

NORTHH
Northern Ontario School of Medicine Research Toward Health Hub
UTOPIAN Data Safe Haven Information Poster

Did you know? Electronic Medical Record (EMR) data can be used to **understand health problems** seen in family practices to **build a better health care system**. There are many important health questions that can only be answered in family practices. Your family doctor/nurse practitioner at this clinic **recognize the value and need for these data to improve your care and the care of others like you**. As part of this, EMR data are transferred to a "Data Safe Haven" while protecting your privacy.

NORTHH - the Northern Ontario School of Medicine (NOSM) Research Toward Health Hub - is working with UTOPIAN at the University of Toronto to create Northern Ontario databases.

What is the NORTHH? NORTHH is a practice-based research network that will support quality improvement and community research in primary care. It can help communities, physicians and practices, and policy-makers learn more about primary care in Northern Ontario.

What is the UTOPIAN Data Safe Haven? The University of Toronto Practice-Based Research Network (UTOPIAN) will coordinate safe and secure management of EMR data. The UTOPIAN Data Safe Haven is a database of electronic medical record data collected in primary care practices in the Toronto area and now across Northern Ontario in practices affiliated with NOSM. The data are de-identified, which means that information such as names or phone numbers is not included in the database.

We store de-identified EMR data for research and quality improvement. For example:

- a) Measure how common some chronic conditions are; these include high blood pressure and diabetes
- b) Understand more about how these conditions are managed today
- c) Discover what could be done to improve care for patients in the future

What type of information is collected? NORTHH collects information about health and care, including how illnesses are diagnosed, treated and managed. In addition to clinical information, the database also includes demographic information such as postal code and gender. Data that can identify people such as names or addresses are not a part of the Data Safe Haven. These will be collected to link, with privacy safeguards, to other health databases for the study of health conditions. To improve the removal of identifiers, they are encrypted, safeguarded and stored separately from the Data Safe Haven.

A copy of the NORTHH data may be forwarded to authorized organizations such as: the Canadian Primary Care Sentinel Surveillance Network (www.cpcssn.ca), the Institute for Clinical Evaluative Studies (www.ices.on.ca) or other prescribed entity and Diabetes Action Canada (diabetesaction.ca). This will be done to support important research projects with full ethics approval and privacy safeguards. With NORTHH, we want to make sure that communities and practices in Northern Ontario can make their own decisions about how their data is used.

What about my privacy? Your privacy is important to us. We are committed to keeping your personal health information safe and confidential at all times. Information collected from the EMR is stored in a secure central electronic system with strong safeguards to protect your privacy.

Questions about the project? If you have any questions or concerns, please discuss them with your doctor first. Participation is completely voluntary. If at any time you wish to opt-out of the study, please tell your doctor or contact the NORTHH group at NORTHH@nosm.ca or UTOPIAN Research Officer at 416-978-7017 or email us at DFCM.UTOPIAN@utoronto.ca.

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