

A patient-oriented approach to determine the top ten research priorities for early stage colorectal cancer.

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Abstract

Background: Colorectal cancer (CRC) is the third most diagnosed cancer. Earlier detection and improved treatments mean that patients are living longer. The perspectives of patients, caregivers, and clinicians are important to our understanding of what problems CRC patients encounter and deem as priorities for future research. Partnering with Canadian clinicians, patients, and researchers, our goal was to determine research priorities for CRC in Canada.

Methods: We followed the well-established priority setting partnership (PSP) outlined by the James Lind Alliance. The goal was to identify and prioritize unanswered questions about early stage (I-III) CRC. Patients, caregivers, and clinicians were surveyed. The responses were categorized using thematic analysis to generate a list of unique questions. An interim prioritization survey was conducted to determine a shorter list of questions which was then reviewed at a final meeting where consensus was used to determine the top ten priorities.

Results: 370 responses were submitted by 185 individuals. The responses were refined to determine a list of 66 unique unanswered questions. The interim prioritization survey was answered by 25 respondents to arrive at a list of top 30 questions. The final consensus meeting included 17 individuals who agreed to the top ten research priorities. The priorities covered a range of topics including screening, treatment, recurrence, side effects management, and decision making.

Interpretation: We determined the top research priorities for early stage CRC using a collaborative partnership of stakeholders from across Canada. The priorities were determined to have significant value and should be pursued by researchers.

Plain language summary

Colorectal cancer (CRC) is the third most commonly diagnosed cancer. The perspectives of patients, caregivers, and clinicians are important to our understanding of what problems CRC patients encounter and deem as priorities for future research. We partnered with clinicians, patients, and researchers from across Canada to determine the top research priorities for early stage CRC. We followed a well-established process to partner with patients as outlined by the James Lind Alliance. Patients, caregivers, and clinicians were surveyed to elicit their questions. The responses were categorized and a list of potential research questions was generated. A second survey was conducted to determine a shorter list of questions which was then reviewed at a final meeting where consensus was used to determine the top ten priorities. The top priority was the prevention of recurrence of CRC. Other priorities covered a range of topics including screening, treatment, recurrence, side effects management, and decision making. Our collaborative partnership of stakeholders from across Canada highlighted 10 priorities for future research for CRC. We encourage funding agencies and research teams to pursue these research questions.

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Background

Colorectal cancer (CRC) is the third most commonly diagnosed cancer in Canada with early stage (I-III) disease representing approximately 80% of CRC diagnoses.¹ Earlier detection and improved treatments means patients are living longer after a diagnosis.² Despite potentially being cured of their disease, research has shown CRC survivors may have negative long-term impacts to their physical and mental health,^{3,4} their quality of life,⁵ and have difficulty navigating the health care system.⁵ With an anticipated increase in CRC incidence and growing population of survivors, more research on survivorship is needed. While some research exists,³⁻⁹ there are still many gaps in knowledge about CRC survivorship.

Tackling this vast topic of CRC survivorship is difficult given the lack of clarity regarding research priorities. Priorities for research in CRC have generally focused on new drug treatments or have been determined by researchers with minimal patient engagement.¹⁰ The unique perspectives of patients and those caring for them (caregivers and clinicians) are rarely sought to determine research priorities.¹¹ As patients are the ones living with their disease, their perspectives about what problems they encounter and what problems are priorities for future research are important.^{11,12} Engaging patients in research is recommended to achieve more patient-oriented research,¹³ to help with efficient use of research funds,¹⁴ and with translation of research to practice.¹⁵

The James Lind Alliance (JLA) was established in 2004 as a non-profit initiative to enable patient, caregiver, and clinician involvement in setting priorities for future research.¹⁶ The JLA methodology is an established and rigorous process based on principles underlying priority setting partnerships (PSPs).¹⁶ Over 70 PSP studies have been conducted in a variety of benign and malignant conditions.¹⁶ The goal of a JLA PSP is to identify and prioritize evidence uncertainties (“questions about healthcare that cannot be answered by existing research”).¹⁶ We

formed a CRC PSP steering committee of clinicians, patients, and researchers from across Canada in September 2018. The objective was to determine the research priorities for those living with and beyond a diagnosis of early stage CRC (ES CRC).

Methods

We followed the methodology outlined by the JLA¹⁶ except that we did not hire an external JLA consultant. Instead we included local JLA methods experts as co-investigators on our study team. Details of the methods are outlined in our protocol which can be found on our study website (www.colorectalcanerpsp.com). We briefly summarize steps 1-5 here (figure 1).

1. Formation of Steering committee

We formed a steering committee composed of 5 CRC clinicians, 4 patients with lived experience of CRC, 1 representative from Colorectal Cancer Canada (a non-profit advocacy group), and 4 researchers with methodological or content expertise (some members had dual roles). At this stage, our committee decided on scope and developed the study protocol.

2. Identification of Potential Research Questions

The steering committee co-developed the initial open-ended survey to gather potential research questions from patients, caregivers and health care providers. The format of the survey and questions were based on prior JLA surveys,^{16, 17-18} our clinical expertise, and patient partner input. Our goal was to gather a broad range of questions related to the experience of living with and beyond ES CRC (supplementary material: initial survey). We pilot tested the survey with approximately 9 people (3 patients, 2 caregivers, 2 clinicians, and 2 patient committee members).

Participants: We used convenience sampling and a variety of recruitment methods including email through professional and advocacy organizations, posters, and social media. People could participate in the survey if they were residents of Canada and were 1) People diagnosed with ES CRC; or 2) Carers of people with ES CRC; or 3) Doctors, nurses or allied health professionals

(e.g. radiation technologists, social workers, psychologists) with clinical experience in ES CRC; or 4) Members of organizations that support CRC patients and their caregivers (e.g. not-for-profit groups). The survey was accessed through the dedicated study website or direct link. Information was collected using the survey platform Qualtrics¹⁹ from June 2019 to December 2019.

3. Categorizing Survey Questions

Survey responses were initially reviewed to remove any out of scope questions. Subsequently, the lead author (CC), an experienced qualitative researcher, coded responses into broad categories using thematic analysis.²⁰ After this step, a list of “indicative research questions”¹⁶ was generated. An excel spreadsheet was used to organize the data, with each iterative step of the analysis recorded separately. The steering committee provided feedback on the themes, wording of questions, and duplication of questions during a two hour in-person meeting. The lead author (CC) in partnership with clinical steering committee members also reviewed the literature to ensure the questions had not already been fully answered with high level evidence.

4. Interim Priority Ranking

An interim prioritization of the questions generated in step 3 was carried out to reduce the long list of questions to a shorter list. This prioritization of questions occurred through a second online survey using the same website and survey platform (supplementary material; second survey) from April 2020 to July 2020. Participants were provided with the long list of questions and asked to rank their top ten from most important (scored as 1) to least important (scored as 10). Participants included members of the steering committee, people who participated in the

first survey and consented to being re-contacted, and anyone who met the inclusion criteria above. We used the same convenience sampling and recruitment methods as above.

5. Final priority setting meeting

A consensus meeting was held to rank the questions on the shortlist and to agree on the top ten. We used small and whole group discussions and placed an emphasis on equity and inclusivity.¹⁶ The consensus meeting followed an adapted nominal group technique and has been well-established.¹⁶ We hired an external experienced JLA moderator to ensure transparency, accountability, and fairness. The consensus meeting was changed to a virtual format because of travel restrictions associated with the COVID pandemic. We followed examples where adaptations to in-person meetings have been published²¹ and also sought informal consultation through the JLA. The process we followed to tailor the final meeting to virtual has been described elsewhere.²²

Patient Engagement

Following principles of the JLA¹⁶ and patient oriented research,¹³ we collaborated²³ with patient partners throughout the research process. Our steering committee included 4 patients with lived experience of either colon or rectal cancer. The steering committee members were from across Canada and met monthly via teleconference for the entire study period (Sept 2018-Sept 2020). Our patient committee members were given equitable voice in the protocol and survey development, recruitment of survey participants, data analysis, and planning for the final meeting. Our final consensus meeting included additional patient and family caregivers who were consulted²³ on the final top ten research priorities. All participants at the final meeting were provided with a gift card to purchase a meal for the day. All members of the steering committee

were invited to provide feedback on the final manuscript and to engage in knowledge dissemination through their local networks.

Statistical analysis

Descriptive statistics were used to summarize the characteristics of the survey respondents. Thematic analysis was used to categorize the initial survey questions.

Ethics approval

This study received approval through our institutional ethics board. HREBA-CC-18-0351

Results

Three hundred and seventy questions were submitted by 185 individuals. Of those, 99 individuals provided complete demographic information (table 1). Approximately 44% of the respondents were patients, 16% were caregivers, 26% were health care providers, 7% were from CRC advocacy organizations, and 5% identified as other. The 370 questions submitted were often written as personal stories or statements. These narratives were initially organized into the following broad categories: diagnosis (13.0%), treatment (9.5%), treatment complications or treatment side effects (14.0%), monitoring for recurrence (12.0%), rehabilitation (12.0%), quality of life (6.5%), lifestyle factors (8.4%), support for patients (7.8%), support for caregivers (3.5%), prevention (6.2%), and miscellaneous (7.0%) (table 2). Thirty-three questions were removed as they were considered out of scope (e.g. there was no question, or the question was not related to CRC). From these broad categories, a set of initial indicative questions was formed by the first author (CC) and reviewed by committee members working in pairs (one clinical and one patient member) to further refine the questions and combine any categories. From this process, a list of 66 unique questions were put forth for the interim prioritization process. Twenty-five people

participated in the interim prioritization (supplementary material: table) where a list of 30 questions (table 3) was generated and was taken to the final consensus meeting.

The final virtual consensus meeting was held on September 23, 2020 and attended by 7 CRC clinicians, 10 CRC patients (2 of which were also members of the advocacy organization Colorectal Cancer Canada), 3 caregivers, 1 moderator, 2 small group facilitators, one logistical support person, and one student observer who did not participate in any discussions. First, the participants were divided into three small groups with equal distribution of patients, caregivers, and clinicians. The groups were provided a copy of the top 30 questions and the group facilitator used an online whiteboard to display the questions and move them to different priority areas (top, middle, or bottom) as the discussion progressed. During a second small group session, the same three groups were guided by the facilitator to prioritize the questions to reach a top ten list. An aggregate ranking was then compiled, using the individual small group rankings, by the logistic support person (CF) and reviewed by the group facilitators. This ranking was then presented to all participants in a large group format. Participants were then assigned to different small groups and a different facilitator to discuss and rank the questions a final time. The revised ranking was again aggregated using the same process. The moderator led the large group in a discussion of the second aggregate ranking and any revisions to the top ten research priorities (table 4) was agreed upon by consensus.

Interpretation

Future research has the potential to improve the lives of those impacted by CRC.^{12,24} Using the well-established process of the JLA, we collaborated with patients, their caregivers, and health care providers from across Canada to jointly determine the top ten future research priorities for ES CRC. The priorities covered a range of topics including improved screening practices, the role of personalized medicine, management of treatment side effects, decision

making, and prevention of recurrence. The broad range of topics indicates there are still many knowledge gaps in CRC survivorship which could be addressed by future research.

The top research priority was prevention of recurrence. Recurrence occurs in over 40% of patients with stage II or III CRC²⁵ and fear of recurrence is reported by up to 60% of CRC survivors.²⁶⁻²⁷ While evidence exists outlining best practices for monitoring for recurrence,²⁸ there is a lack of comprehensive understanding about the most effective tertiary prevention strategies (e.g. modifiable risk factors, chemoprevention).²⁹ Further research to determine the most effective methods of preventing recurrence could improve the quality of life by reducing fear of recurrence and would allow CRC survivors to maintain their health.²⁹

Two of the top ten priorities focused on screening. CRC screening represents an effective method of early detection.³⁰ When diagnosed in early stages, CRC is treatable, with high rates of survival.³⁰ Screening rates however remain low with just over half of participants in the Canadian Community Health Survey reporting being up-to-date with current screening.³¹ In addition, with rising incidence of CRC in those younger than aged 50,³² some countries are now recommending screening starting before the age of 50.³³ Effective policies, practices and initiatives to improve screening rates, and the determination of the efficacy of screening individuals under 50 years old, represents a key component of CRC management in the future.

Screening tests for CRC currently include either the Fecal Immunochemical Test (FIT) test, the Fecal Occult Blood Test (FOBT), or colonoscopy depending on regional clinical practice guidelines and personal history/risk for cancer.³⁰ While the FIT test is effective and non-invasive, it has poor rates of detecting stage I cancer³⁴ and is not recommended to replace colonoscopies in at risk populations.³⁵ In addition, limited access to colonoscopy and risks associated with the procedure mean that it is not ideally suited for primary screening.³⁰ Ideally,

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3 future research into novel screening tests for CRC could result in more sensitive, specific, and
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8 Five of the top ten priorities were focused on either new treatments for CRC or the
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10 management of short and long term side effects associated with current treatments. Personalized
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12 medicine (or precision medicine), refers to medical treatments tailored to individuals, often
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14 through a unique understanding of their genes and proteins.³⁶ Personalized medicine in cancer is
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16 a rapidly expanding area of research due to the expectation that it will provide more effective
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18 treatments with fewer side effects.³⁶ Currently, over 100 molecules have been reported as
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20 biomarkers for CRC, which have potential for diagnosis and/or treatment.³⁶ Further research is
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22 needed to clarify the effectiveness, feasibility, accessibility, and cost-to-benefit ratios of
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24 implementing personalized medicine into CRC care.
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28 While the future of CRC treatment using personalized medicine holds promise in
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30 decreasing treatment related sequelae, patients in the short term currently struggle to manage
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32 many side effects from treatment (e.g. peripheral neuropathy, changes to bowel function, social
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34 isolation, return to work issues, and financial instability).²⁸ For example, up to 31% of patients
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36 treated with oxaliplatin chemotherapy had peripheral neuropathy 5 years following treatment.³⁷
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38 In addition, up to 80% of CRC survivors experience some degree of bowel changes
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40 (incontinence, frequency, urgency, emptying difficulties) with up to 40% experiencing severe
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42 symptoms.³⁸ These side effects can have significant impact on functional ability, return to work,
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44 and overall quality of life.^{28,38} High quality evidence is lacking on the efficacy of interventions to
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46 manage the side effects specific to CRC. Future research could guide the development of
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48 tailored, comprehensive supportive care (e.g. rehabilitation, psychosocial support), and
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integrative oncology strategies to ensure patients and their families are best equipped to optimize their health and wellbeing.

The topics of information and decision making were also in the top ten priorities. Specifically, how to best inform patients and families throughout the CRC trajectory to promote informed decision making and how to ensure information about new treatments, clinical trials, and other research studies is accessible, were research priorities. Patients who are fully informed make better decisions leading to improved health outcomes.³⁹ However, providing effective education remains a barrier to informed decision making, especially in terms of communicating retainable information.⁴⁰ Some evidence supports tools such as decision aids,³⁹ however, further research can help clarify best practices for providing information and ultimately optimizing informed decision making.

Limitations

Our study has several limitations. First, while we invited participation from across Canada and included a variety of different stakeholder groups, our sample was small and the majority were Albertans. The survey participants may not be representative of the broader CRC community. In addition, just over half of the participants provided us with complete demographic information. We decided, as a committee, to leave the demographic questions to the end of the survey as we felt the research priorities were more important to collect. From the demographic information provided, there was representation from caregivers, clinicians, patients, and stakeholders. The missing demographic information may or may not represent bias. Finally, our sample included mostly White respondents, meaning research priorities by those of different racial or ethnic backgrounds may not be represented. We are reassured that many of the broader themes and questions generated were similar to JLA studies in other cancer populations.^{17-18,41-43} Finally, we deviated from the JLA process by conducting our final consensus meeting virtually.

While in-person meetings are typically preferred to ensure engagement of all participants, we were able to achieve a high level of engagement and satisfaction (supplementary material; post-meeting survey) while meeting study timelines, reducing the burden of travel costs and time, and ensuring the safety of participants.

Lessons learned from patient engagement

We followed established guidelines for working with patient partners as outlined by the JLA,¹⁶ the Strategy for Patient Oriented Research (SPOR),⁴⁴ and included committee members with experience in patient engagement. These resources were essential to ensure a meaningful and partnered approach. As researchers and clinicians, we learned from patients and caregivers about their experience of illness and navigating the health care system, and their unique perspectives on how to shape future research to best meet their needs. To build an environment of equal input from all committee members, we took time to explore knowledge gaps with our patient partners, explain the research process, and encouraged them to provide regular feedback. We also found our patient partners provided many new ideas about how to engage with the broader CRC community across Canada. Our patient partners emphasized the importance of ongoing follow-up after our final meeting to stay engaged with the work and to participate in the knowledge dissemination process.

Conclusion

Future research has the potential to further improve the lives of those affected by CRC. In order to provide the greatest benefit to patients and families, their direct input is necessary in the development of research questions. We determined the top ten research priorities for early stage CRC using a collaborative partnership of patients, their caregivers, and health care professionals from across Canada. The 10 priorities are by no means inclusive of all the research topics that

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can improve the lives of CRC patients and their families. However, these 10 questions were determined to have significant value and should be pursued by researchers and clinicians.

Contributors: Colleen Cuthbert, Nancy Nixon, Michael Vickers, Setareh Samimi, Krista Rawson, Barry Stein, Garry Laxdal, Lorilee Dundas, Diane Huband, Christie Farrer and Winson Cheung conceptualized and designed the study and were involved in data collection, analysis, and interpretation of data and drafting the manuscript and revising for content. Emily Daze conceptualized and designed the second survey, was involved in data collection, analysis, drafting the manuscript and revising for content. Ravi Ramjeesingh and Safiya Karim contributed to acquisition of data and revised the manuscript for critically important intellectual content. All authors approved the final version of the submitted manuscript and agreed to act as guarantors of the work.

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Data Sharing: Aggregate data for relevant research is available to other investigators on request to the corresponding author.

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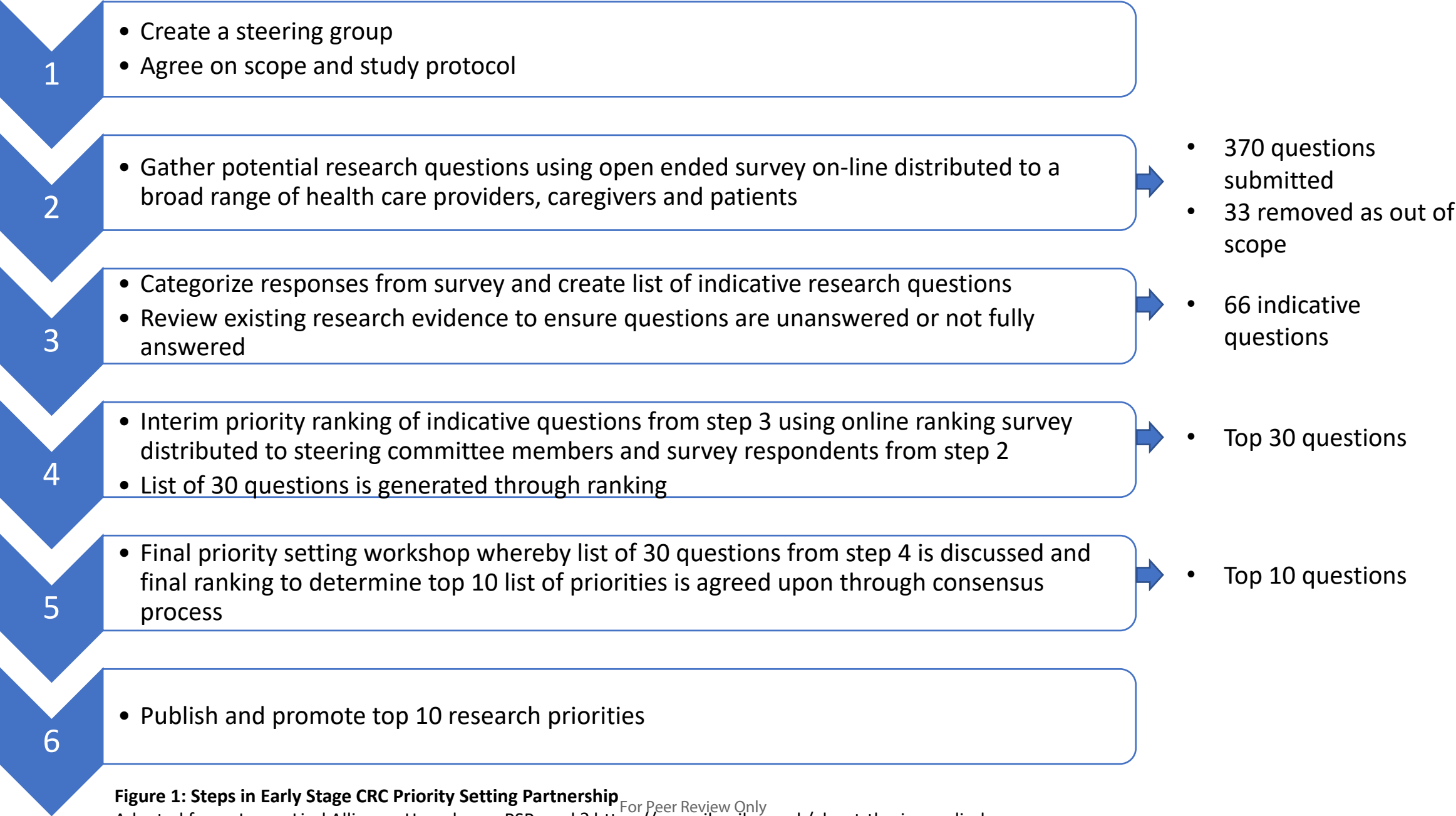


Figure 1: Steps in Early Stage CRC Priority Setting Partnership
Adapted from: James Lind Alliance: How does a PSP work? <https://www.jla.nihr.ac.uk/about-the-james-lind-alliance/downloads/JLA-PSP-process-final.pdf>

For Peer Review Only

Table 1: Demographic Information of survey participants

	First JLA Survey n=185 participants						
	CRC Patients (n=44)	Family Caregivers (n=16)	other (n=5)	Health Care providers (n=26)	Advocacy Group Member (n=7)	Total n=99*	Total (%)
Age							
18-29	0	2	0	2	0	4	4%
30-39	3	3	0	1	0	7	7%
40-49	5	1	0	9	4	19	19%
50-59	11	4	2	11	1	29	29%
60-69	16	6	2	2	1	27	27%
70-79	8	0	1	1	1	11	11%
80+	1	0	0	0	0	1	1%
Prefer not to say	0	0	0	0	0	0	
Sex							
Male	22	3	4	8	2	39	39%
Female	22	13	1	18	5	59	59%
Ethnicity							
White or Caucasian	43	15	5	24	6	93	93%
East Asian							
Black							
Indigenous							
South Asian			0	2		2	2%
Mixed	1					1	1%
Prefer not to say		1			1	2	2%
Colorectal Cancer Stage							
I	9					9	21%
II	8					8	18%
III	27					27	62%
Years since diagnosis							
1-5 years	26					26	59%
5-10 years	12					12	27%
10+ years	6					6	14%
Health Profession							
Nursing				12		12	46%
Surgeon				1		1	4%

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Medical Oncologist				6		6	23%
Radiation Oncologist				1		1	4%
Nurse Practitioner							
Pharmacist				1		1	4%
Other				5		5	19%
Place of Residence							
British Columbia	2	1		1	2	6	7%
Alberta	21	5	3	15	2	46	51%
Saskatchewan	1	2				3	3%
Manitoba	2	3	0	4	2	11	12%
Ontario	12	3	0	5	1	21	23%
Quebec	3	1	1	0		5	5%
Atlantic (PEI, Nova Scotia, Newfoundland, New Brunswick)	3	1	1	1		6	7%
Rural	7	1	2			10	11%
Urban	36	15	3		7	61	68%

*only 99 participants provided demographic information

Table 2: Categories of research questions with examples of raw data and initial indicative question

Category	Raw Data	Initial Indicative Question
Diagnosis	<i>"We typically test for colorectal cancer in men at age 50. Can we change this to 45 to catch this cancer at an even earlier stage?"</i> <i>"colonoscopy should be started at age 40 not 50, I had cancer at 45"</i>	What is the feasibility and necessity of beginning screening at an early age given the rise in CRC in those under age 50?
Treatment	<i>"What about holistic methods of treating cancer?"</i> <i>"Why is change of diet not included in treatment?"</i>	What is the evidence for complimentary and alternative treatments?
Treatment complications or side effects	<i>"How can peripheral neuropathy be better treated?"</i> <i>"Is there better ways to treat neuropathy? Hands are an important part in everyday life, to disregard the devastating events chemo can play with the use of our hands is very upsetting to me personally?"</i>	What can be done to treat peripheral neuropathy in the short and long term?
Monitoring for recurrence	<i>"How is the impact concerning different lifestyles to prevent recurrence?"</i> <i>"What can I do other than scheduled colonoscopies?"</i>	What are the most effective ways to prevent recurrence?
Rehabilitation	<i>"What about chronic bowels symptoms what are the best ways to improve bowel problems?"</i>	What are the best methods for providing rehabilitation to improve chronic bowel symptoms?
Quality of Life	<i>"Finances are running out, because of the neuropathy I am no longer able to work. I am looking for therapy to help with the pain management but nothing is covered."</i> <i>"The Chemo caused it and should be covered."</i>	What is the long-term financial toxicity of a CRC diagnosis and how can patients and their families be better supported financially?
Lifestyle factors	<i>"How do I sort through all the information about healthy diet?"</i>	What is the best diet to follow and how can this information be systematically provided to patients and their families?

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	<i>“There is a lot of dis-information on the internet about what helps and by how much.”</i>	
Support for patients	<i>“Are there internet sources of support for patients?” “How can patients learn about all the supports that are available?”</i>	What is the best way to provide information/education about supports available to CRC patients and their families?
Support for caregivers	<i>“Are there courses that caregivers take to teach them basic skills in caring for the patient (I am thinking very specifically of assisting patients with things like removing colostomy bag, etc.)?” “Where can they (caregivers) go for support?”</i>	How can education and access to support for caregivers be improved?
Prevention	<i>“Why isn’t there more education on this (prevention) and why aren’t there more campaigns about prevention and risk factors?”</i>	How can people be better informed about the risk factors for colon cancer?
Miscellaneous	<i>“My concerns are more related to knowledge translation, policy and practice guidelines. Why did I have to learn about cancer fatigue video from McMaster from my friends instead of my doctor?”</i>	What are the policy and practice guidelines that are needed to improve the patient experience during the diagnosis phase?

Table 3: Top 30 research priorities

What are the most effective ways to prevent recurrence?	1
What additional policy, practice, and educational initiatives are needed to improve screening rates and how does this apply to screening for those who are under the age of 50?	2
How can long term changes to bowel function (including having an ostomy) be best managed, what is the role of rehabilitation in managing changes to bowel function, and are there new ways of managing this side effect that are being investigated?	3
What is the role of personalized medicine, including immunotherapy, to tailor treatments based on patient and tumor characteristics? Would personalized medicine improve efficacy while decreasing side effects of CRC treatment?	4
Are we able to find a test that is more sensitive or specific when used for screening for CRC?	5
What is the cumulative financial toxicity of a CRC diagnosis and how can patients and their families be better supported to manage this?	6
How can patients be better informed about clinical trials and other research and how can access to clinical trials and new treatments be improved?	7
Can we predict who will get peripheral neuropathy (e.g. numbness and tingling in fingers and toes) and what is the best way to prevent peripheral neuropathy?	8
What is the evidence for complimentary and alternative medicine in a) the treatment of cancer and b) the prevention and/or management of short term and long term side effects from treatments?	9
What is the best method to ensure that patients are fully informed and supported to make decisions during a) the diagnostic phase (e.g. diagnosis, prognosis, follow-up tests) and b) treatment phase? Are there any methods that can aid explanation and retention of information?	10
What is the best way to monitor patients for side effects during treatment, especially those who are vulnerable such as those living in rural and remote area, are older, or have multiple other health problems (e.g. heart disease, diabetes etc.)?	11
How can CRC patients and their families be better informed about the role of family history and the need for screening of family members to ensure earlier diagnosis of CRC?	12
What is the best way to educate patients about the risks of recurrence and ways to reduce recurrence?	13
How can health care professionals (e.g. Physicians, Nurse navigators, Nurse Practitioners, Social workers, Psychosocial etc.) be best utilized to provide the required care for patients and families throughout the cancer trajectory. What policy and practice guidelines need to be implemented to improve access to these different type of health care professionals?	14

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What are the different treatment options and how can we best inform patients to make shared decisions in their treatment?	15
What is the best way to provide support specific to CRC at diagnosis, during treatment, and post-treatment to patients and their families?	16
What additional policy, practice and educational initiatives are needed to ensure: a) health care providers are better informed and equipped to diagnose CRC earlier in those who are symptomatic? b) delays in diagnosis are avoided to ensure earlier detection and treatment?	17
Are new methods for detecting recurrence being develop so that it can be caught earlier?	18
What is the best way to provide information after cancer treatment about prognosis, monitoring for recurrence, and follow-up care?	19
How can we improve efficiency in our health care system to improve access to the right information and the right care at the right time for CRC patients and their families?	20
What are the best methods for treating peripheral neuropathy in the short and long term?	21
What is the best diet to follow and how can this information be systematically provided to patients and their families?	22
Is total neoadjuvant treatment (TNT) approach a more effective way to treat rectal cancer than the previous standard, and could it eliminate need for surgery in some patients?	23
What is the best model of follow-up care and how can this be standardized across Canada to ensure continuity of care and early detection of recurrence?	24
What are the most effective ways of informing the general public of the sign and symptoms of CRC?	25
What is the role of the gut microbiome in preventing CRC?	26
What is the best way to prevent and manage short term and long term cognitive changes (brain fog)?	27
How can the long term mental health impacts (fear of recurrence, anxiety, depression) be better managed?	28
How can patients and families be better informed about what to expect, what resources exist, and how to access the resources they need in post-treatment recovery ?	29
How can patients living long term with an ostomy or LARS (lower anterior resection syndrome) be better supported?	30

Table 4: Top 10 research priorities for CRC

Top 10 Research Priorities

1. What are the most effective ways to **prevent recurrence**?
2. What additional policy, practice, and educational initiatives are needed to **improve screening rates** and how does this apply to screening for those who are under the age of 50?
3. How can **long term changes to bowel function** (including having an ostomy) be best managed, what is the role of **rehabilitation** in managing changes to bowel function, and are there new ways of managing this side effect that are being investigated?
4. What is the role of **personalized medicine**, including immunotherapy, to tailor treatments based on patient and tumor characteristics? Would personalized medicine improve efficacy while decreasing side effects of CRC treatment?
5. Are we able to find a **test** that is **more sensitive or specific** when used for **screening for CRC**?
6. What is the cumulative **financial toxicity** of a CRC diagnosis and how can patients and their families be better supported to manage this?
7. How can patients be better **informed about clinical trials and other research** and how can access to clinical trials and new treatments be improved?
8. Can we predict who will get **peripheral neuropathy** (e.g. numbness and tingling in fingers and toes) and what is the best way to prevent peripheral neuropathy?
9. What is the evidence for **complimentary and alternative medicine** in a) the treatment of cancer and b) the prevention and/or management of short term and long term side effects from treatments?
10. What is the best method to ensure that **patients are fully informed and supported to make decisions** during a) the diagnostic phase (e.g. diagnosis, prognosis, follow-up tests) and b) treatment phase? Are there any methods that can aid explanation and retention of information?

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Supplementary Material : GRIPP 2 short form

GRIPP reporting item	Description	Section Reported
1. Aims	Report the aim of PPI in the study	Reported in introduction
2. Methods	Provide a clear description of methods used for PPI in the study	Reported in methods section
3. Study Results	Outcomes: Report the results of PPI in the study, including both positive and negative outcomes	Reported in results sections and patient engagement section
4. Discussion and conclusions	Outcomes: Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Reported in patient engagement section and discussion/conclusions
5. Critical perspective	Comment critically on the PPI in the study, reflecting on the things that went well and those that did not, so others can learn from this experience	Reported in the patient engagement section

Supplementary Material: JLA CRC survey 1

COLORECTAL CANCER SURVEY

A diagnosis of colorectal cancer can affect people's lives in many ways. As a patient or caregiver, please think about your experience with colorectal cancer, from the time you were first told until now, and the questions that you would like to see answered by research (a systematic process of answering a question).

As a health professional, please think about your experiences with colorectal cancer patients. Are there any questions that you would like to see answered by research?

Questions may relate to any aspect of colorectal cancer including prevention, diagnosis, treatment, treatment complications, recurrence, rehabilitation, quality of life, lifestyle factors, or support.

We have divided the survey into different sections related to colorectal cancer.

You may answer as many sections as you wish, and you can submit as many questions as you want.

1. Do you have any questions about the **DIAGNOSIS** of colorectal cancer?

Diagnosis means getting tested (example: colonoscopy) for cancer if you have concerns, symptoms, or risk factors.

2. Do you have any questions about the **TREATMENT** of colorectal cancer?

Treatment means anything to remove, destroy, or control the cancer (example: radiation, surgery, chemotherapy, immunotherapy).

3. Do you have any questions related to **TREATMENT COMPLICATIONS or TREATMENT SIDE EFFECTS?**

Treatment complications or side effects can be related to any type of treatment.

4. Do you have any questions about **MONITORING FOR COLORECTAL CANCER RECURRENCE?**

Monitoring means getting tested (example blood test) or watching for symptoms (example weight loss) to see if the cancer comes back. Recurrence means that the cancer comes back or happens again.

6. Do you have any questions related to **REHABILITATION** for colorectal cancer patients?

Rehabilitation means to maintain or restore physical or emotional function before, during, or after cancer treatment.

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7. Do you have any questions related to **QUALITY OF LIFE**?
Quality of life means anything relating to enjoying your life including emotional and mental health, physical health, social relationships, finances, employment, self esteem, and respect.

8. Do you have any questions related to **LIFESTYLE FACTORS**?
Lifestyle factors can include physical activity, health diet, proper sleep, stress management, and smoking cessation.

9. Do you have any questions related to **SUPPORT** for colorectal cancer patients?
Support refers to helping patients from the time of diagnosis onward and may include health care, community support, family support, or support groups.

10. Do you have any questions related to **SUPPORT** for colorectal cancer **FAMILY CAREGIVERS**?
Support refers to helping caregivers from the time of diagnosis onward and can include health care, community support, or support groups.

11. Do you have any questions about how **PREVENTION** might help others from getting colorectal cancer ?
Prevention means stopping cancer before it starts.

12. Do you have any **OTHER QUESTIONS** about colorectal cancer that didn't fit into the other categories?

Supplementary material: Second Survey

Step 1: in the **left hand box** please tick the ten questions where you think more research is needed. This list contains 66 research questions, so please read through to the end.

Step 2: in the **right hand box**, please rank the selected questions into order of importance to you. (1=most important and 10=least important)

Tick the ten most important questions to you	Research Questions about stage I-III colorectal cancer (CRC)	Rank your selected top ten (1=most important, 10=least important)
	What additional policy, practice, and educational initiatives are needed to improve screening rates and how does this apply to screening for those who are under the age of 50?	
	What additional policy, practice and educational initiatives are needed to ensure: a) health care providers are better informed and equipped to diagnose CRC earlier in those who are symptomatic? b) delays in diagnosis are avoided to ensure earlier detection and treatment?	
	Are we able to find a test that is more sensitive or specific when used for screening for CRC?	
	How can CRC patients and their families be better informed about the role of family history and the need for screening of family members to ensure earlier diagnosis of CRC?	
	What are the most effective ways of informing the general public of the sign and symptoms of CRC?	

	Has the fit test improved CRC survival rates?	
	What is the best method to ensure that patients are fully informed and supported to make decisions during a) the diagnostic phase (e.g. diagnosis, prognosis, follow-up tests) and b) treatment phase? Are there any methods that can aid explanation and retention of information?	
	What is the evidence for complimentary and alternative medicine in a) the treatment of cancer and b) the prevention and/or management of short term and long term side effects from treatments?	
	How can patients be better informed about clinical trials and other research and how can access to clinical trials and new treatments be improved?	
	What is the role of personalized medicine, including immunotherapy, to tailor treatments based on patient and tumor characteristics? Would personalized medicine improve efficacy while decreasing side effects of CRC treatment?	
	Is total neoadjuvant treatment (TNT) approach a more effective way to treat rectal cancer than the previous standard, and could it eliminate need for surgery in some patients?	
	What is the best way to provide information after cancer treatment about prognosis, monitoring for recurrence, and follow-up care?	

	What is the best method of informing patients and families of the side effects (short and long term) of colorectal cancer treatments?	
	What is the best way to monitor patients for side effects during treatment, especially those who are vulnerable such as those living in rural and remote area, are older, or have multiple other health problems (e.g. heart disease, diabetes etc.)?	
	Can we predict who will get peripheral neuropathy (e.g. numbness and tingling in fingers and toes) and what is the best way to prevent peripheral neuropathy?	
	What are the best methods for treating peripheral neuropathy in the short and long term?	
	How is fatigue in the short and long term best managed?	
	How can patients and their families be better prepared and cope with the sexual health/relationship changes and body image changes that may occur during and after cancer treatment?	
	What is the cumulative financial toxicity of a CRC diagnosis and how can patients and their families be better supported to manage this?	
	What are the most common short and long term side effects of treatment and how are they best managed?	

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	How can long term changes to bowel function (including having an ostomy) be best managed, what is the role of rehabilitation in managing changes to bowel function, and are there new ways of managing this side effect that are being investigated?	
	What is the best way to prevent and manage short term and long term cognitive changes (brain fog)?	
	What is the best model of follow-up care and how can this be standardized across Canada to ensure continuity of care and early detection of recurrence?	
	What is the best way to educate all health team members (GPs/surgeons/GI) about appropriate follow-up and monitoring for recurrence?	
	What is the best way to educate patients about the risks of recurrence and ways to reduce recurrence?	
	How can the long term mental health impacts (fear of recurrence, anxiety, depression) be better managed?	
	What is the best way to provide information at the time of recurrence and how can patients and families best be supported?	
	What is the optimal timing and type of investigations to check for recurrence?	

	Are new methods for detecting recurrence being develop so that it can be caught earlier?	
	What are the most effective ways to prevent recurrence?	
	What additional policy, practice, and educational initiatives are needed to ensure access to services such as supportive care and rehabilitation?	
	How can patients and families be better informed about what to expect, what resources exist, and how to access the resources they need in post-treatment recovery ?	
	What is the best way to provide rehabilitation to CRC patients in the post-treatment period?	
	Is there a way to optimize physical and mental health prior to undergoing treatment for CRC?	
	Is there a role for a standardized post-treatment care for CRC patients and their families?	
	What is the role of pelvic floor physio in rehabilitation?	
	What is the role of standardized education to support patients both during and after treatment?	

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	How can patients living long term with an ostomy or LARS (lower anterior resection syndrome) be better supported?	
	What is the role of peer support and/or social support for improving quality of life?	
	How can patients be better prepared for returning to work?	
	What are the long term impacts to quality of life? Are there specific programs or treatments that can improve quality of life?	
	What is the best way to manage long term pain for CRC patients?	
	What is the best way to provide psychological, social, and financial support to CRC patients patients who have long term changes to their bowel function (including an ostomy)?	
	How can disruptions or changes to sleep during and after treatment be managed better?	
	How can patients be supported (education, access) to participate in physical activity?	
	What is the role of stress and stress management programs for those living after a CRC diagnosis?	

	What lifestyle factors help in recovery from treatment and long term wellbeing (including decreasing risk or recurrence) and how can this information best be communicate to patients?	
	What is the best diet to follow and how can this information be systematically provided to patients and their families?	
	What is the best method to ensure equitable access to education and support for healthy lifestyles ?	
	What is best way to support behavior change and improve participation in healthy lifestyles?	
	How can CRC patients be supported in achieving/maintaining a healthy body weight?	
	What are the most preferred and effective types of support for CRC patients and their families and how can equitable access to support be ensured?	
	What is the best way to provide support specific to CRC at diagnosis, during treatment, and post-treatment to patients and their families?	
	How can health care professionals (e.g. Physicians, Nurse navigators, Nurse Practitioners, Social workers, Psychosocial etc.) be best utilized to provide the required care for patients and families throughout the cancer trajectory. What policy and practice guidelines need to be implemented to	

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	improve access to these different type of health care professionals?	
	What is the role of symptom tracking (through digital or other means) in supporting patients throughout the cancer trajectory?	
	How can information about community supports be best communicated to patients, caregivers and health care provides?	
	How can support for caregivers be made feasible, tailored to their needs, and accessible?	
	What types of support do caregivers prefer and what is the role of peer support for caregivers?	
	How can health care providers be better informed and equipped to teach patients about causative factors and prevention of CRC?	
	How can the general public be better information about the causes/risk factors for CRC?	
	What is the role of diet in prevention of CRC?	
	What is the role of the gut microbiome in preventing CRC?	
	What are the different treatment options and how can we best inform patients to make shared decisions in their treatment?	

	How can we improve efficiency in our health care system to improve access to the right information and the right care at the right time for CRC patients and their families?	
	What changes in the health care system would assist patients and families in advocating for themselves?	
	What changes in policy or practice guidelines could improve the patient experience leading up to and at the time of diagnosis and following (e.g. starting with family physician to specialist to treatment)?	

Supplementary Table: Characteristics of Survey Participants for Interim Prioritization n=25

	Second Survey (interim prioritization)					
	CRC Patients (n=13)	Family Caregiver s (n=2)	Health Care Providers (n=7)	Advocacy Group Member (n=3)	Total (n=25)	Total (%)
Age						
18-29			1		1	4%
30-39						
40-49			3		3	12%
50-59	6		2	1	9	36%
60-69	5	2		2	9	36%
70-79						
80+	2				2	8%
Prefer not to say			1			
Sex						
Male	4		3	2	9	36%
Female	9	2	4	1	16	64%
Ethnicity						
White or Caucasian	12	2	6	3	23	92%
East Asian			1		1	4%
Black						
Indigenous						
South Asian						
Mixed						
Prefer not to say	1				1	4%
Colorectal Cancer Stage						
I						
II	4				4	31%
III	8				8	62%
IV+	1				1	8%
Years since diagnosis						
1-5 years	7				7	54%
5-10 years	4				4	31%
10+ years	2				2	15%
Health Profession						
Nursing			2		2	29%
Surgeon						
Medical Oncologist			3		3	43%
Radiation Oncologist						

Nurse Practitioner						
Pharmacist						
Other			2		2	29%
Place of Residence						
British Columbia						
Alberta	9	1	5	1	16	64%
Saskatchewan						
Manitoba						
Ontario	2	1	1		4	16%
Quebec	2		1	2	5	20%
Atlantic (PEI, Nova Scotia, Newfoundland, New Brunswick)						
Rural	4		1		5	20%
Urban	9	2	6	3	20	80%

Supplementary Material: Post-virtual meeting satisfaction survey results

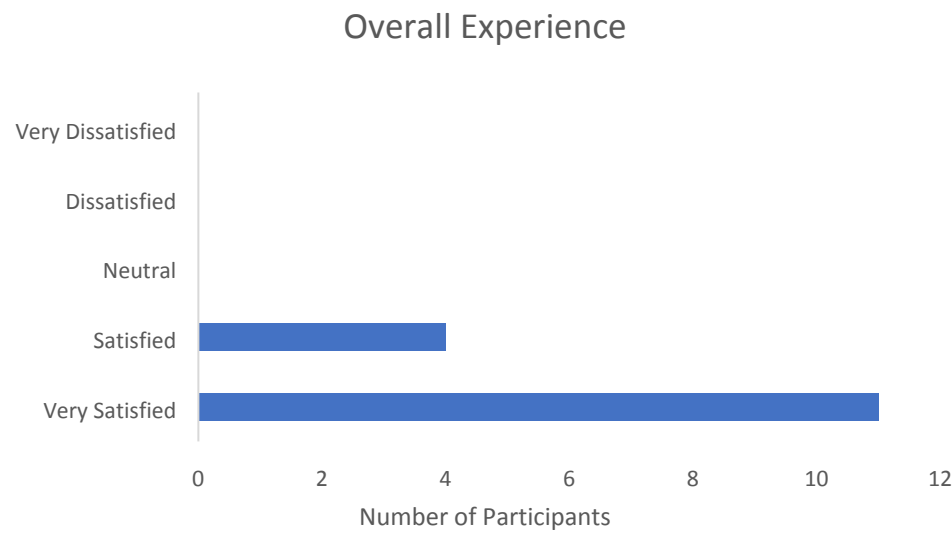


Figure 1: Overall experience with virtual meeting

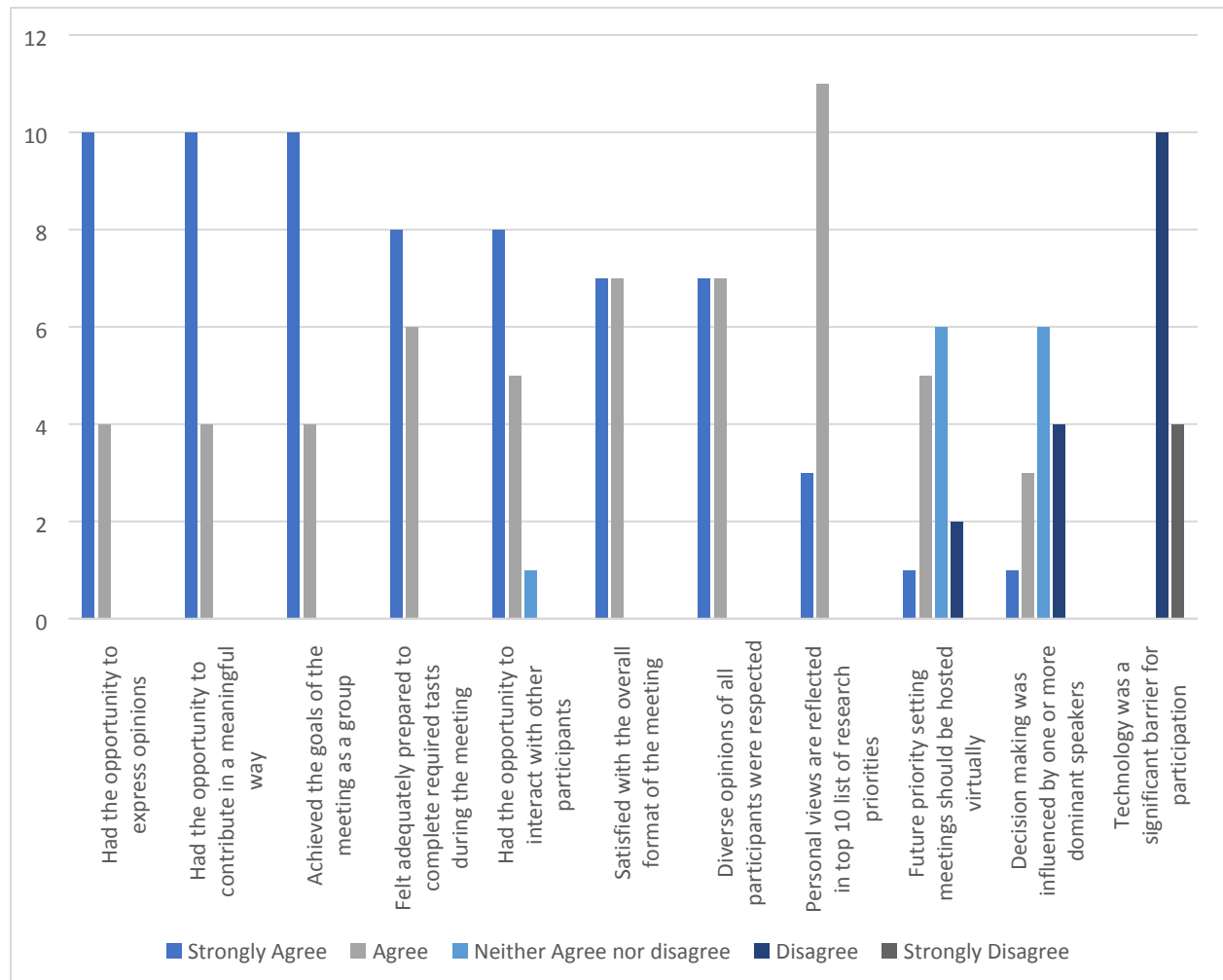


Figure 2: Participants views on engagement components of virtual meeting