An Important Resource in Colorectal Screening Research

Colorectal cancer is the second most common cause of death from cancer in the U.S. It is also a cancer that can be prevented, because most colorectal cancers start off as small growths called polyps, some of which can turn into cancer over 5-10 years. During a colonoscopy, a lighted tube examines the inside lining of the colon (large intestine). Polyps can painlessly be removed during the test, which means that they would not be able to turn into cancer. In this way, colonoscopy can help to decrease the chances of getting colorectal cancer.

However, there are still many things that doctors need to learn about colonoscopy. For example, should some people get the test more or less often or start getting the test sooner? In order to find the answers to these questions, the NH Colonoscopy Registry (NHCR) was developed with support from the National Cancer Institute (NCI) and the America Cancer Society. NHCR collects information on colonoscopies throughout New Hampshire. The registry collects information to help learn the best use of colonoscopy for colorectal cancer screening and prevention.

New Hampshire Colonoscopy Registry







Phone: 1-800-249-9908 E-mail: nhcr@dartmouth.edu

WHAT IS A COLONOSCOPY REGISTRY?

The Colonoscopy Registry is a computer database of information collected from participating patients and their doctors, which contains information about the colonoscopy exam, pathology results, and a brief patient survey that is sent to patients a month after the procedure.

The purpose of a colonoscopy registry is to learn more about how medical, environmental, and inherited factors affect colon cancer. The hope is to find ways to improve screening and to prevent colon cancer from occurring.

WHAT CAN I DO TO HELP?

On the day of your colonoscopy you will be given additional information on NHCR. Please read it over and consider participating in this registry. If you agree to participate, you will be asked to complete 2 questionnaires, one on the day of your procedure and another short one that we will send to you in the mail 30 days after your procedure. The information you give us will be entered into the NHCR database, along with your examination results and pathology reports if a polyp was removed or biopsied.

We may contact you or your doctor by mail in the future to access more information.

If after you read the NHCR consent form you decide not to participate, just let your nurse know that you would like to decline to participate in the registry. Participation in this registry is voluntary and does not affect your medical care.

I WOULD LIKE TO PARTICIPATE. HOW DO I ENROLL?

- 1. On the day of your colonoscopy, read over the NHCR information that you are given and sign the consent form.
- 2. Complete the brief patient survey.
- 3. Complete the follow-up survey that you receive in the mail 30 days after your procedure.

If you have any questions about your participation in NHCR, please don't hesitate to contact us. We are available Monday - Friday, 8:00 AM - 4:30 PM.

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HOW WILL MY PRIVACY BE PROTECTED?

We place a high priority on protecting information that can identify you; therefore it is stored in locked file cabinets and on encrypted password-protected computer files. Your name and other personal information will never be included in the same computer file as the rest of your information. Data transferred to other researchers will be transmitted only in a password protected and encrypted format. Data transmitted on Compact Discs (CDs) will also be stored in a password protected and encrypted format.

The data in the registry will be maintained indefinitely and used only for research purposes. The results of any research will be statistically analyzed and individuals will not be identified in any reports or publications. Your privacy is strictly maintained.