

# *Research Participants' Rights to Access Information about Themselves held by Public Research Institutions*

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## **Introduction**

The growth in longitudinal studies that involve collection and banking of personal information and biological samples from research participants over many years has generated wide-ranging analysis of associated ethical, legal and social aspects, especially issues of consent, privacy and confidentiality, handling of research findings, and benefit sharing.<sup>1</sup> One issue, however, that has received relatively little attention in the discussion of research databanks is the right of participants to request access to information about themselves held by researchers. Over the course of a long-term study, much information about participants will be collected and recorded, including participant responses to study questionnaires and other instruments, records of physical measures, and results from analyses of blood or other biological samples that may be conducted for some studies.

As discussed below, a key fair information principle is that individuals ought to be able to know about and access personal information about themselves, especially information held by public institutions. Indeed, freedom of information laws across Canada codify a right to access information held by public bodies, subject only to specified exceptions.<sup>2</sup> What is the scope of a research participants' right to obtain access to information about themselves held by researchers in public institutions, such as universities? How does legislation apply to

records created for research purposes? What factors should researchers consider in developing policies to handle access requests?

To address these and related questions, this paper discusses the development of Canadian legal principles concerning access to personal information, focusing particularly on health information. It begins with a brief overview of Canadian common law principles about access to health care records, then turns to the development of statutory access to information rules. Legislative provisions that apply to records obtained or created for research purposes are summarised and practical considerations for developing access to information policies are discussed.

## **Canadian Common Law: *McInerney v. MacDonald***

To open the discussion of information access rights, it is worth looking back to the 1992 Supreme Court of Canada decision in *McInerney v. MacDonald*.<sup>3</sup> This litigation concerned the common law right of a patient to access records held by her physician. Dr. McInerney provided copies of records she had created, but refused to release copies of reports she had received from other physicians. In her view, those documents were the property of the other physicians and Ms. McInerney should contact them directly to request access.



Ruling in the patient's favour, the Supreme Court of Canada held that a patient has a right to access their health care records and that a physician should provide access to all records that informed the patient's treatment, including records obtained from other health care providers. The Court based this access right on the fiduciary relationship between the physician and the patient and noted that "a patient has a vital interest in the information contained in his or her medical records."<sup>4</sup> While the relationship between researcher and participant may arguably be characterised as fiduciary in limited circumstances, such as the relationship between a physician-researcher and a patient-participant in a clinical trial,<sup>5</sup> the *McInerney* case is nonetheless notable in emphasising the importance of access to information about oneself. The nature of the information contained

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in research records is similar to the Supreme Court's description of information contained in medical records: "at least in part, medical records contain information about the patient revealed by the patient ... Of primary significance is the fact that the records consist of information that is highly private and personal to the individual. It is information that goes to the personal integrity and autonomy of the patient."<sup>6</sup>

Moreover, the Court noted that access to records about oneself may be necessary for a patient to ascertain that a health care provider has, in fact, discharged their duty to act in the patient's best interests: "it is important that the patient have access to the records ... to ensure the proper functioning of the doctor-patient relationship and to protect the well-being of the patient. If there has been improper conduct in the doctor's dealings with his or her patient, it ought to be revealed."<sup>7</sup> This same reasoning may apply to a research participant's interest in obtaining access to personal information held in

research records, especially if access to the information may be relevant to the individual's ongoing, informed consent to participate. For instance, a person who became a research participant as a child may, upon developing capacity to give their own consent to continued participation, request access to information collected about them earlier in their life.<sup>8</sup>

While these are points of analogy between access to health care records and access to records compiled for research, it must be noted that the Supreme Court in *McInerney* limited the direct scope of its decision by stating it "does not extend to information arising outside the doctor-patient relationship."<sup>9</sup> Yet, when the case was before the New Brunswick Court of Appeal, the majority observed presciently "that a noticeable trend has developed favouring an individual's right of access to personal information."<sup>10</sup> Indeed, that trend began to emerge in the latter decades of the 20<sup>th</sup> century and culminated, in Canada, with enactment of provincial and federal statutes that codify information access rights.<sup>11</sup>

## **The Trend to a Right of Access to Information about Oneself**

### **Fair information principles**

In the 1970s, several influential American and European governmental commissions examined the growing technological capacity to store vast amounts of computerised data about citizens and began to formulate fair information practices.<sup>12</sup> The principle of individual access was common among recommendations for fair information handling practices; as a U.S. report stated: "There must be a way for an individual to find out what information about him is in a record and how it is used."<sup>13</sup> In 1980, the Organization for Economic Cooperation and Development (OECD) adopted guidelines for the protection of personal information.<sup>14</sup> These guidelines included an "individual participation" principle which states that an individual should have a right to access information about themselves. The OECD guidelines influenced development of fair information principles in other jurisdictions, including the Canadian Standards Association (CSA) Model Code for the Protection of Personal Information.<sup>15</sup> Principle 9 of the CSA Model Code states: "Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information, and shall be given access to that information."<sup>16</sup> This Model Code



was subsequently adopted into law to form the core principles of the federal *Personal Information Protection and Electronic Documents Act*.<sup>17</sup>

### Development of statutory access rights

At the time of the Supreme Court's decision in *McInerney v. MacDonald*, there was no consistent legislative approach to access to information across Canada. The legal situation is markedly different today as access to information legislation currently exists in all Canadian jurisdictions.<sup>18</sup> The legislation varies, however, in its application to different types of organisations, with separate statutes typically regulating public and private sector bodies. Researchers should be aware of legislation that will apply to the organisation that acts as a data repository for long-term studies. This paper focuses on research led by university-based investigators where databanks are held by these public institutions. Thus, the discussion addresses provincial statutes that apply to universities; Table 1 identifies examples of relevant legislation and key provisions concerning access to personal information and exceptions to access to research-related information.

### General access to information provisions

A legislative purpose that is common across all these statutes is to allow individuals a right of access to records containing personal information about themselves that are in the custody or under the control of public bodies. This access right is subject to limited and specific exceptions set out in the statutes. The laws typically define "personal information" as recorded information about an identifiable individual. Some statutes elaborate to explain that personal information includes information about an individual's health status, health care history, genetic or inheritable characteristics, and other details. It is important to note that personal information may be defined or interpreted to include opinions about an individual expressed by another person. In a research context, opinions about an individual may be collected through study instruments such as questionnaires; for example, a mother participating in a birth cohort study may give her opinions about her child's behaviour and development. According to some access to information statutes, these opinions could be considered the personal information of the child.

Under access to information statutes, individuals must submit a written request for access to personal information and a fee payment may be required. The custodian of the records generally has a statutory duty to assist the applicant by making a reasonable search for records responsive to the request and to respond within a specified time period (typically 30 days).<sup>19</sup> A question may arise as to whether coded records constitute information about an 'identifiable individual.' If the custodian of the records can readily re-link coded records with a specific participant, such records would likely be considered 'personal information' for the purposes of access to information legislation. Where information is stored electronically, the custodian may be obliged to produce a paper record for the applicant.<sup>20</sup>

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### Exceptions to Disclosure

#### Research information

Provincial access to information statutes that apply to public sector institutions typically state that they do not apply to research information of an employee of a post-secondary educational body.<sup>21</sup> Does this exception from disclosure mean, however, that research participants cannot obtain information about themselves held by researchers? Several arguments suggest this exception to disclosure should not be used as a general bar to withhold access to personal information requested by a research participant.

First, a key purpose of such legislation is to ensure a right of access to personal information, subject only to *limited* exceptions. Ontario's *Freedom of Information and*



*Protection of Privacy Act* illustrates this point by stating that a purpose of the legislation is “to provide a right of access to information under the control of institutions in accordance with the principles that, (i) information should be available to the public, [and] (ii) necessary exemptions from the right of access should be limited and specific...”<sup>22</sup> Information and Privacy Commissioners have emphasised that exceptions to disclosure must not be interpreted in an overbroad manner. In a 2008 decision concerning the research information disclosure exception, Ontario’s Commissioner observed that “the Legislature did not intend to create an exclusion from the application of the *Act* whose reach would be broader than is necessary to accomplish” the goals of protecting academic freedom and competitiveness.<sup>23</sup>

Second, and as a related point, records that contain personal information about a participant differ from documents that describe research methods and hypotheses, draft analyses, and materials being prepared for dissemination through avenues such as peer-reviewed academic journals. Disclosure of the latter types of information could compromise scholarly confidences and competitiveness, but releasing to a participant records containing personal information about her/himself does not pose this same risk.

While a case law search did not reveal a decision where a Commissioner or court considered a participant’s right of access to personal information held by a researcher, several decisions have addressed the issue of what types of records constitute ‘research information.’ British Columbia’s Commissioner applied a disclosure exception provision in a 2000 decision about access to a research protocol.<sup>24</sup> In this case, a third party who had concerns about public spraying of an insecticide sought access to a protocol, a research instrument, and other data related to research on the impacts of the spraying. The Commissioner ruled that certain records, including a study protocol that disclosed details of a study method and a questionnaire to be administered to study participants, could not be accessed under freedom of information legislation. He stated that the statutory provision protecting research information from disclosure “is intended to protect individual academic endeavour. It will protect the intellectual value in ... research information developed by an employee of a post-secondary educational body, for her professional purposes, by protecting it from disclosure to those who might exploit it to her disadvantage.”<sup>25</sup> Similarly,

in a 2008 decision, Ontario’s Commissioner upheld McMaster University’s decision to refuse to disclose to a third party details about clinical trials being conducted by university researchers.<sup>26</sup> While these decisions limit the ability of a third party to access research records, they do not imply that an individual participant should be limited in accessing information about her/himself collected over the course of a research study.

Indeed, some statutes narrow the circumstances in which research information may be protected from access requests. Alberta’s and Ontario’s legislation state that information obtained through research may be withheld if disclosure “could reasonably be expected to deprive the employee ... of priority of publication.”<sup>27</sup> It may be unlikely, however, that disclosing records to a participant who makes an access request will jeopardize publication activities. Ontario’s statute also states that the custodian “may refuse to disclose to the individual to whom the information relates personal information ... that is a research or statistical record.”<sup>28</sup> It is important to note that this is a *discretionary* exception to disclosure; in other words, the custodian *may* choose to withhold the requested information, but may equally exercise discretion to disclose it to the individual who seeks access. And providing access may well be more consistent with a key purpose of such legislation – that is, giving individuals a right of access to information about themselves.

Finally, as mentioned earlier, it may be argued that research participants have an interest in accessing information about themselves held by researchers in order to make an informed choice to continue participating in the research. This may especially be the case for a young person whose parent authorised their initial involvement in the research, but who is at a level of maturity to make their own choice. To make an informed decision about continuing participation, s/he may request access to records to understand fully the types of information that researchers hold about the participant and are using for research purposes.

### Harm to self or third parties

In addition to restrictions on access to records related to research, legislation typically contains other provisions that limit disclosure of information in specified circumstances. Common reasons for which information may be withheld include:



- the disclosure could reasonably be expected to threaten the health or safety of a third party;<sup>29</sup>
- the disclosure could reasonably be expected to cause serious and immediate harm to the health or safety of the person who made the request;<sup>30</sup> or
- the disclosure would reveal personal information about another individual (and that individual has not consented to release of the information).<sup>31</sup>

Refusal to disclose information on the ground that it would cause serious harm to the individual applicant abrogates individual access rights and may only be justified with clear evidence of the risk of harm. In some jurisdictions, there may be a statutory requirement to obtain the opinion of a physician or psychiatrist.<sup>32</sup> Where a research participant requests access to records

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containing information about her/himself, it may be unlikely that disclosure of such information would present a risk of harm to third parties. This situation may arise in a study involving family or group members where one individual states a negative opinion of another while completing a questionnaire. As noted earlier, that opinion may be considered the personal information of the individual whom it concerns. In rare circumstances, disclosure of that negative opinion may raise concerns about risk of reprisal if the recipient of the information can link the opinion to the person who expressed it to researchers.

In some research contexts, information about more than one participant may be ‘co-mingled’ in a record, such as in birth cohort studies where information about parent and child are recorded in the same document.<sup>33</sup> If one individual seeks access to the record, researchers may

need to remove information about the other individual before disclosing it, unless they have consent from the other party to disclose the record in its entirety. Access to information statutes typically state that disclosure of personal health information about one person to another without consent is presumed to be an unreasonable invasion of privacy.<sup>34</sup>

## Access to Research Findings?

Does a right of access to personal information include a right to access research results pertaining to the individual? The issue of researchers’ obligation to return results to participants has been discussed and debated extensively elsewhere,<sup>35</sup> but the literature typically focuses on the scope of researchers’ ethical duty to inform participants of results rather than the right of participants to obtain results through access to information legislation.<sup>36</sup> Consider two types of information about a research participant: first, a survey the participant completes that asks questions about her history of allergies; second, results of a genotypic assay showing that this same participant has a genetic variant being studied for its association with certain type of allergies. The survey contains personal information about the participant *provided by* the participant so it would seem non-controversial to provide this record to the participant if she made an access to information request. But what about the research result concerning her genetic characteristics? Does this finding constitute personal information that the participant may obtain under access to information legislation?

Some researchers may express concern about disclosing the results of research tests, particularly where the clinical validity of the information is uncertain; indeed, some studies have a policy of returning results only if they have clear clinical significance.<sup>37</sup> If the genetic findings were recorded in the individual’s medical record, however, the individual would have a right to access the information based on the *McInerney v. MacDonald* decision. Should the information be treated differently because it is in a research record and not a medical record?

Interestingly, in the United States, this distinction is relevant to a research participant’s right to access information. According to the Privacy Rule under the *Health Insurance Portability and Accountability Act*,<sup>38</sup> individuals have a right to access information held in



a 'Designated Record Set,' which includes medical and billing records.<sup>39</sup> Information obtained through research but that is then recorded in a medical record, or is recorded in a research setting and used to inform clinical decisions (e.g. a recording of high blood pressure noted in a research lab notebook), is accessible under the Privacy Rule.<sup>40</sup> The following explanation provides further guidance on the U.S. rule:

However, information that is generated in research and lacks clinical validity or clinical utility generally will be considered outside of the Designated Record Set (unless it is recorded in the medical chart or billing records). The Privacy Rule allows a researcher to delay access to the Designated Record Set until the end of the study (e.g., in the case of a randomized controlled trial). But, the investigator must inform the subject of such a delay in the authorization to use or disclose identifiable health information.<sup>41</sup>

This type of distinction is not clearly made in Canadian access to information laws. The term "personal information" is generally defined broadly to mean recorded information about an identifiable individual, including health-related and genetic information. Information is not excluded simply because it is of unknown clinical certainty or utility for the individual. Speculative concerns that a participant may experience psychological distress from learning uncertain results is likely insufficient to justify non-disclosure under the 'risk to self' provisions noted above. Provisions that protect research information from disclosure may be applied to limit access to results of research investigations, but the custodian of the information would bear the onus of justifying the non-disclosure.

## Conclusions

Researchers who establish longitudinal studies that involve collection and retention of information about participants over many years should develop policies to address handling of participant requests for access to personal information. As this article has discussed, statutes across Canada give individuals a legal right to access personal information held by public bodies; moreover, facilitating a right to access personal information is consistent with research ethics principles that emphasise ongoing, informed consent, as well as fair

information handling principles. In developing access to information policies, researchers should consider the following questions:

- What information about the research initiative and general findings will be routinely shared with participants? A study website or newsletter may be used to communicate general information about the research, including study findings that do not contain individual details.
- What records may be disclosed to the participant on request? For example, documents containing information originally provided by the individual, such as questionnaires or other research instruments completed by the participant.
- Will results of routine physical measures such as height, weight, or blood pressure be disclosed to the participant on request?
- Will results of research tests where clinical relevance is unknown be disclosed to the participant on request?
- What types of information may raise concerns about disclosure for reasons such as:
  - ▶ Disclosure may present a risk of harm to a third party?
  - ▶ Disclosure may present a risk of harm to the participant?
  - ▶ The record reveals confidential research details (that would not otherwise be shared with the participant during informed consent discussions) and disclosure may harm academic freedom and research competitiveness?
- If a record contains information about more than one participant, what processes are in place to protect the privacy of the other individual? (For example, severing this information from the record or obtaining the individual's consent for release of the information.)

Where researchers have a policy of *not* disclosing information requested by a participant, researchers ought to be prepared to justify this decision by demonstrating that other interests outweigh the interest of the participant in having access to information about themselves held by public institutions. Finally, as other practical considerations, researchers ought to consider



whether information access rights will be communicated to participants during informed consent discussions and, once the research is in progress, who will be responsible for managing access to information requests. Consultation with an institution's central privacy and access to information office will be of assistance in developing appropriate policies and procedures.

*Nola M. Ries is a Research Associate with the Health Law Institute, University of Alberta, and Assistant Professor, Faculty of Law, University of Victoria. Funding support is acknowledged from the Allergy, Genes and Environment Network (AllerGen NCE and the Alberta Innovates Health Solutions, Interdisciplinary Chronic Disease Collaboration (ICDC) Team Grant). The author is grateful to Timothy Caulfield for comments on a draft of this paper.*

**Table 1: Sample provisions of access to information statutes applicable to university-based researchers**

Jurisdiction	Statute	Key Provisions (paraphrased from the statute unless extracts appear in quotation marks)
British Columbia	<i>Freedom of Information and Protection of Privacy Act</i> , R.S.B.C. 1996, c. 165	<p>Schedule 1: Personal information means recorded information about an identifiable individual.</p> <p>s. 3(1)(e): Act does not apply to “a record containing teaching materials or research information of employees of a post-secondary educational body.”</p> <p>s. 17(2); The head of a public body may refuse to disclose “research information if the disclosure could reasonably be expected to deprive the researcher of priority of publication.”</p>
Alberta	<i>Freedom of Information and Protection of Privacy Act</i> , R.S.A. 2000, c. F-25	<p>s. 1(n): Personal information means recorded information about an identifiable individual and includes health and health care history information, genetic information, and anyone else’s opinions about the individual.</p> <p>s. 4(1)(i): The Act does not apply to “research information of an employee of a post-secondary educational body.”</p> <p>s. 25(1)(d): The head of a public body may refuse to disclose “information obtained through research by an employee of a public body, the disclosure of which could reasonably be expected to deprive the employee or the public body of priority of publication.”</p>
Manitoba	<i>Freedom of Information and Protection of Privacy Act</i> , C.C.S.M. c. F175	<p>s. 1: Personal information means recorded information about an identifiable individual and includes information about the individual’s health and health care history, genetic information about the individual, and opinions of others about the individual.</p> <p>s. 4(g): The Act does not apply to “teaching materials or research information of an employee of an educational institution.”</p> <p>s. 28(1)(d): The head of the public body may refuse to disclose “innovative scientific or technical information obtained through research by an employee of a public body or the Government of Manitoba.”</p>

Table 1 continued on page 12



**Table 1: Sample provisions of access to information statutes applicable to university-based researchers (continued)**

Jurisdiction	Statute	Key Provisions (paraphrased from the statute unless extracts appear in quotation marks)
Ontario	<i>Freedom of Information and Protection of Privacy Act</i> , R.S.O. 1990, c. F.31	<p>s. 2(1): “Personal information” means recorded information about an identifiable individual, including information relating to medical, psychiatric, or psychological history and the views or opinions of another individual about the individual.</p> <p>s. 18(1)(b): The head of an institution may refuse to disclose “information obtained through research by an employee of an institution if the disclosure could reasonably be expected to deprive the employee of priority of publication.”</p> <p>s.49(f): The head of an institution “may refuse to disclose to the individual to whom the information relates personal information ... that is a research or statistical record.”</p> <p>s. 65(8.1)(a): “This Act does not apply to a record respecting or associated with research conducted or proposed by an employee of an educational institution or by a person associated with an educational institution.”</p>
Nova Scotia	<i>Freedom of Information and Protection of Privacy Act</i> , S.N.S. 1993, c. 5	<p>s. 3(1)(i): Personal information means recorded information about an identifiable individual, including information about the individual’s health care history, inheritable characteristics, and anyone else’s opinions about the individual.</p> <p>s. 19B (2): The head of a local public body may refuse to disclose details of the academic research being conducted by an employee of the local public body in the course of the employee’s employment.</p>
Newfoundland & Labrador	<i>Access to Information and Protection of Privacy Act</i> , S.N.L. 2002, c. A-1.1	<p>s. 2(o): Personal information means recorded information about an identifiable individual, including information about the individual’s health care status or history, inheritable characteristics, and the opinions of a person about the individual.</p> <p>s. 5(1)(h): The Act does not apply to a record containing “research information of an employee of a post-secondary educational institution.”</p>

## Endnotes

1 Literature on this topic is vast, but for recent volumes that discusses many of these issues, see e.g. Jane Kaye & Mark Stranger, eds. *Principles and Practice of Biobank Governance* (Surrey, UK: Ashgate, 2009) and Bernice Elger, Nikola Biller-Andorno, Alexandre Mauron & Alexander M. Capron, *Ethical Issues in Governing Biobanks* (Surrey, UK: Ashgate, 2008).

2 See Table 1 for legislative examples.

3 *McInerney v. MacDonald*, [1992] 2 S.C.R. 138 [“*McInerney*”].

4 *Ibid.*

5 See e.g. Paul B. Miller & Charles Weijer, “Fiduciary Obligation in Clinical Research” (2006) 34 *Journal of Law, Medicine and Ethics* 424.

6 *McInerney*, supra note 3.



- 7 *Ibid.*
- 8 As a related issue, some scholars have argued that researchers who store minors' DNA for general population biobanks should "not make these DNA samples (or individual genetic sequence data) accessible outside the biobank until donors are recontacted as adults and given their own informed consent." David Gurwitz, Isabel Fortier, Jeantine E. Lunshof & Bartha Maria Knoppers, "Children and Population Biobanks" (2009) 325 *Science* 818 at 819.
- 9 *McInerney*, supra note 3.
- 10 This passage is quoted in the Supreme Court of Canada ruling, *ibid.* See also *McInerney v. MacDonald* (1990), 66 D.L.R. (4th) 736 (N.B.C.A.)
- 11 See e.g. British Columbia *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165 [BC FOIPPA], Alberta *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25 [AB FOIPPA]; Ontario *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31 [ON FOIPPA]; Nova Scotia *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5; federal *Privacy Act*, R.S.C. 1985, c. P-21.
- 12 See e.g. U.S. Secretary's Advisory Committee on Automated Personal Data Systems, *Records, Computers and the Rights of Citizens* (1973) online: <<http://aspe.hhs.gov/datacncl/1973privacy/tocprefacemembers.htm>>; Great Britain, Home Office, *Report of the Committee on Privacy* (1972) (Rt. Hon. Kenneth Younger, Chairman); U.S. Privacy Protection Study Commission, *Personal Privacy in an Information Society* (1977), online: <<http://aspe.hhs.gov/datacncl/1977privacy/toc.htm>>.
- 13 Secretary's Advisory Committee, *ibid.*
- 14 Organisation for Economic Co-operation and Development, *OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data* (adopted 23 September 1980, and as amended) online: <[http://www.oecd.org/document/18/0,3343,en\\_2649\\_34255\\_1815186\\_1\\_1\\_1\\_1,00.html](http://www.oecd.org/document/18/0,3343,en_2649_34255_1815186_1_1_1_1,00.html)>.
- 15 Canadian Standards Association, *Model Code for the Protection of Personal Information*, online: <<http://www.csa.ca/cm/ca/en/privacy-code/publications/view-privacy-code>>.
- 16 *Ibid.*
- 17 *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5.
- 18 For a thorough review of relevant legislation, see Michael Power, *Halsbury's Laws of Canada – Access to Information and Privacy* (Markham, Ont.: LexisNexis Canada, 2006).
- 19 See e.g. BC FOIPPA, ss. 6,7 and AB FOIPPA, ss. 10, 11, supra note 11.
- 20 See e.g., BC FOIPPA, s. 6(1)(a) and AB FOIPPA, s. 10(2), supra note 11.
- 21 Some statutes state that the title of a research project and funding amount are not covered by the protection against disclosure. See e.g. Saskatchewan's *Local Authority Freedom of Information and Protection of Privacy Act*, S.S. 1990-91, c. L-27.1, s. 17(4): "Where possible, the university must disclose the title of and amount of funding for specific academic research projects." See also Nova Scotia's *Freedom of Information and Protection of Privacy Act*, supra note 11, s. 19B (3): "Where possible, the head of a local public body shall disclose the title and amount of funding being received with respect to the academic research...."
- 22 ON FOIPPA, supra note 11, s. 1.
- 23 *University of Western Ontario (Re)*, 2008 CanLII 36903 (ON I.P.C.). See also *University of Guelph (Re)*, 2009 CanLII 50531 (ON I.P.C.), where the scope of the Act's protection for research information is illustrated by the following quotation made by a member of the legislative assembly in debate: "So as not to jeopardize the work being done at these institutions, though, the freedom-of-information provision would take into account and respect academic freedom and competitiveness. Clearly we understand the importance of the university post-secondary sector when it comes to doing research and innovative study programs. Thus we wouldn't want to jeopardize that academic freedom, or the competitive environment that is created accordingly." Quoting M.P.P. Wayne Arthurs in Third Reading of the legislative amendments.
- 24 Order 00-36, *Inquiry regarding a Capital health Region Research Protocol* (David Loukidelis, Information and Privacy Commissioner) 11 August 2000, online: <<http://www.oipcbc.org/orders/Order00-36.html>>. For another decision that concerns an access to information request for a research funding application and personal information about investigators, see *Saskatchewan Health Research Foundation (Re)*, 2009 CanLII 71734 (SK. I.P.C.). In 2008, the Ontario Information and Privacy Commissioner
- 25 *Ibid.*



- 26 McMaster University (Re), 2008 CanLII 36902 (ON I.P.C.)
- 27 AB *FOIPPA*, supra note 11, s. 25(1)(d); ON *FOIPPA*, supra note 11, s. 18(1)(b).
- 28 ON *FOIPPA*, supra note 11, s.49(f).
- 29 See e.g. BC *FOIPPA*, supra note 11, s. 19(1): “The head of a public body may refuse to disclose to an applicant information, including personal information about the applicant, if the disclosure could reasonably be expected to (a) threaten anyone else’s safety or mental or physical health, or (b) interfere with public safety.” ON *FOIPPA*, supra note 11, s. 20: “A head may refuse to disclose a record where the disclosure could reasonably be expected to seriously threaten the safety or health of an individual.”
- 30 See e.g. BC *FOIPPA*, *ibid.*, s. 19(2): “The head of a public body may refuse to disclose to an applicant personal information about the applicant if the disclosure could reasonably be expected to result in immediate and grave harm to the applicant’s safety or mental or physical health.” See also ON *FOIPPA*, *ibid.*
- 31 See e.g. BC *FOIPPA*, *ibid.*, s. 22; ON *FOIPPA*, *ibid.*, s.1.
- 32 See e.g. AB *FOIPPA*, s. 18(2), supra note 11.
- 33 The issue of co-mingling or ‘entanglement’ of information has been raised in the context of biobanking where biological materials such as placental tissues contain information about both mother and child. For further discussion of this issue, see e.g. Nola M. Ries, “Growing Up as a Research Subject: Ethical and Legal Issues in Birth Cohort Studies involving Genetic Research” (2007) 15 Health L.J. 1 and Soren Holm, “Informed Consent and Bio-banking of Material from Children” (2005) 1:1 Genomics, Society and Policy 16.
- 34 See e.g. BC *FOIPPA*, supra note 11, s. 17(4): “A disclosure of personal information is presumed to be an unreasonable invasion of a third party’s personal privacy if (a) the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation....” and ON *FOIPPA*, supra note 11, s. 21(3): “A disclosure of personal information is presumed to constitute an unjustified invasion of personal privacy where the personal information, (a) relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation....”
- 35 See e.g. Fiona A. Miller, R. Christensen, Mita Giacomini & Jason Scott Robert, “Duty to Disclose What? Querying the Putative Obligation to Return Research Results to Participants” (2008) 34 Journal of Medical Ethics 210; Bartha Maria Knoppers & Claude Laberge, “Return of ‘Accurate’ and ‘Actionable’ Results: Yes!” (2009) 9 American Journal of Bioethics 107; and Bartha Maria Knoppers, Yann Joly, J. Simard & F. Durocher, “The Emergence of an Ethical Duty to Disclose Genetic Research Results: International Perspectives” (2006) 13 European Journal of Human Genetics 1170.
- 36 Other studies have examined public and participant opinions about return of results. See e.g. Juli Murphy *et al.*, “Public Expectations for Return of Results from Large-Cohort Genetic Research” (2008) 8:11 American Journal of Bioethics 36; this study found that “focus group participants voiced a strong desire to be able to access individual research results.”
- 37 For discussion of how six birth cohort studies handle the issue of return of results, see Nola M. Ries, Jane LeGrandeur & Timothy Caulfield, “Handling Ethical, Legal and Social Issues in Birth Cohort Studies Involving Genetic Research: Responses from Studies in Six Countries” (2010) 11:4 BMC Medical Ethics, online: <<http://www.biomedcentral.com/content/pdf/1472-6939-11-4.pdf>>.
- 38 *Health Insurance Portability and Accountability Act*, 45 Code of Federal Regulations, §164.501.
- 39 See Lawrence Livermore National Laboratory, Institutional Review Board, *Frequently Asked Questions about HIPAA* (October 2009), online: <[https://irb.llnl.gov/faqs/faq\\_23.html](https://irb.llnl.gov/faqs/faq_23.html)>.
- 40 *Ibid.*
- 41 *Ibid.*

