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Privacy, Confidentiality and Data Security: Handbook of Research Policies and Procedures



**Institute
for Work &
Health**

Research Excellence
Advancing Employee
Health

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Prepared by the IWH Privacy Committee

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1.0 Why a handbook?

This handbook is intended to help all IWH-affiliated persons¹ become acquainted with IWH privacy policies and practices as they relate to the use of personal information for research purposes.

We regard the access to personal information for research purposes as an important privilege. Protecting the privacy of individuals whose personal information is used in our research and the confidentiality of personal information in our custody is an integral commitment and responsibility of IWH. Staff of the Institute are expected to comply at all times with the Institute's privacy protection policies and procedures and to contribute to the integrity of our privacy protection culture.

How this handbook is organized

Following an introduction that describes the Institute and our privacy commitment, this handbook presents a summary of research ethics principles, a description of the current legislative framework governing personal information in Ontario, and a summary of the 10 privacy protection principles that shape current information privacy practices. This background information is followed by specific information on the Institute's privacy protection policies and procedures, including our research ethics review practices, our commitment to describing the privacy impacts of our research, and our policies and practices concerning organizational, physical and technical security. IWH's Privacy Committee, in consultation with other IWH staff, prepared the policies and procedures outlined in this handbook

2.0 About the Institute for Work & Health

The Institute's mission

The Institute for Work & Health is an independent, not-for-profit organization whose mission is to promote, protect and improve the safety and health of working people

¹ All staff and visiting staff

by conducting actionable research that is valued by employers, workers and policy-makers.

The Institute values:

- a healthy workplace for all people;
- applying our research to improve the safety and health of workers;
- consultation with, and listening to, our stakeholders through exchanging ideas and knowledge;
- the independence of our work and the credibility this provides;
- producing work of recognized excellence;
- the opinions others have of the scientific merit and practical value of our work;
- contributing to the public good;
- good stewardship of our resources;
- a transdisciplinary, team-based approach to our work
- representative and participatory decision-making processes

Who we are

The Institute has been providing research and evidence-based practical tools for clinicians, policy-makers, employers and labour since 1990.

Our research helps to answer questions across two broad domains:

- preventing work-related injury and illness; and
- preventing or managing disability and improving recovery for injured workers

Knowledge transfer and exchange is a core focus of the Institute. Grounded in evidence-based principles and practices, the Knowledge Transfer & Exchange department works with the Institute's stakeholders, including clinicians, workplaces and policy-makers, to exchange information and research findings.

The Institute operates with the support of the Province of Ontario. In addition to this core funding, the Institute receives grants from funding agencies such as the Canadian Institutes of Health Research, the U.S. National Institutes of Health, the Social Sciences and Humanities Research Council of Canada and workers' compensation boards across Canada. These competitive grants help to support

research on work and health issues and the transfer of messages resulting from the research.

The Institute is governed by a Board of Directors composed of senior business, labour and academic leaders. The Institute's President is the organization's senior officer.

The Institute has formal affiliations with four Ontario universities: University of Toronto, University of Waterloo, McMaster University and York University. The Institute's association with the university community and its access to workplaces and key sources of data have made it a respected training centre. Scientists, students and policy-makers from around the world have come to consult and study at the Institute. They have made strong contributions to the Institute's research program, while gaining first-hand experience and vital connections to the work and health research community.

3.0 Privacy commitment

The mandate of the Institute for Work & Health is to conduct and share research that supports efforts to reduce injury, illness and disability in the Ontario workforce. This mandate includes research on primary prevention interventions in the workplace, effective and efficient methods of both health-care delivery and approaches to safe and timely return to work for individuals with work-related injuries or diseases. This includes examining labour market experiences and their health consequences and the design of disability compensation systems. This mandate is underpinned by our commitment to respect personal privacy, safeguard the confidentiality of personal information in our custody, and ensure a secure environment for electronic and physical records containing personal information.

IWH meets this commitment by:

- establishing clear principles and policies for the protection of personal information, emphasizing high standards of organizational, technical and physical security practices and protocols;
- communicating privacy protection policies and practices to IWH staff, affiliates and stakeholders;

- restricting access to personal information to those members of the organization who have authorized access for research purposes;
- submitting research protocols involving personal information to external research ethics boards;
- designating the position of IWH Privacy Officer to oversee the Institute's privacy protection policies and practices;
- ensuring all staff are trained in the principles and practices of personal information protection and requiring all staff to annually commit, in writing, to respect the Institute's principles, policies and practices in the protection of personal information; and
- ensuring that the Institute's policies and practices are consistent with the best national and international standards of privacy protection in health research and legislative requirements.

4.0 Ethical principles guiding research involving human participants

Respect for the privacy of persons who are the participants of research is but one dimension of research ethics involving human participants. Research involving human participants is based on a fundamental moral commitment to advancing human welfare, knowledge and understanding. Researchers, universities, governments and private institutions undertake or fund research involving human participants for many reasons; for example, to alleviate human suffering, to validate social or scientific theories, to dispel ignorance, to analyze policy and to understand human behaviour and the evolving human condition.

The Institute for Work & Health is committed to respecting the ethical principles involving human participants in research based on frameworks disseminated by the Interagency Advisory Panel on Research Ethics (<http://www.pre.ethics.gc.ca/>). The Interagency Advisory Panel is mandated by the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC), to promote high ethical standards of conduct in research involving humans through the development, evolution, interpretation, and implementation of the *Tri-Council Policy*

Statement: Ethical Conduct for Research Involving Humans (TCPS)
http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf.

5.0 Privacy protection principles

The Canadian Standards Association (CSA)'s 10 principles for the protection of personal information have informed the legislative objectives of the federal legislation Bill C-6 (Personal Information Protection and Electronic Documents Act [PIPEDA]) and Ontario's health information privacy protection legislation (the *Personal Health Information Protection Act*, 2004).

These principles were also used in the development of a comprehensive guideline statement from the Canadian Institutes of Health Research (CIHR), released in September 2005, titled *Guidelines for Protecting Privacy and Confidentiality in the Design, Conduct and Evaluation of Health Research: Best Practices*². These principles and the guideline statement from CIHR, as well as key documents from the Information and Privacy Commissioner of Ontario, have informed the privacy protection practices at the Institute for Work & Health.

Accountability

Procedures for ensuring confidentiality and security of data are strictly enforced to protect data against loss, destruction or unauthorized use. The Privacy Officer, under the direction of the President of the Institute for Work & Health, is responsible for the Institute's compliance with the principles, policies and procedures described in this handbook. The Institute is also accountable for ensuring that research studies are implemented under the oversight of Research Ethics Boards. In addition, staff are reminded that privacy is everyone's responsibility.

Identifying purposes

The purposes for which IWH scientists propose to use personal health information will be described in research proposals and study designs/plans before personal

² http://www.cihr-irsc.gc.ca/e/documents/et_pbp_nov05_sept2005_e.pdf

information is collected or obtained. Personal information collected or obtained by Institute scientists is to be used for research and statistical purposes only.

Consent

Consistent with the ethical principle of the autonomy of research participants, individuals participating in research projects that directly collect personal information will be provided with a description of the purposes of the research, an assessment of the benefits of participation and an assessment of the potential harms of participation. Research participants will have the freedom to consent to participate. In the case of research projects that propose to use personal information in the absence of individual participant consent, the Institute for Work & Health will refer to the guidance provided by the comprehensive guideline statement from the Canadian Institutes of Health Research's *Guidelines for Protecting Privacy and Confidentiality in the Design, Conduct and Evaluation of Health Research: Best Practices* and by guidance received from Research Ethics Board review of the balancing of harms and benefits.

Limiting collection

The Institute for Work & Health will limit the collection of personal information to that which is necessary to fulfill the research purposes of the study.

Limiting use, disclosure and retention

All administrative, registry or survey data received by IWH will be used only for research and statistical purposes. All primary data are used only for the purposes identified prior to the collection of the data. The IWH will not disclose personal information in its custody to third parties, unless the research purpose is consistent with the original purpose of the collection and the research protocol has been reviewed and approved by a Research Ethics Board.

In reporting research results and findings, the Institute for Work & Health will present quantitative data in an aggregated form and will present anonymized data in qualitative research to prevent the potential identification of individual research participants.

Personal information is retained and securely archived as is required for research projects for periods varying from five to 10 years. In a project-specific research agreement, earlier destruction may be a requirement.

Accuracy

Personal information collected for research purposes will be as accurate and complete as possible at the time of collection.

Safeguards

All personal information in the custody of the Institute for Work & Health will be protected from unauthorized access and disclosure. The methods of protection include:

- organizational security, such as employee training, employee confidentiality agreements, limiting access on a need-to-use basis, and consequences for breaches of policy;
- physical security, such as locked facility with tracked key access, locked filing cabinets and restricted access to offices, and on-site security after hours; and
- technical security, such as the use of firewalls and passwords, the encryption of data and the anonymization of personal information by removing person-identifiable variables.

Openness

IWH makes information about its policies and practices relating to the management and protection of personal information readily available, with the exception of procedures for IT security. The IWH Privacy Officer is the designated individual responsible for ensuring privacy policies and practices are communicated clearly and openly.

Individual access

In the event a research participant wishes to review his or her personal information following collection and use in a research study, the Institute for Work & Health will comply with reasonable requests. Study participants will be given information about the study when they grant their consent to participate. This right of access will be limited to information collected directly from research participants who consented to

participate in the research project. The Institute will not provide access to information contained in secondary data sources.

The IWH Privacy Officer is responsible for responding to information requests from a research participant concerning the confidentiality protection policies and practices at the Institute, responding to a research participant request to review personal information, and ensuring privacy policies and practices are communicated clearly and openly.

Challenging compliance

A research participant who wishes to address a concern about compliance with the Institute's privacy policies and practices may direct this concern to the Principal Investigator and/or the IWH Privacy Officer. General questions or information requests about a research study may be directed to the Principal Investigator or Project Coordinator.

6.0 Legislative framework: Personal information and research

Throughout this handbook, we describe principles, policies and procedures for the protection of personal information. As a research organization with a mandate to improve understanding of effective methods for protecting the safety and health of workers, much of the personal information of research interest to the Institute describes the health status of individuals. The collection, use and disclosure of personal health information in the Province of Ontario is governed by regulations established by Bill C31 (PHIPA), which came into effect on November 1, 2004. In addition, personal information that does not meet the PHIPA definition of health information is governed in Ontario by the provisions of the *Freedom of Information and Protection of Privacy Act* (FIPPA).

Throughout this handbook, the term personal information encompasses the definitions of both (1) personal information as defined in FIPPA and (2) personal health information defined in PHIPA. The Institute for Work & Health will conduct privacy protection research practices in compliance with the general principles established in PHIPA. In addition, in specific research projects that involve the

disclosure of personal health information to the Institute from a health information custodian as defined by PHIPA, the Institute will comply with the requirements of Section 44 of the Act.

Under FIPPA, personal information is defined as recorded information about an identifiable individual, including: information relating to the race, nationality or ethnic origin, colour, religion, age, sex, sexual orientation or marital or family status of the individual; information relating to the education or the medical, psychiatric, psychological, criminal or employment history of the individual; and information relating to financial transactions in which the individual has been involved.

The federal privacy law, the *Personal Information Protection and Electronic Documents Act* (PIPEDA) has been promulgated in phases. As of January 1, 2004, the Act covers the collection, use or disclosure of personal information in the course of any commercial activity within a province that has not enacted substantially similar legislation. The Act also regulates the transfer of personal information for commercial purposes across provincial and national boundaries. As a non-profit research institute, the provisions of the federal legislation concerning the regulation of intra-provincial and inter-provincial commercial transactions of personal information will generally not apply to the Institute's research activities.

Under Bill C31, the *Personal Health Information Protection Act* (PHIPA), personal health information is defined as identifying information about an individual whether oral or recorded, if the information:

- relates to the physical or mental health of the individual, including information that consists of the individual's family health history;
- relates to the provision of health care to the individual, including the identification of a person as a provider of health care to the individual;
- is a plan of service within the meaning of the *Long-Term Care Act, 1994*;
- relates to payments or eligibility for health care in respect of the individual;
- relates to the donation by the individual of any body part or bodily substance, or is derived from testing of such body part or substance;
- is the individual's health number; or
- identifies the individual's substitute decision-maker.

Personal health information also includes other identifying information that is contained in the same record with the information described above. Information is

“identifying” when it identifies an individual or when it is reasonably foreseeable in the circumstances that it could be used, either alone or with other information, to identify the individual.

7.0 IWH privacy protection policies and procedures

The policies and procedures for the collection, use and disclosure of personal information used in research at IWH are located on the IWH wiki. The site is structured as follows:

- Chapter 1: Privacy
- Chapter 2: Security
- Chapter 3: Compliance
- Chapter 4: Governance and risk management

Research ethics review policies and procedures

All research protocols proposing to use personal information are required to present a copy of the research protocol to a Research Ethics Board (REB). The REB may be based at a health-care institution or a university. Where personal information is collected or disclosed by a health-care institution, REB approval may be required.

It is the responsibility of the Principal Investigator to prepare a REB submission and to respond to any concerns raised in the ethics review. All proposed research, whether funded from internal IWH resources, external granting agencies or contract-funding sources, must receive REB review and approval before research activity can commence.

Investigators are always encouraged to discuss questions or concerns about the REB review requirements with the IWH Privacy Officer and the Director of Operations or their delegate.

Training

All new IWH employees are required to review the privacy handbook and the e-policy as part of their orientation. Workshops are offered annually, and attendance is mandatory for new employees.

All IWH employees must sign a confidentiality agreement³ as a condition of employment.

Information breach

A privacy breach is the loss of, unauthorized access to, or disclosure of personal information. Some of the most common privacy breaches happen when personal information is stolen, lost or mistakenly shared. (Office of the Privacy Commissioner of Canada, <https://www.priv.gc.ca/en/privacy-topics/privacy-breaches/>) The IWH has a procedure for containing breaches. If employees feel there has been a breach, they are asked to contact the Privacy Officer

To report a breach, to make a request or comments, or to get more information on IWH research studies or general privacy policies and procedures, please e-mail: PrivacyOfficer@iwh.on.ca.

³ The ethical conduct agreement and the confidentiality agreement are incorporated within the Policy on Ethical Conduct in Research and are signed by all staff members upon start of employment and reviewed annually during performance reviews.