

Appendix 3: JLA CRC 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?	

	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?	

	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 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	

	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)?	