

Canadian Institutes of Health Research: Guidelines on privacy of health information

By: Anne Dooley

The Canadian Institutes of Health Research (CIHR) held a consultation on its Draft Best Practice Guidelines on Privacy, Confidentiality and Security of Personal Health Information in Research in Toronto, on August 24th. The draft covers ten interconnected core elements involved in human research:

- ❑ determining research objectives and justifying the data needed;
- ❑ limiting the collection of personal data;
- ❑ determining if consent from individuals is required;
- ❑ recruiting prospective research participants;
- ❑ informing prospective research participants about the research;
- ❑ managing and documenting consent;
- ❑ safeguarding data confidentiality;
- ❑ limiting access to personal data;
- ❑ retaining, destroying and archiving data; and
- ❑ ensuring accountability and transparency.

The draft is the result of several years of discussion with the research community, and is intended to balance respect for the privacy of individuals with the recognition of the social value of health research. Consumers are included among the stakeholders, as are researchers, administrators, Research Ethics Board members and managers, governments both provincial and federal, industry, ethicists, and others. The inclusion of so many interests at the table is significant.

As everyone is aware, there are a diversity of often complex laws and policies relating to security and privacy of information in Canada, and the same is true in other countries. This increases the challenges faced by researchers, and especially those that are engaged in cross border projects. But researchers aren't the only ones that need to be aware of these rules. Ordinary citizens rely on the integrity, honesty and assurances of individuals working within our health care system and the safeguards assumed to be built into the system itself to protect their personal information from unauthorized eyes and uses.

Research provides information that leads to improvement in the health of Canadians, but along with medical advances come advances in technology including the technology of recording and storing of information. Just one of the questions raised during discussions dealt with how the individuals and activities of the various experts who maintain the information networks and electronic databases that record, transfer and archive personal information should be dealt with.

In Saskatchewan there is a stir of controversy over a new program with good intentions that informs women of the results, good or bad, of their latest PAP smears by letter from the Saskatchewan Cancer Agency, not from their doctors. There is an expectation of privacy and confidentiality in health matters, but in this case no consent was sought from

or provided by patients for this transfer of information or for the method of informing patients. In fact, neither patients nor the public had been informed about this program when the first letters appeared in post boxes. This is a real situation. Also real are the health records that from time to time are found in alley dumpsters instead of being properly disposed of as required. There's no doubt that good guidance is necessary. The guidelines, when formally adopted, will provide assistance with privacy, confidentiality and security concerns to those designing and conducting health research, guidance for Research Ethics Boards and institutions when evaluating research projects, and will help promote a coherent policy across Canada for the protection of privacy in health research.