

Appendix 1: JLA CRC initial survey

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.

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?