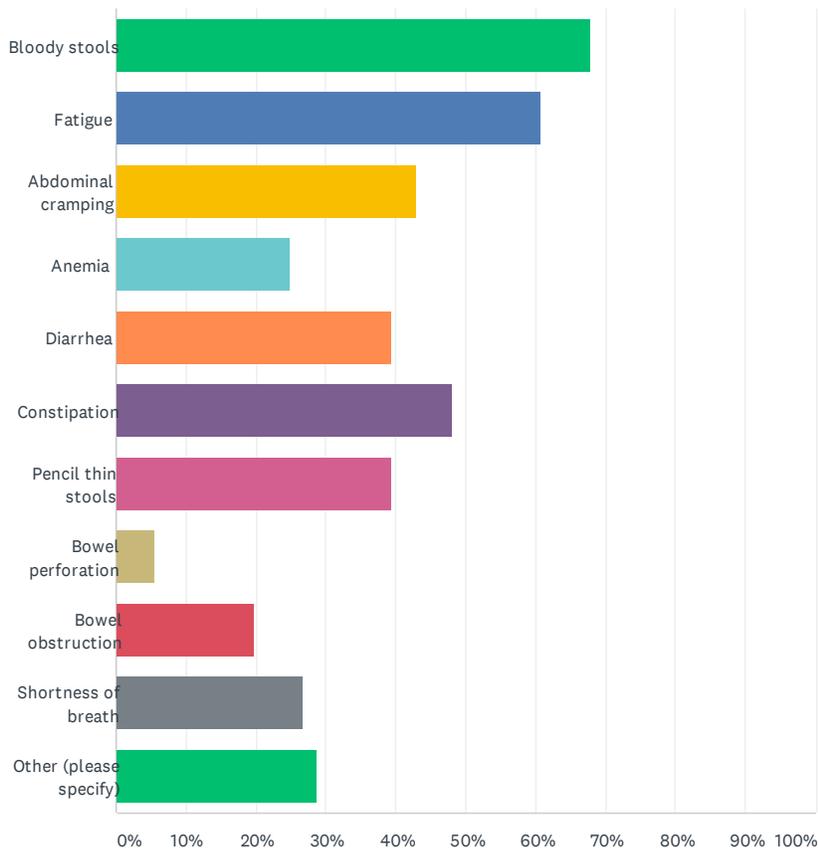
Answered: 65 Skipped: 20



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

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

Answered: 56 Skipped: 29



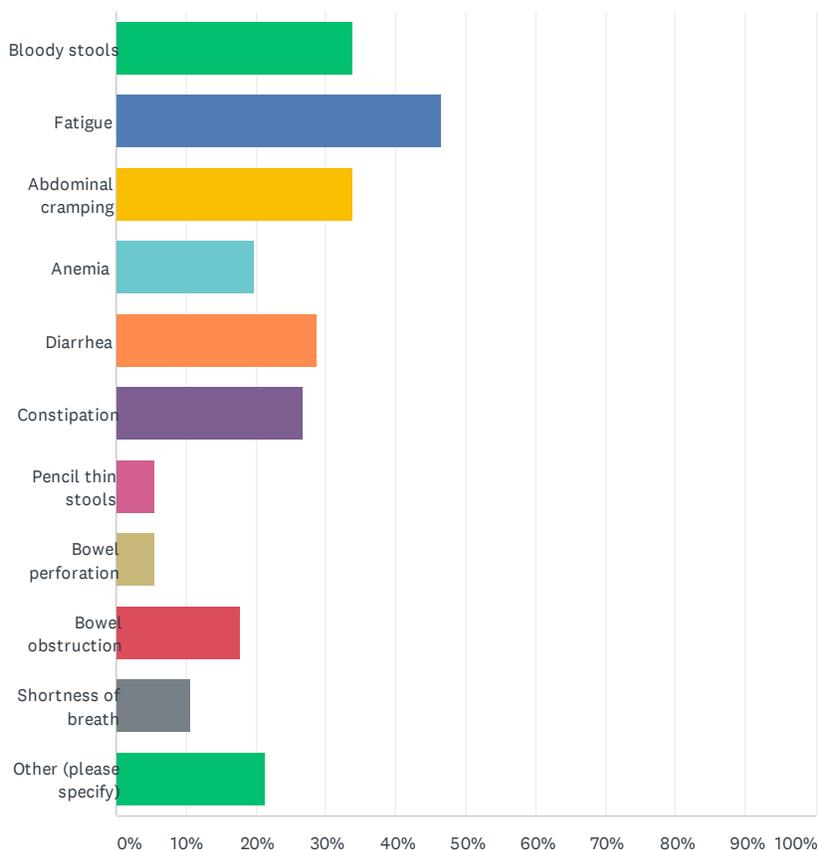
ANSWER CHOICES	RESPONSES
Bloody stools	67.86% 38
Fatigue	60.71% 34
Abdominal cramping	42.86% 24
Anemia	25.00% 14
Diarrhea	39.29% 22
Constipation	48.21% 27
Pencil thin stools	39.29% 22
Bowel perforation	5.36% 3
Bowel obstruction	19.64% 11
Shortness of breath	26.79% 15
Other (please specify)	28.57% 16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



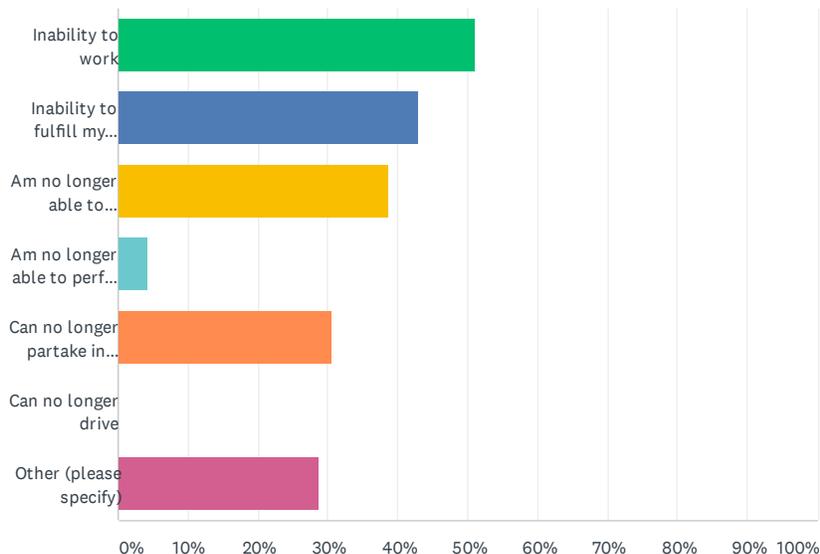
ANSWER CHOICES	RESPONSES
Bloody stools	33.93% 19
Fatigue	46.43% 26
Abdominal cramping	33.93% 19
Anemia	19.64% 11
Diarrhea	28.57% 16
Constipation	26.79% 15
Pencil thin stools	5.36% 3
Bowel perforation	5.36% 3
Bowel obstruction	17.86% 10
Shortness of breath	10.71% 6
Other (please specify)	21.43% 12
Total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



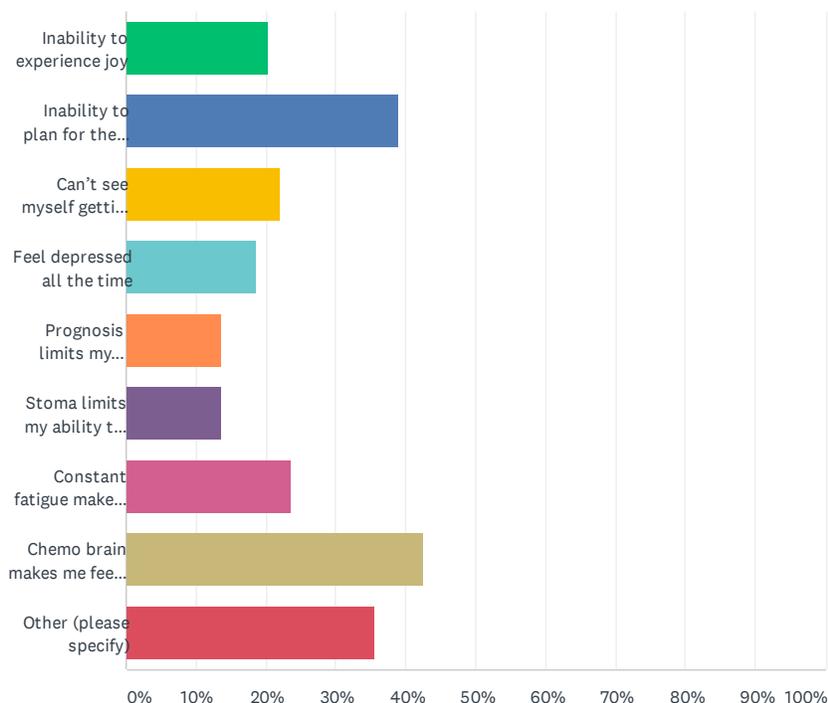
ANSWER CHOICES	RESPONSES	
Inability to work	51.02%	25
Inability to fulfill my family obligations	42.86%	21
Am no longer able to exercise	38.78%	19
Am no longer able to perform volunteer work	4.08%	2
Can no longer partake in social activities	30.61%	15
Can no longer drive	0.00%	0
Other (please specify)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



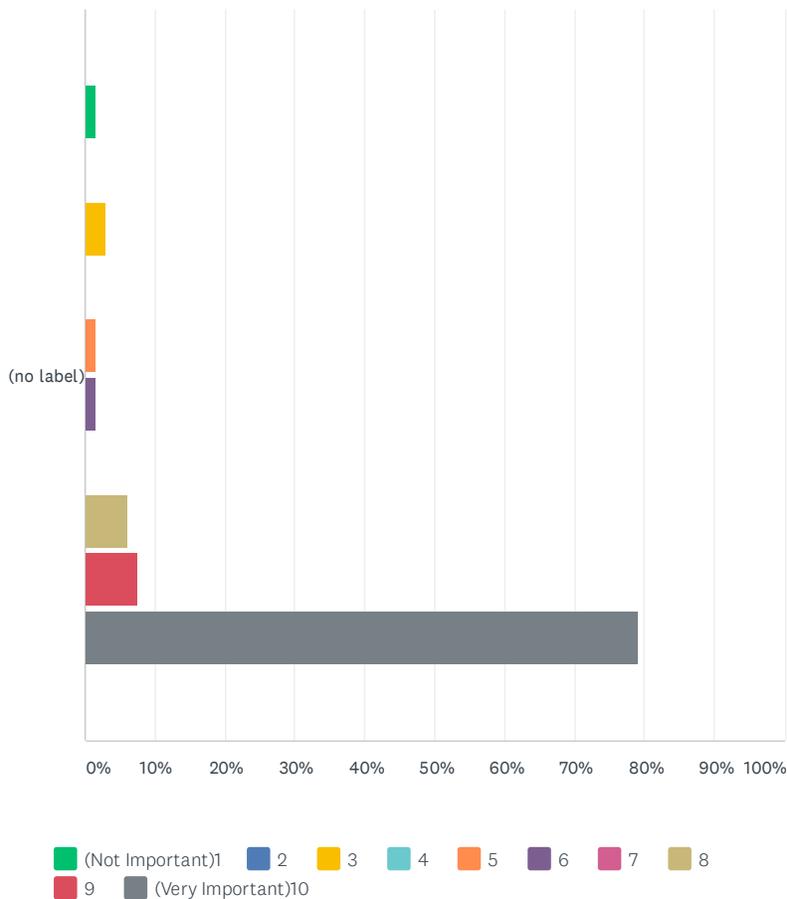
ANSWER CHOICES	RESPONSES	
Inability to experience joy	20.34%	12
Inability to plan for the future or think about the future	38.98%	23
Can't see myself getting better	22.03%	13
Feel depressed all the time	18.64%	11
Prognosis limits my ability to cope	13.56%	8
Stoma limits my ability to leave the house 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”?

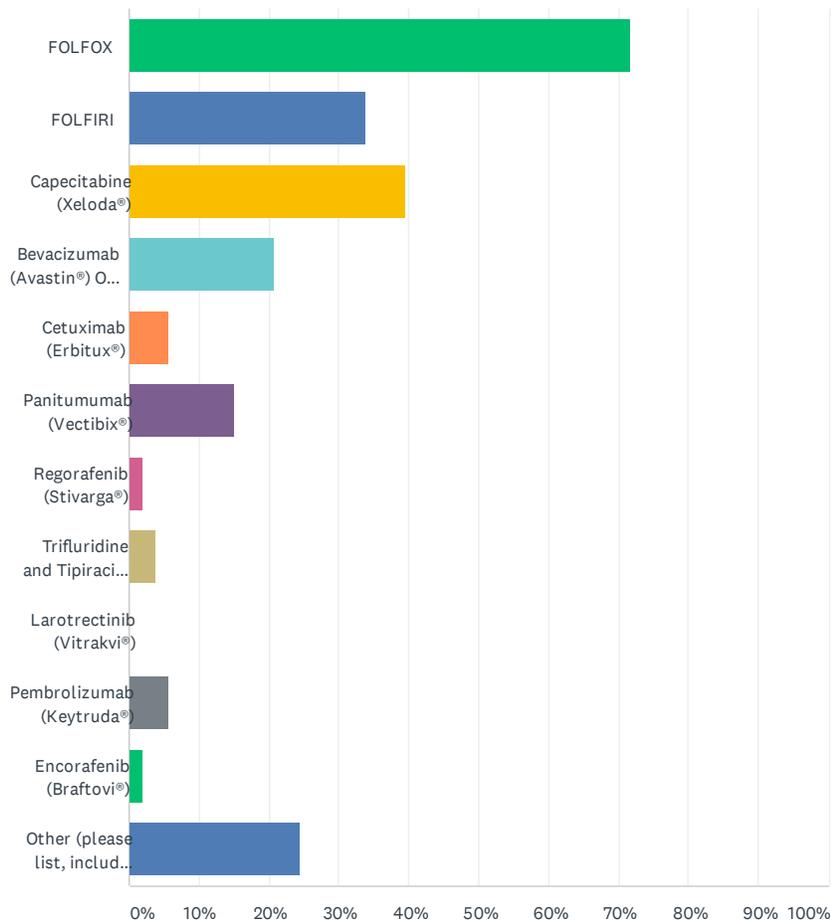
Answered: 67 Skipped: 18



	(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



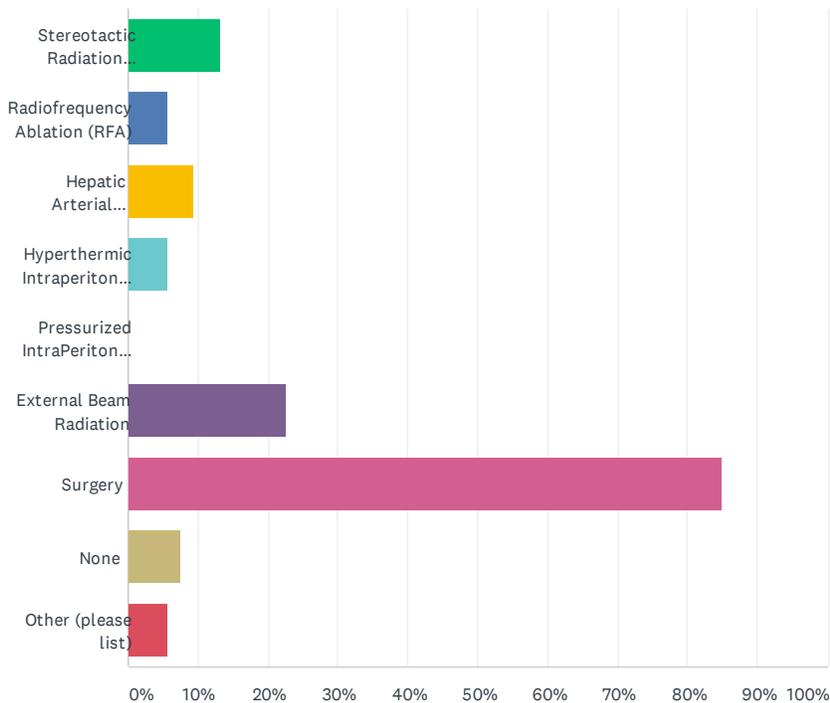
ANSWER CHOICES	RESPONSES	
FOLFOX	71.70%	38
FOLFIRI	33.96%	18
Capecitabine (Xeloda®)	39.62%	21
Bevacizumab (Avastin®) OR MVASI	20.75%	11
Cetuximab (Erbix®)	5.66%	3
Panitumumab (Vectibix®)	15.09%	8
Regorafenib (Stivarga®)	1.89%	1
Trifluridine and Tipiracil (Lonsurf®)	3.77%	2
Larotrectinib (Vitrakvi®)	0.00%	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

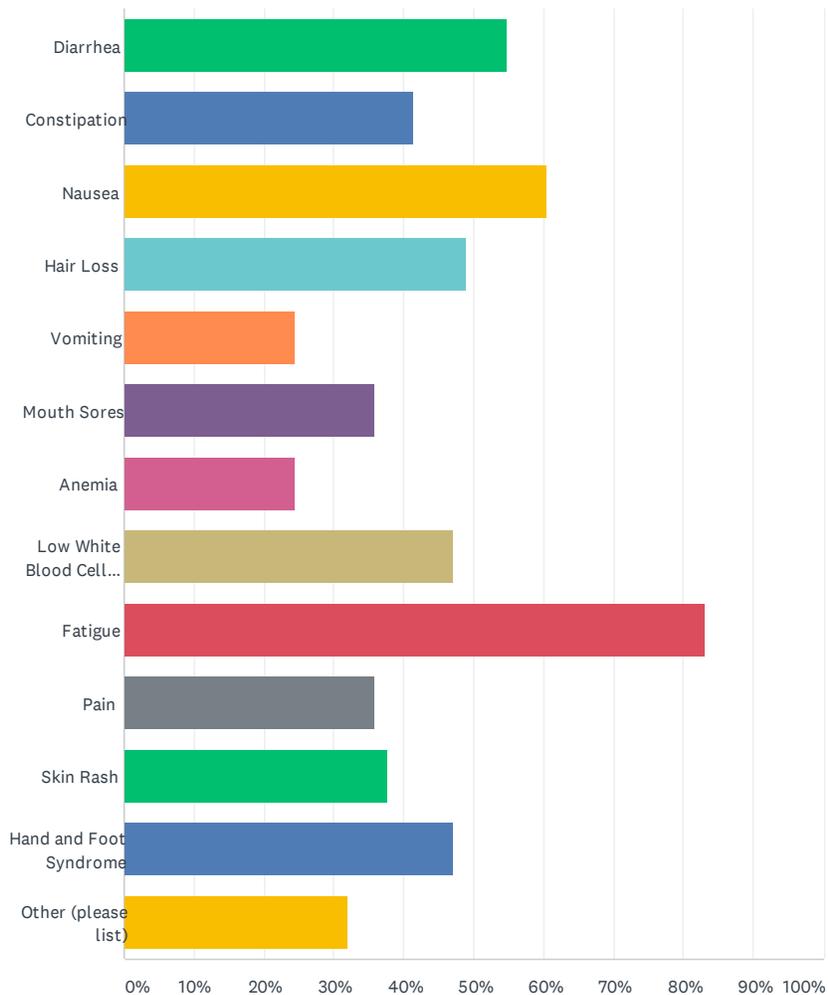


ANSWER CHOICES		RESPONSES	
Stereotactic Radiation Therapy (SRT)		13.21%	7
Radiofrequency Ablation (RFA)		5.66%	3
Hepatic Arterial Infusion Pump (HAIP) Chemotherapy		9.43%	5
Hyperthermic Intraperitoneal Chemotherapy (HIPEC)		5.66%	3
Pressurized IntraPeritoneal Aerosol Chemotherapy (PIPAC)		0.00%	0
External 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



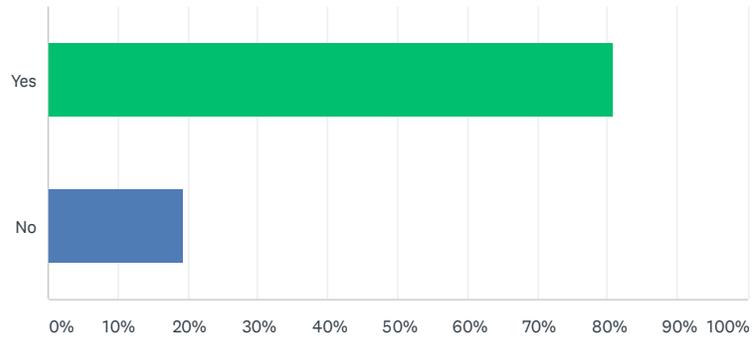
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

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?

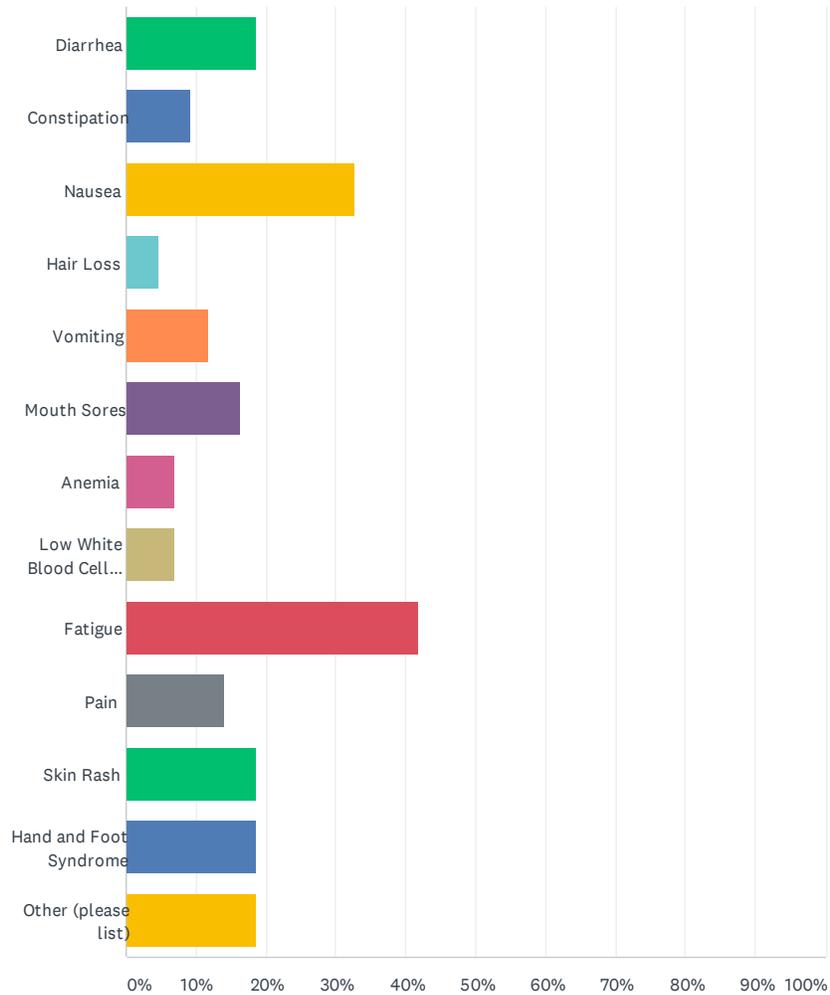
Answered: 52 Skipped: 33



ANSWER CHOICES	RESPONSES	
Yes	80.77%	42
No	19.23%	10
<b>TOTAL</b>		<b>52</b>

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



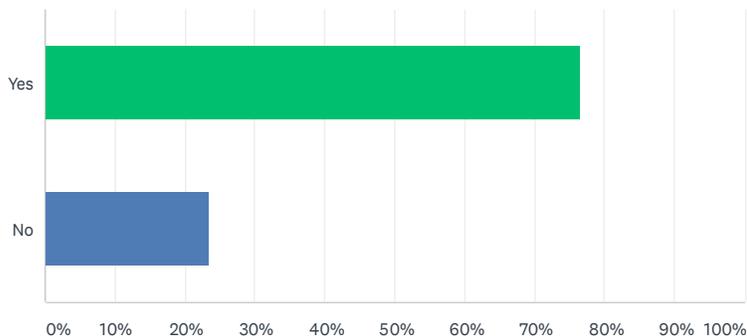
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

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



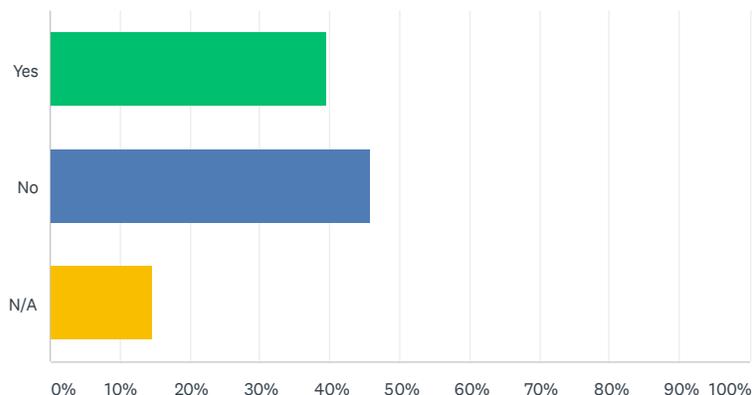
ANSWER CHOICES	RESPONSES	
Yes	76.47%	39
No	23.53%	12
TOTAL		51

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

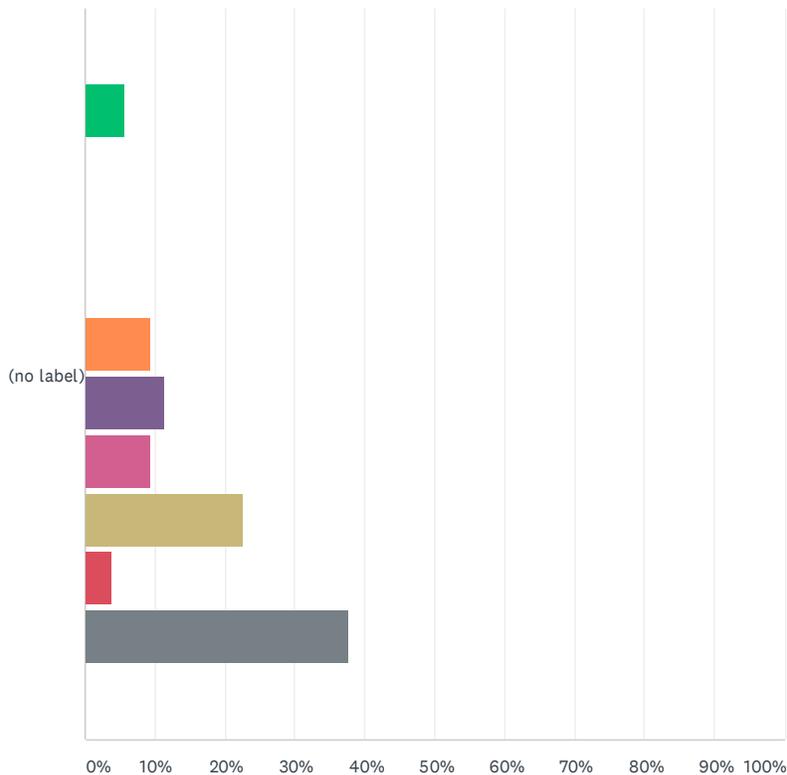


ANSWER CHOICES	RESPONSES	
Yes	39.58%	19
No	45.83%	22
N/A	14.58%	7
<b>TOTAL</b>		<b>48</b>

#	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

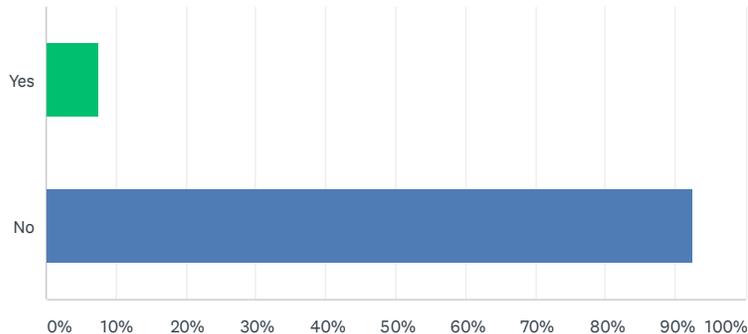


■ 1 (Not important) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Very important)

	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

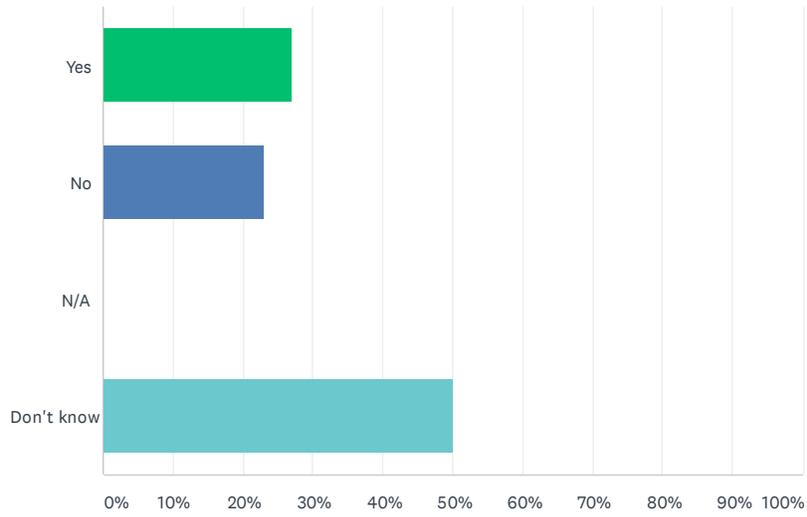


ANSWER CHOICES	RESPONSES	
Yes	7.55%	4
No	92.45%	49
<b>TOTAL</b>		<b>53</b>

#	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?

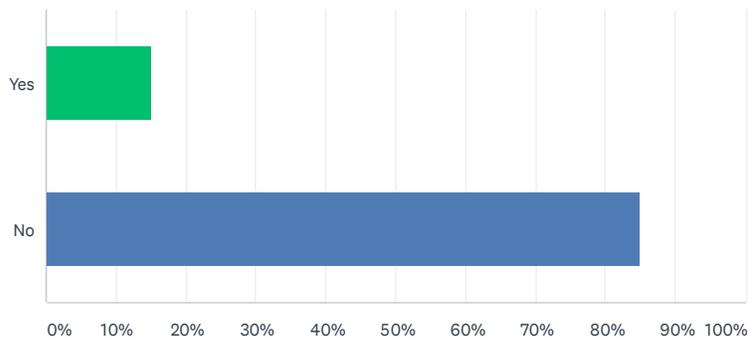
Answered: 52 Skipped: 33



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

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

Answered: 53 Skipped: 32

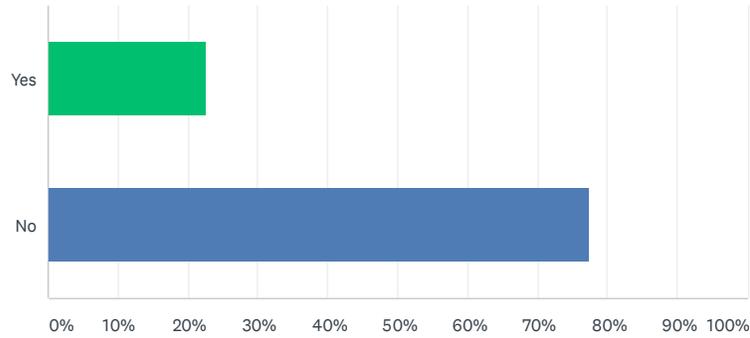


ANSWER CHOICES	RESPONSES
Yes	15.09% 8
No	84.91% 45
<b>TOTAL</b>	<b>53</b>

#	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?**

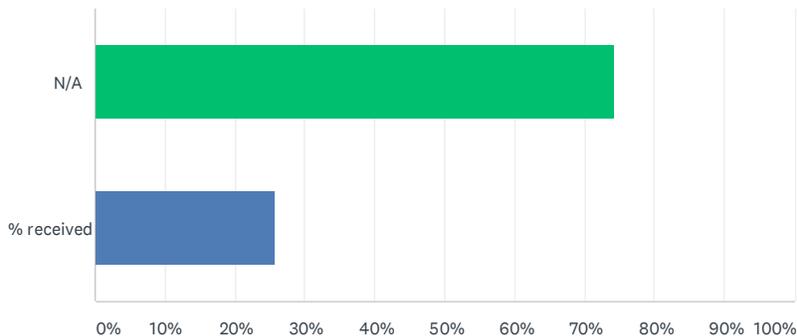
Answered: 53 Skipped: 32



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

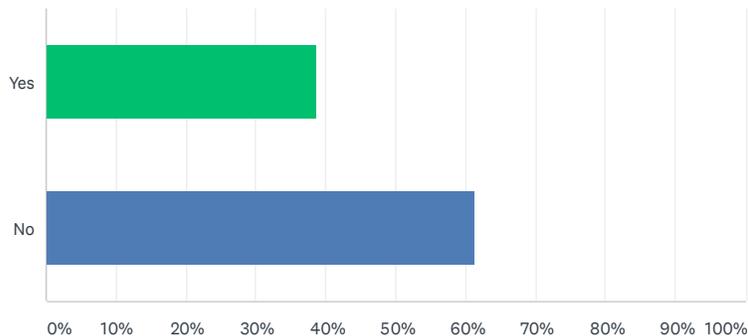


ANSWER CHOICES	RESPONSES	
N/A	74.36%	29
% received	25.64%	10
<b>TOTAL</b>		<b>39</b>

#	% 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

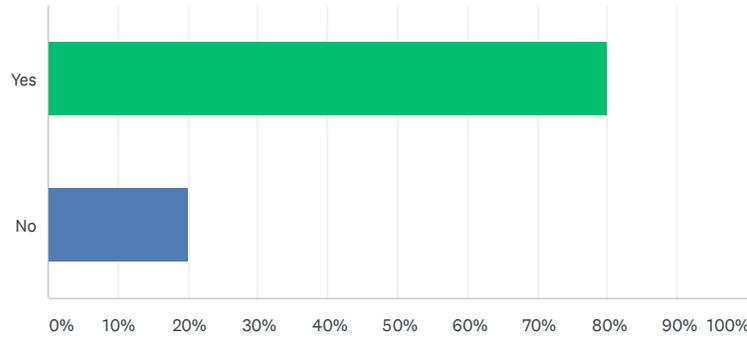


ANSWER CHOICES	RESPONSES	
Yes	38.78%	19
No	61.22%	30
<b>TOTAL</b>		<b>49</b>

#	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



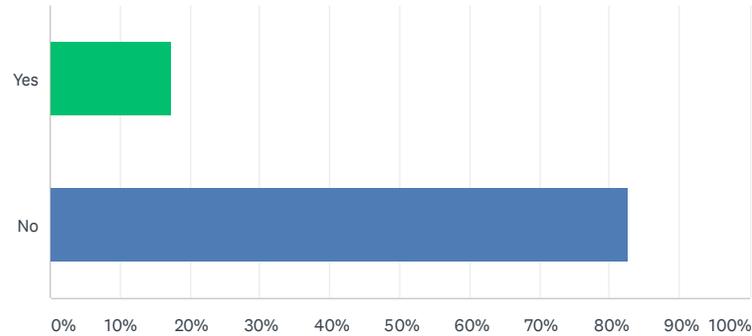
ANSWER CHOICES	RESPONSES	
Yes	80.00%	40
No	20.00%	10
TOTAL		50

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

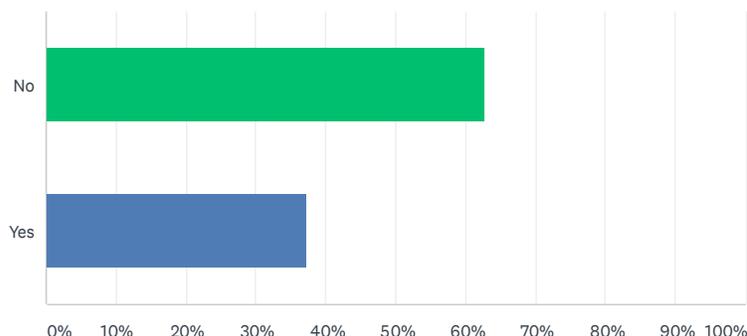


ANSWER CHOICES	RESPONSES	
Yes	17.31%	9
No	82.69%	43
<b>TOTAL</b>		<b>52</b>

#	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

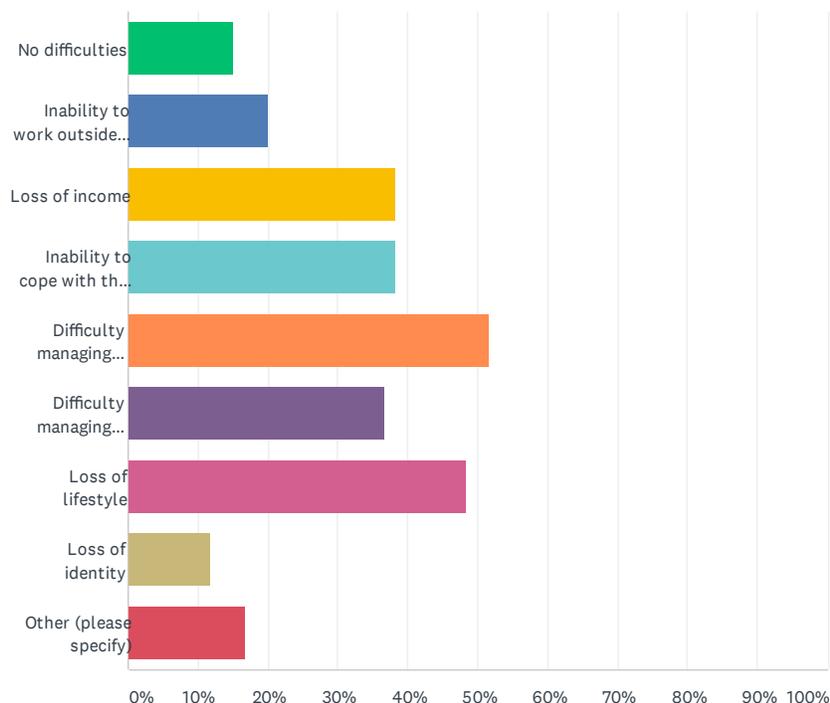


ANSWER CHOICES	RESPONSES	
No	62.75%	32
Yes	37.25%	19
TOTAL		51

#	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 hsvc 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



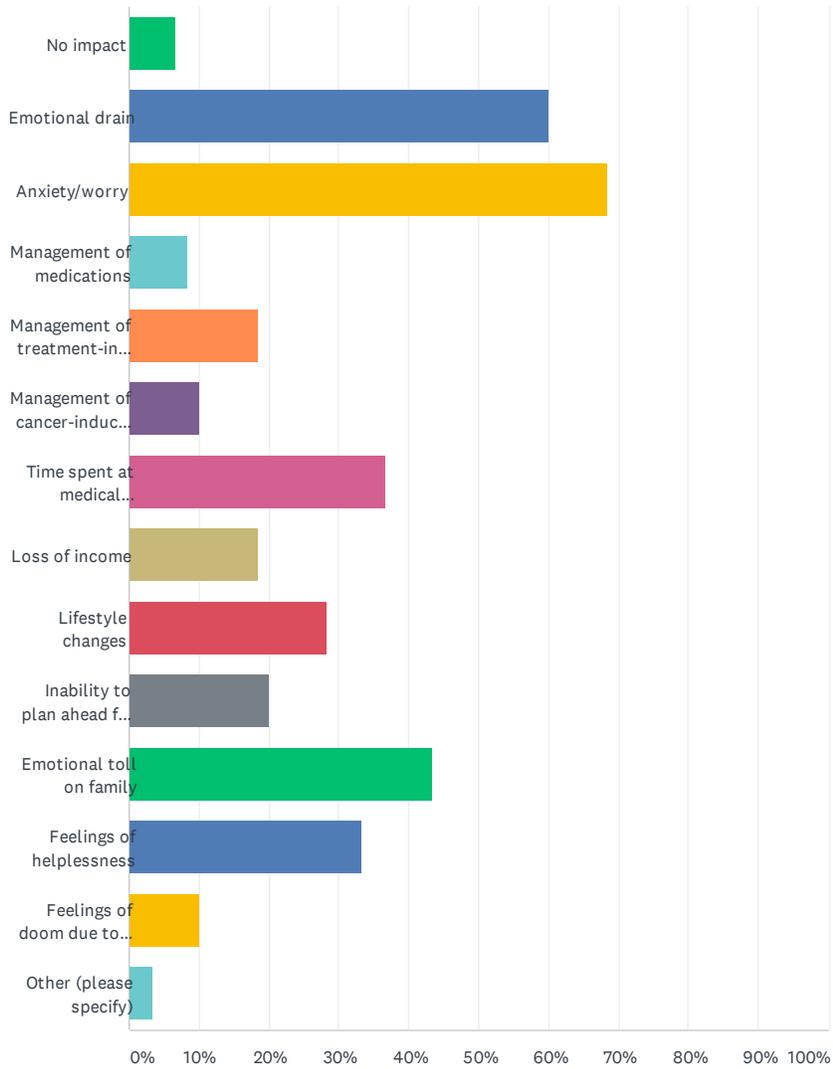
ANSWER CHOICES	RESPONSES	
No difficulties	15.00%	9
Inability to work outside of the home	20.00%	12
Loss of income	38.33%	23
Inability to cope with the diagnosis	38.33%	23
Difficulty managing treatment-induced side effects	51.67%	31
Difficulty managing cancer-induced symptoms	36.67%	22
Loss of lifestyle	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



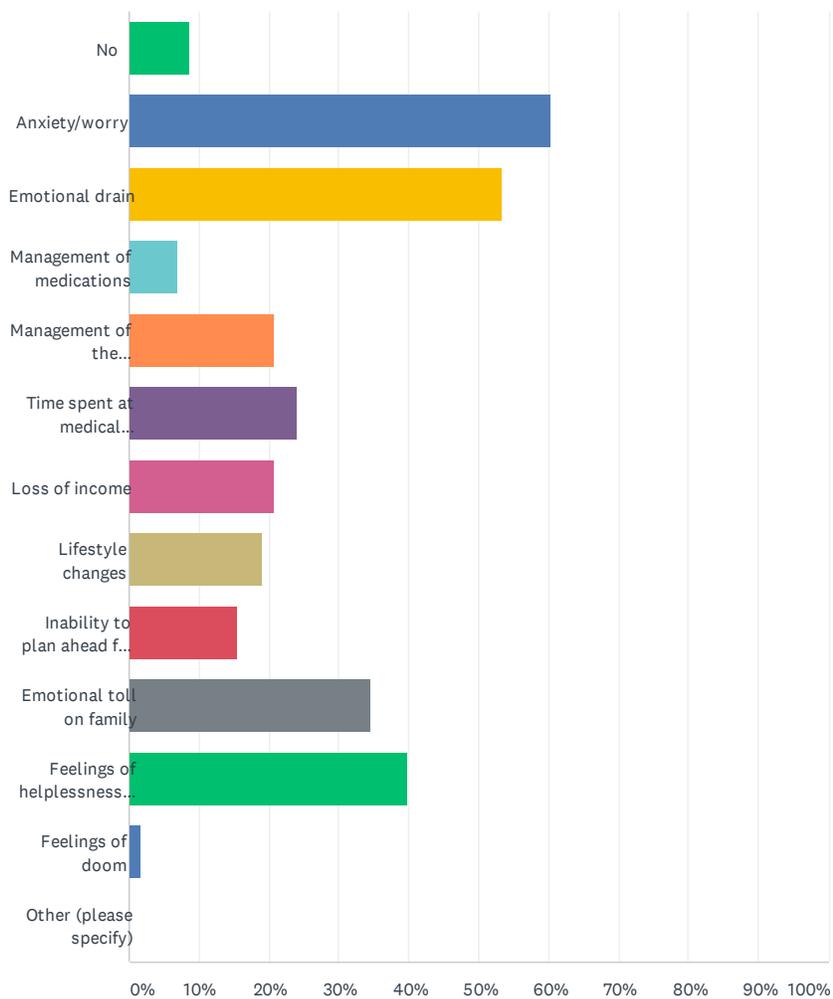
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

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



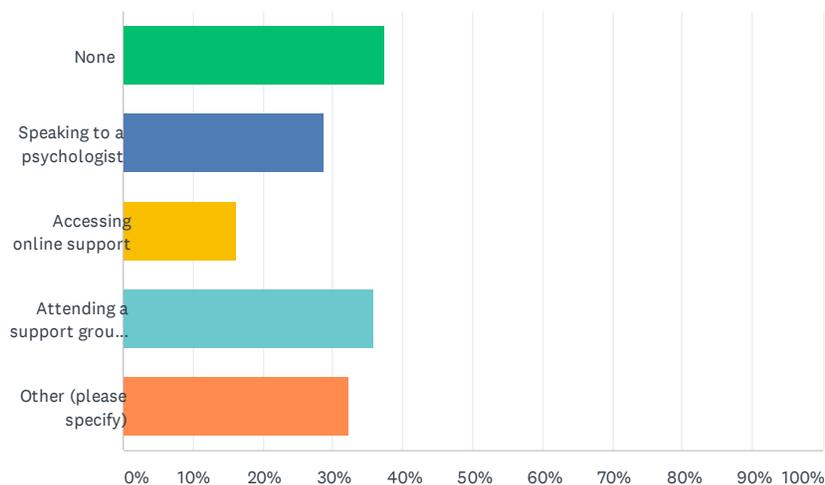
Patient & Caregiver Perspective Survey – Colorectal Cancer Resource & Action Network (CCRAN)

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

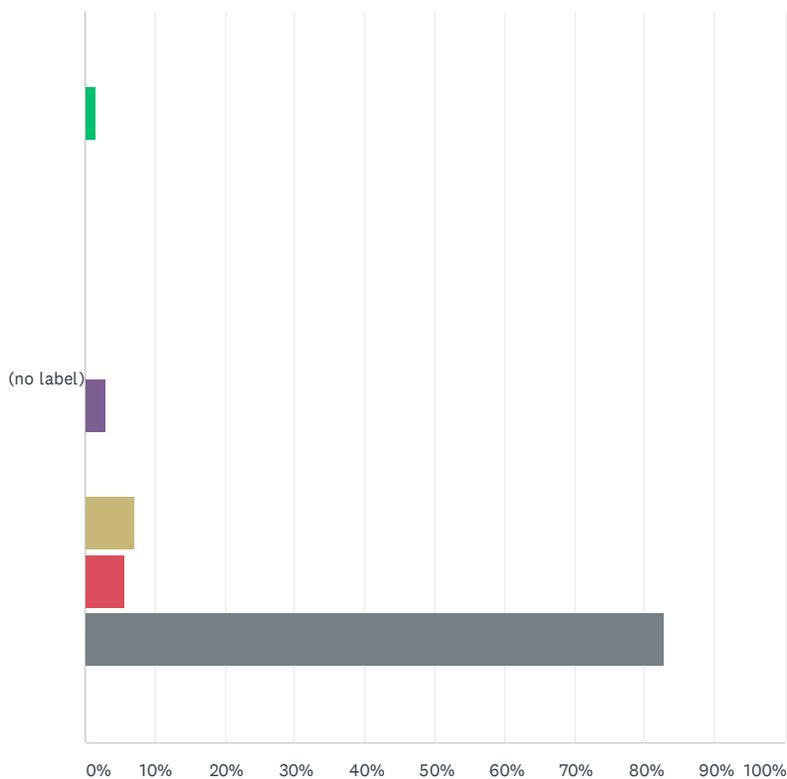


ANSWER CHOICES	RESPONSES
None	37.50% 21
Speaking to a psychologist	28.57% 16
Accessing online support	16.07% 9
Attending a support group (please specify which group below)	35.71% 20
Other (please specify)	32.14% 18
Total Respondents: 56	

#	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	██████████ 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

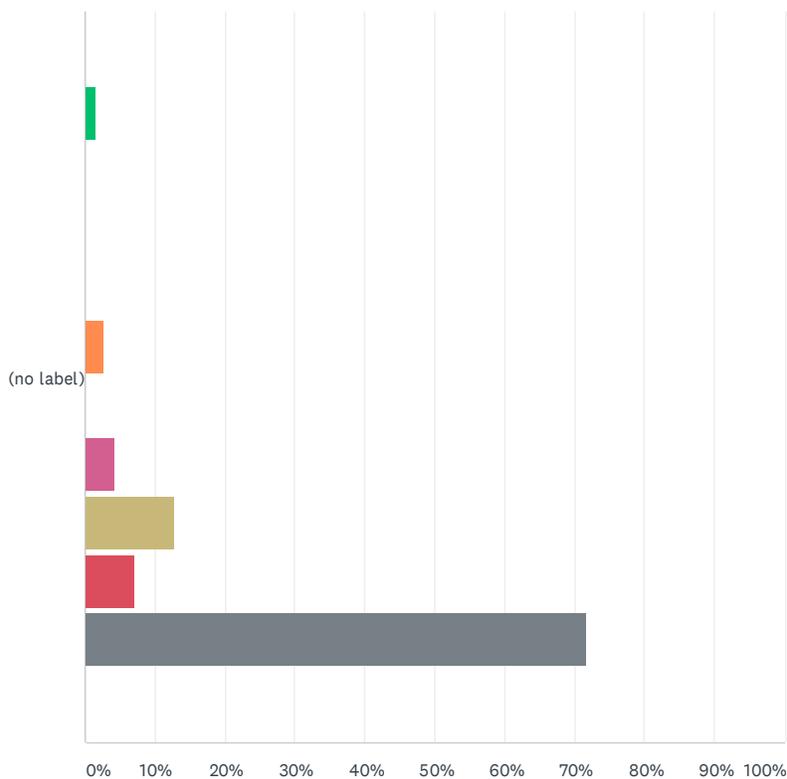


■ 1 (Not important) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Very important)

	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

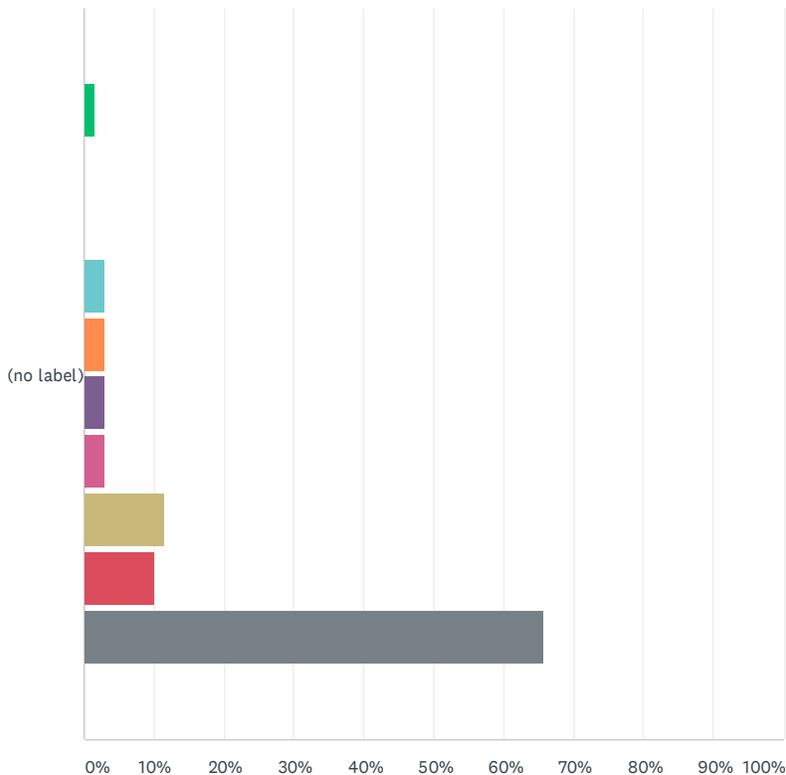


■ 1 (Not important) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Very important)

	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

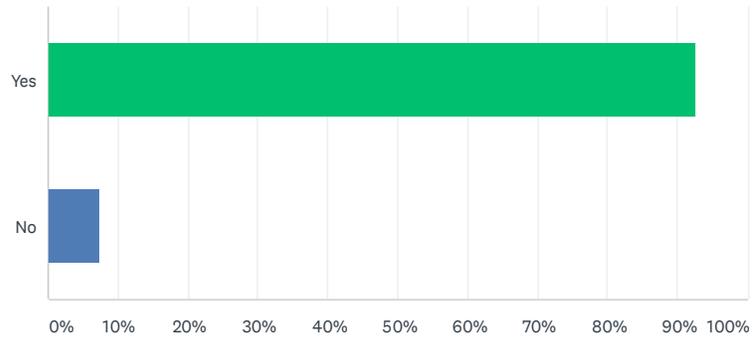


■ 1 (Not important) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Very important)

	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?

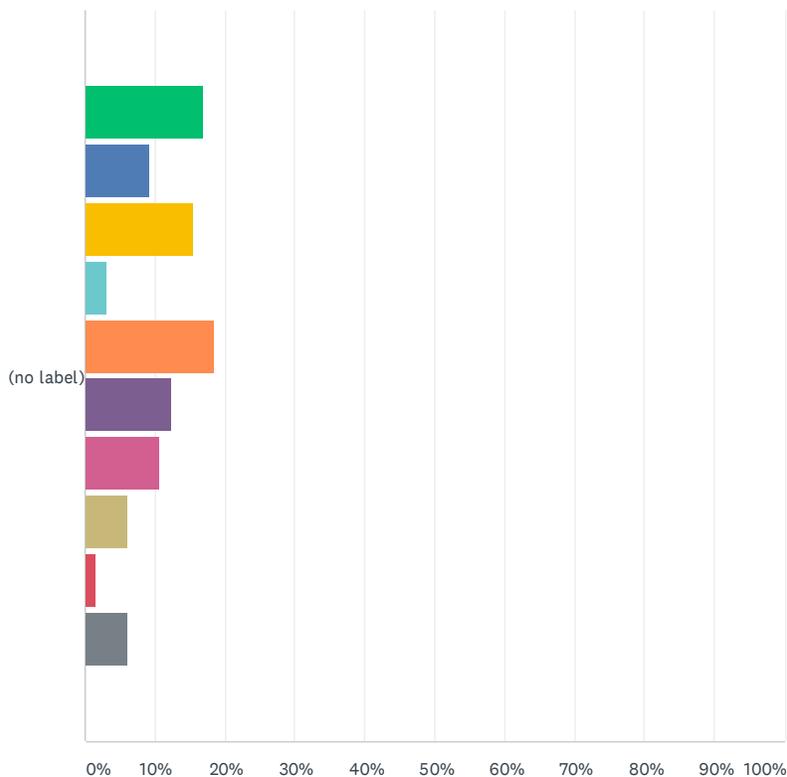
Answered: 69 Skipped: 16



ANSWER CHOICES	RESPONSES	
Yes	92.75%	64
No	7.25%	5
<b>TOTAL</b>		<b>69</b>

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

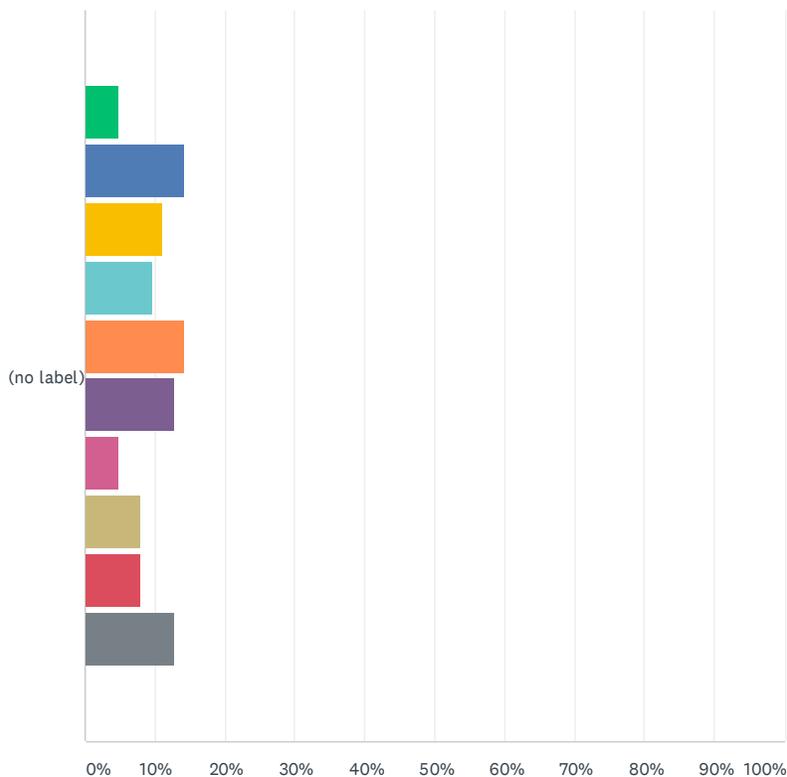


■ 1 (No side effects) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Significant side effects)

	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

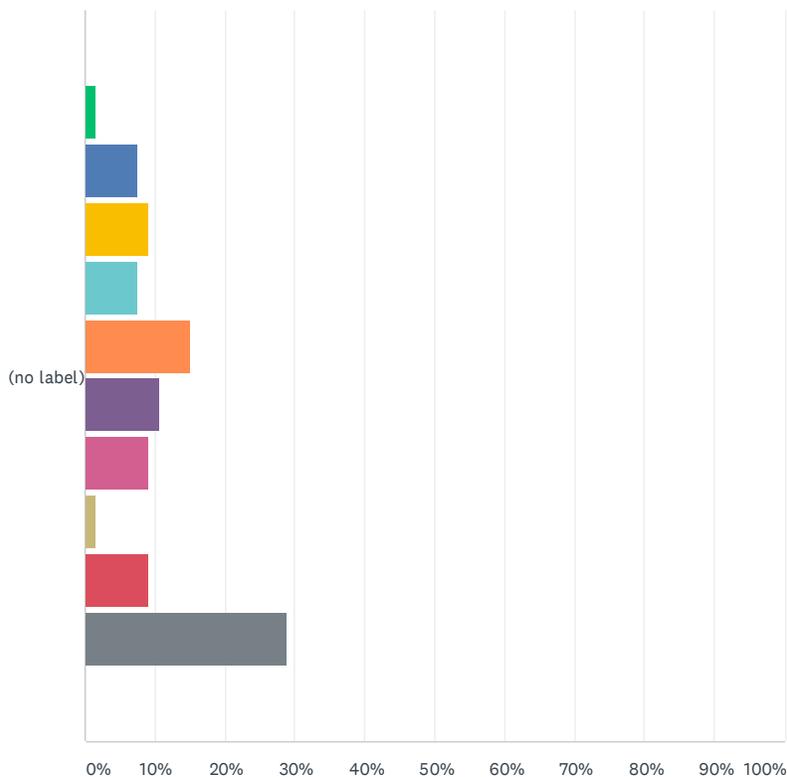


■ 1 (No side effects) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Significant side effects)

	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

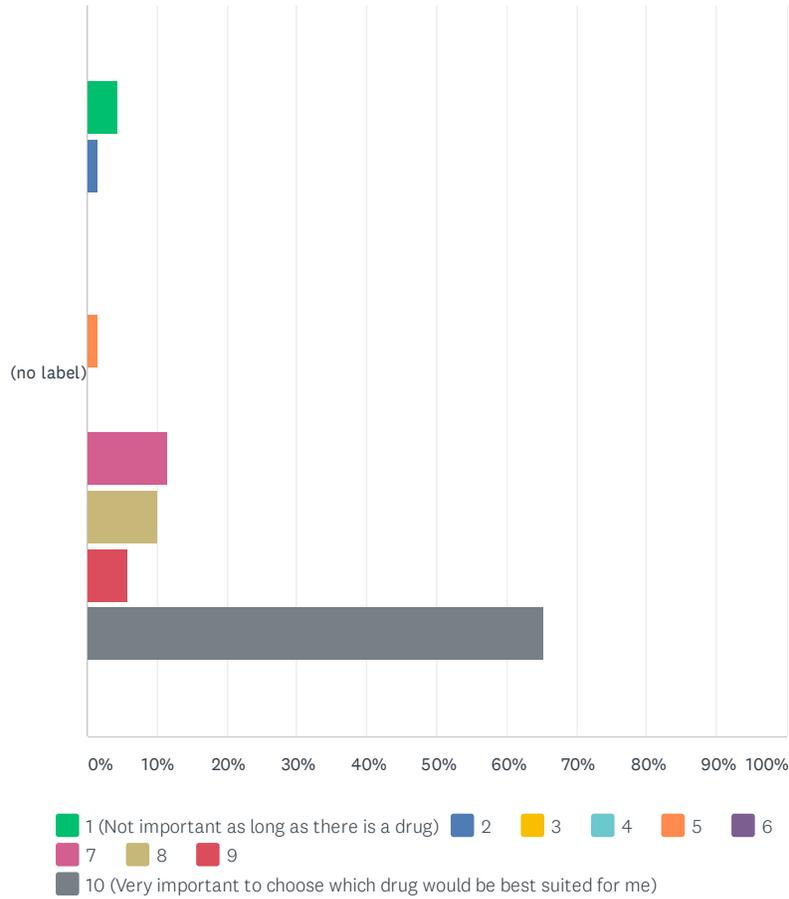


■ 1 (No side effects) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Significant side effects)

	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?

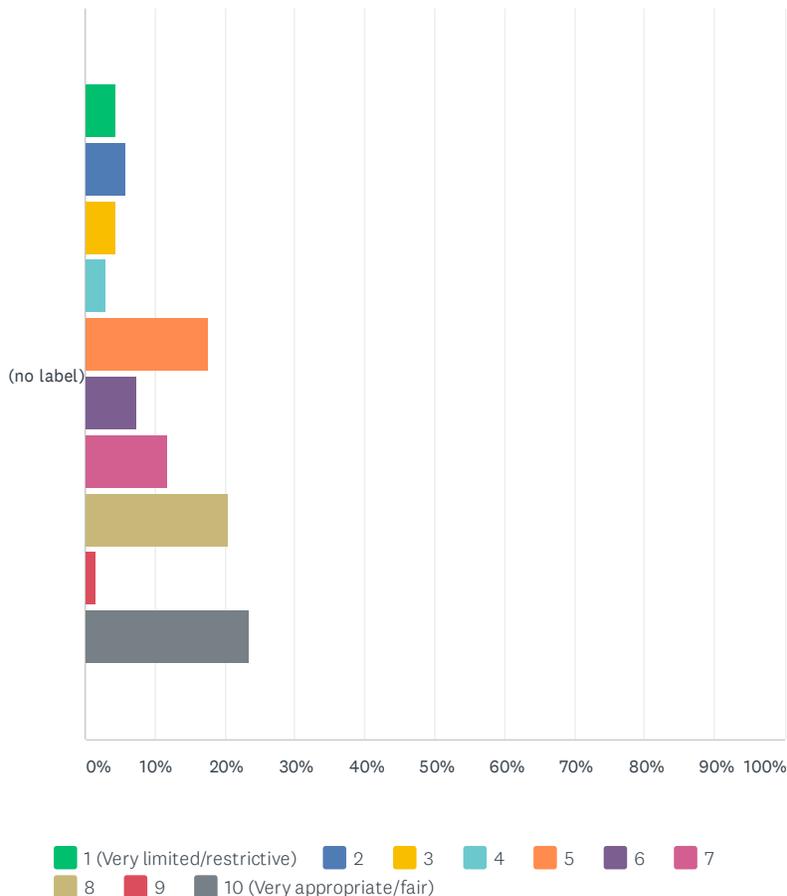
Answered: 69 Skipped: 16



	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?

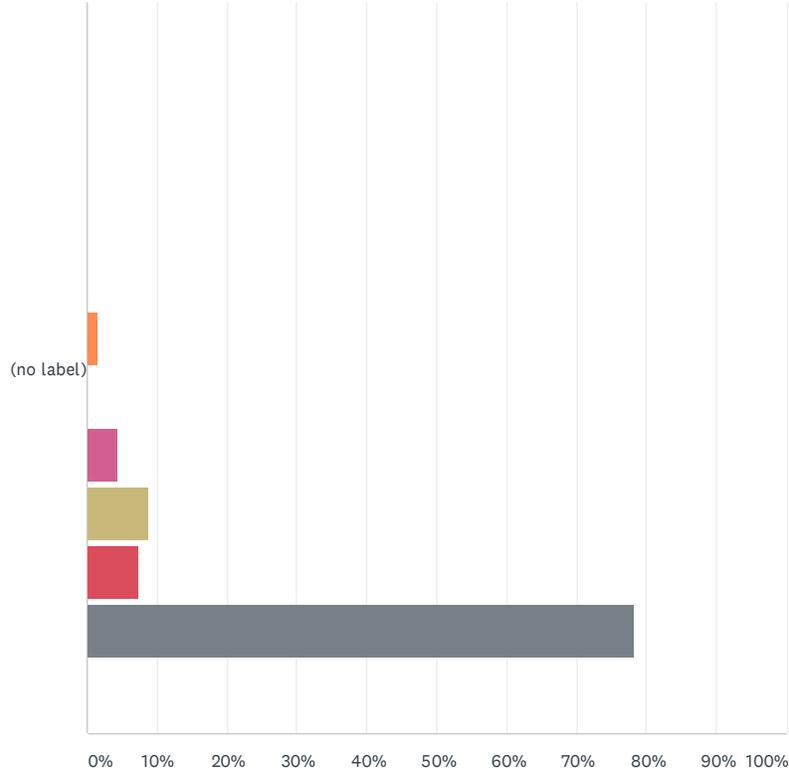
Answered: 68 Skipped: 17



	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%	68
	3	4	3	2	12	5	8	14	1	16	

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

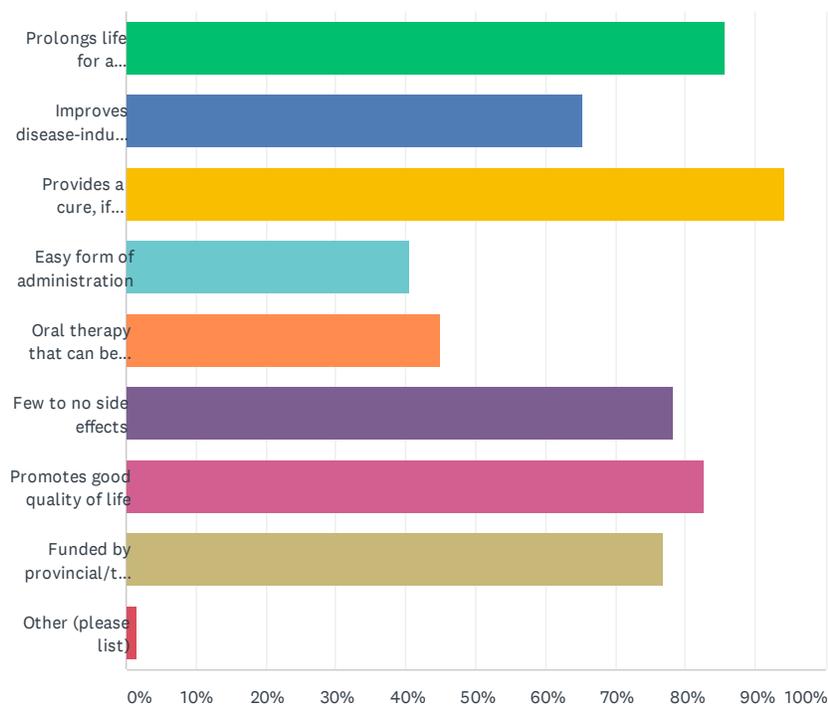


■ 1 (Not important) 
 ■ 2 
 ■ 3 
 ■ 4 
 ■ 5 
 ■ 6 
 ■ 7 
 ■ 8 
 ■ 9 
 ■ 10 (Very important)

	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

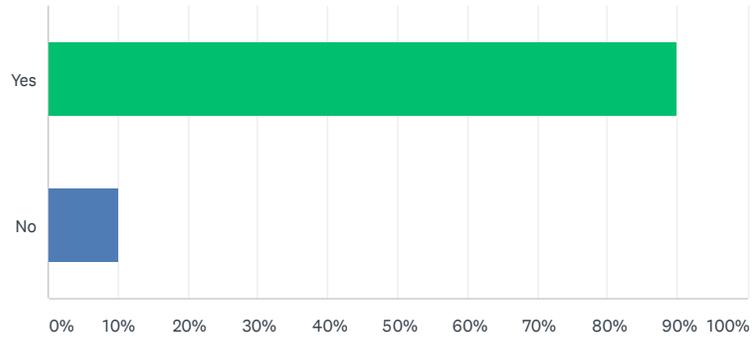


ANSWER CHOICES	RESPONSES
Prolongs life for a substantial amount of time	85.51% 59
Improves disease-induced symptoms	65.22% 45
Provides a cure, if possible	94.20% 65
Easy form of administration	40.58% 28
Oral therapy that can be taken at home	44.93% 31
Few to no side effects	78.26% 54
Promotes good quality 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
<b>TOTAL</b>		<b>69</b>

# 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	██████████ 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)

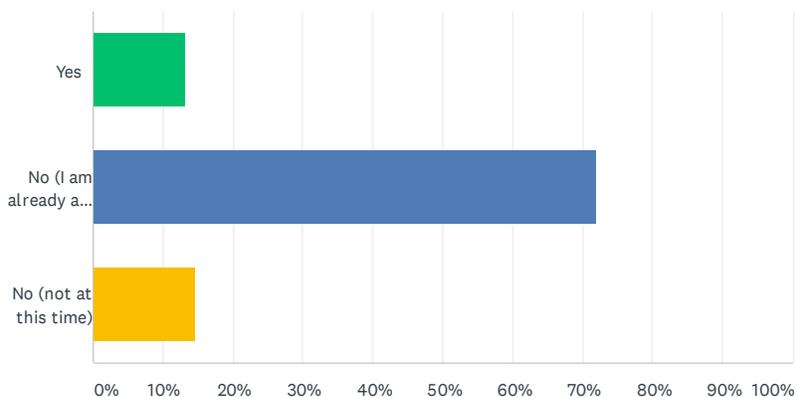
	immunotherapy clinical trial gave us the results we were desperately waiting for.	
20	My cancer is in remission for 2 1/2 years now, I am hoping for a cure.... any access to further therapies will be more than welcome to treat this terrible disease affecting millions of Canadians each year	12/8/2020 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
<b>TOTAL</b>		<b>68</b>

#	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	I believe I am. [REDACTED]	12/6/2020 5:56 PM