



Overview of the Newfoundland and Labrador Cancer Care Registry (NLCCR)

The NLCCR is managed by the Provincial Cancer Care Program at Eastern Health. Although the Provincial Cancer Care Program falls under Eastern Health's responsibility, it serves the entire province.

The NLCCR consists of five separate programs; three are cancer screening programs and two are used for surveillance, or tracking, purposes. The programs include:

1. Breast Screening
2. Colon Screening
3. Cervical Screening
4. Tumour Surveillance
5. Systemic Therapy (Chemotherapy) Surveillance

Newfoundland and Labrador's Personal Health Information Act governs the Newfoundland and Labrador Cancer Care Registry (NLCCR) and directs how the registry can collect, use, and share your health information. This information is needed to support and provide the best health care possible. If you have questions or concerns about why or how the information is collected, used, or shared, please contact the program office at 1-844-777-4438.

If you have questions about the NLCCR's authority to collect, use or share information please contact the Eastern Health Access and Privacy Office at (709) 777-8025.

The Newfoundland and Labrador Cancer Care Registry



www.easternhealth.ca

The Newfoundland and Labrador Cancer Care Registry (NLCCR) aims to:

- improve patient care;
- provide information to support decision making and identify priorities in health care;
- collect information to better understand cancer risks and the effects of cancer;
- measure change over time;
- positively impact cancer care delivery, research and policy; and
- improve delivery of screening programs.

Collecting, Using, and Sharing of Information in the NLCCR

The NLCCR, under the Provincial Cancer Care Program, is authorized to collect health information without consent under *Newfoundland and Labrador's Personal Health Information Act, 2008* (PHIA).

Under PHIA, the NLCCR has an “authorized registry” status. This means that the registry can collect, use and share health information to support the delivery of health care with respect to screening for colorectal, cervical and breast cancer, monitoring chemotherapy delivery and tracking cancer rates.

Registry status comes with certain obligations under PHIA. For example, the NLCCR’s information and privacy practices must be reviewed by the Office of the Information and Privacy Commissioner periodically to maintain this special designation.

Types of information the NLCCR collects:

For Cancer Screening Programs:

- a person’s **screening services** (e.g. home stool tests, mammograms, Pap tests) and **results** information;
- a person’s **health information**, such as colorectal cancer history, cervical cancer history or breast cancer history; and
- a person’s **contact information**, such as a person’s name and address.

For Chemotherapy and Disease Tracking:

- a person’s chemotherapy **treatment information** such as type of drug/drugs received, dose of drug, and cost of drug; and
- a person’s **disease information** such as type of cancer and stage at diagnosis.

Consent is not required to collect, use and share information in the NLCCR. This information is used to improve quality of cancer care in Newfoundland and Labrador.

In the case of the colorectal, breast and cervical screening programs, a person may choose to withdraw from taking part in or receiving communications from these programs by contacting the appropriate screening program:

Colon Screening

1-855-614-0144

Breast Screening

1-800-414-3443

Cervical Screening

1-866-643-8719

For further information about the NLCCR, please visit:

www.easternhealth.ca/CancerCare