Cancer Health™

Anyone Who’s Had Colorectal Cancer Can Join This New Research Effort

The hope is that de-identified data sent to the Count Me In initiative will lead to better knowledge and therapies.

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Count Me In, a nonprofit cancer research initiative, is inviting all patients across the United States and Canada who have ever been diagnosed with colorectal cancer to participate in research and help drive new discoveries related to this disease. The Colorectal Cancer Project which launches today will enable patients to easily share their samples, health information and personal lived experiences directly with researchers in order to accelerate the pace of research. The resulting de-identified data from patients participating in the project will help lead to better understanding of this disease and ultimately better therapies for colorectal cancer.

Patients who have been diagnosed with colorectal cancer at any point in their lives can join the project by visiting JoinCountMeIn.org/colorectal. From there, patients will be invited to share information about their experience through surveys and to provide access to medical records as well as saliva samples and optional blood, stool, and/or stored tissue samples for study and analysis. Researchers from the Broad Institute of MIT and Harvard and Dana-Farber Cancer Institute use this information to generate databases of clinical, genomic, molecular, and patient-reported data that is then de-identified and shared with researchers everywhere. Insights gleaned from the research will also be shared with patients participating in the project. To date, more than 9,000 patients with different cancers have joined Count Me In and shared their data.

The launch of the Colorectal Cancer Project comes at a time when a particularly concerning increase in colorectal cancer incidence among younger individuals has been observed. Since 1994, colorectal cancer has increased by 51 percent in individuals younger than 50, according to the National Cancer Institute. The rising incidence of young-onset colorectal cancer has recently led the American Cancer Society to revise its colorectal screening guidelines to start earlier at age 45 instead of 50.

“Colorectal cancer is the second leading cause of cancer death in the U.S. and is on track to become the leading cause of cancer death in people aged 20 to 49 by 2030. These cancers are developing in otherwise young and healthy people who have no risk factors,” said Kimmie Ng, MD, MPH, the director of the Young-Onset Colorectal Cancer Center at Dana-Farber and co-scientific leader of the Colorectal Cancer Project. “Understanding why these rates are rising is what keeps me up at night and why we have redoubled our efforts to tackle this problem. The Colorectal Cancer Project will connect patients and researchers to accelerate the search for answers and solutions to this troubling trend."

Colorectal cancer also disproportionately affects African Americans who are approximately 20% more likely to get colorectal cancer and about 40% more likely to die from the disease than most other racial groups according to the American Cancer Society.

Inviting all colorectal cancer patients from any age, background, or stage to join the project adds tremendous scientific value to the data that is ultimately generated. The inclusion of a larger, more diverse patient population enables the study of patients who may have received a particular therapy for treatment of their disease, patients who might share a specific rare mutation in their tumor, or those from a specific age group or background who are otherwise underrepresented in existing research studies.

"We still do not know why there is an alarming rise in colorectal cancer in young adults," said Andrea Cercek, MD, Co-Director, Center for Young Onset Colorectal and Gastrointestinal Cancers Memorial Sloan Kettering Cancer Center and co-scientific leader of the Colorectal Cancer Project. "What we do know is that this is a global phenomenon that affects otherwise healthy individuals with no known risk factors. The Colorectal Cancer Project will provide researchers important information that will lead to a better understanding of this disease."

Count Me In's research model also seeks to empower all individuals living with cancer, including those from marginalized communities who have historically been excluded from research, no matter where they live, to contribute to groundbreaking cancer research. Due to the fact that the majority of cancer patients have not had the opportunity to participate in research — because most cancer patients are cared for in community settings where this type of research is not done — most patients have never been asked if they'd like to contribute their tissue samples and medical information for research.

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