PRIVACY IS A PARTNER, NOT A FOE, IN MEDICAL RESEARCH

VANCOUVER SUN –– AUGUST 16, 2012 –– OPED

By Elizabeth Denham

Medical research is vital to all British Columbians. It saves lives and decreases morbidity. It improves our health outcomes and creates efficiencies in health care. And attracting research dollars is good for B.C.'s economy.

In recent weeks, there has been a lively debate about the barriers researchers encounter in accessing health data for medical research. Many participants in this debate allege that privacy law and policies are the culprits. I disagree.

As B.C.'s information and privacy commissioner, I am confident that it is possible to facilitate research and protect privacy at the same time. I have no doubt that medical research is in the public interest. In my view, privacy and research are partners, not adversaries, in the pursuit of better health outcomes. Protecting privacy and promoting research are both laudable public policy goals and both are important to British Columbians.

Opinion polling consistently demonstrates that citizens generally sup-port giving academic and clinical researchers access to their health data, in de-identified form, or when the research requires it, in identifiable form. But their support depends on robust protection of the personal health information collected in the course of that research.

Protection of privacy matters in medical research, because the data is never "just data": It is sensitive health information provided by individuals in good faith, in the context of receiving care. If that personal information is lost, compromised or improperly accessed, it can have a significant effect on a person's sense of autonomy, dignity and trust in the health care organizations, research institutions and the health care system as a whole. Moreover, if people cannot be assured their privacy will be respected, they may be less willing to participate in future research. So, protecting privacy is essential if we want to maintain public support for medical research.

Fortunately, B.C.'s current legal framework facilitates privacy-positive health research; our legal commitment to privacy protection is not an obstacle. Our laws and policies are in line with international ethical and legal standards, and strike an appropriate balance between the needs of researchers to access data and the right to privacy.

One of the statutes that I oversee, the Freedom of Information and Protection of Privacy Act, allows public bodies such as the Ministry of Health and health authorities to disclose information for a research purpose.

Nevertheless, privacy concerns have been raised about the effect of this legislation. So, in an effort to address this issue head-on, I brought together a small but representative group of thoughtful individuals including data stewards, elected officials, government representatives and members of the health research community to have a lively and frank discussion about the state of medical research and data access in B.C.

There was unanimous agreement around the table that there is a problem. The problem is real and it is systemic. Researchers in British Columbia are simply not getting access to the health data they need to conduct medical research. This is unacceptable.

Barriers identified at the meeting included a troubling lack of information about what data types are avail-able to researchers, persistent data silos that make accessing data across and within health agencies an exercise in frustration, data stewards with no efficient processes to approve data access requests and inefficient administration, including duplicate paperwork and lengthy approval timelines, which result in significant delays.

While I am pleased that the round-table participants confirmed that B.C.'s robust privacy laws are not getting in the way, I will remain vigilant in ensuring these laws do not become impediments to vital medical research.

The Ministry of Health has com-mitted to improve its record, ensuring that researchers obtain more timely access to necessary data. Participants at the roundtable were keen to talk about administrative solutions to remove impediments, streamline the request process, and reduce the paperwork required for researchers seeking approval, while ensuring accountability for the release and security of the data. They identified the need to explore greater use of de-identified data and broader sup-port for data sources such as Population Data B.C., a multi-university data resource facility.

What is needed now is for members of the legislature to enunciate the importance of health research, for the ministry of health to articulate their vision and make it a priority, and for stakeholders to continue the dialogue begun at the roundtable.

Now more than ever, it is important to keep the channels of communication open and to collaborate on lasting solutions to address the systemic problems that have been identified.

Elizabeth Denham is information and privacy commissioner for British Columbia. A public report of the commissioner's roundtable on health research is available at: www.oipc.bc.ca