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 provided to the UTOPIAN Data Safe Haven while protecting your privacy.

What is UTOPIAN Data Safe Haven

The UTOPIAN Data Safe Haven is used to securely collect electronic medical record data in family practices and primary care sites across Ontario. This is being locally coordinated by the University of Toronto Practice-Based Research Network (UTOPIAN). The data undergoes standardization and de-identification processes, which means that information such as names or phone numbers is not included in the finalized UTOPIAN Database.

The UTOPIAN Database stores de-identified EMR data for research and quality improvement. For example, through the UTOPIAN Database, family physicians and researchers can:

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?

The UTOPIAN Data Safe Haven 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 final UTOPIAN Database. 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 UTOPIAN Database.

A copy of the UTOPIAN Database may be forwarded to authorized organizations such as: the Canadian Primary Care Sentinel Surveillance Network (www.cpcssn.ca), ICES (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.

Data collected as part of this study may also be used for clinical research and analysis of health problems facing patients. It is also used to provide feedback to your family doctor or nurse practitioner and the information can be used to improve quality of care. More details are available at the UTOPIAN website: https://www.dfcm.utoronto.ca/about-utopian.

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 UTOPIAN Research Officer at 416-978-7017 or email us at DFCM.UTOPIAN@utoronto.ca.