The Réseau de recherche en soins primaires de l’Université de Montréal (RRSPUM) is a primary care practice-based research network (PC-PBRN) participating in the Canadian Primary Care Sentinel Surveillance Network (CPCSSN). It and 9 other PC-PBRNs comprise the first pan-Canadian public health surveillance and research project using patient data from providers’ (sentinels’) electronic medical records (EMRs). To collect and use anonymized electronic health data, each PC-PBRN works with research ethics boards (REBs) to establish procedures that comply with its province’s privacy laws. Among the provinces, Quebec’s privacy laws are the most stringent, which poses challenges for researchers. The handling of personal information is governed by the Civil Code of Quebec; and 2 acts pertaining to the public and private sectors. These mandate individuals’ right to control access to their health data and require explicit (opt-in) consent for the data’s use, even if the data do not directly identify them. Other privacy regimes across Canada permit implicit (opt-out) consent and apply only to identifying information.

The RRSPUM team had to develop distinct patient consent protocols to comply with distinct privacy laws for private and public sector institutions. For public sector institutions, Quebec’s An Act Respecting Health Services and Social Services governs the handling of health information. It permits the use of health data for research purposes without the individual’s explicit consent, provided researchers obtain permission from their health institution’s director of professional services after REB approval. The REB reviews researchers’ proposed protocols and dictates required changes. Patient notice protocols can differ among REBs. The RRSPUM proactive patient notification protocol ensures patients are informed and respects their privacy rights to control access to their health data. It enables Quebec’s contribution to meaningful chronic disease surveillance and research, and provides valuable feedback to health care providers about their patients and practices.

The RRSPUM team used a different protocol for private clinics. The Central REB for the Ministère de la santé et des services sociaux requires that patients sign a consent form of several pages. The Central REB and RRSPUM developed a procedure for obtaining explicit (opt-in) consent: reception staff ticked a box on the EMR’s top page when the patient received the CPCSSN brochure and consent form, then ticked a second box when the patient returned the signed form. After several months, the opt-in rate is 40%, which is less than optimal for research.

While the proactive consent protocol satisfies privacy demands, its implementation incurs costs, such as the printing of brochures and forms for the clinic’s total patient population, and the time reception staff spend notifying patients. However, these expenses diminish over time.

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Competing interests None declared

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