



## ***ICE Population Health Data Repository – Data Use Guidelines***

This guide is designed to outline your responsibilities as a data user, and the process of acquiring and using data from the PHDR.

### **1. Ethical use of data**

**1.1. License Agreement** - All users of PHDR data are required to sign an agreement with the Population Health Data Repository and the data owner ensuring that users agree to the following responsible and ethical use of the data:

- (a) Data may only be used for research purposes.
- (b) Any information that relates the particulars obtained from any individual identifiable person, business or organization cannot be disclosed
- (c) Use of these data products in the pursuit of any commercial or income-generating venture is strictly prohibited. As well, the distribution, sale, donation, transfer or exchange of any portion of these data to anyone else is expressly prohibited.
- (d) Excerpts of the data may be published in research communications such as theses, scholarly articles and research reports. The owner of the data must be acknowledged in these communications.
- (e) Data obtained under this agreement remain the property of the owner of the data. Derivative data sets representing modifications to the data are also licensed unless otherwise stated. Any additional terms and conditions imposed by the owner of the data are also binding.
- (f) Data will reside only in the secure location identified in the proposal. All copies of the data must be erased upon the completion of the research.

### **1.2. Confidentiality**

Each investigator who stores their data with the PHDR has taken great care to protect the identity of their participants and to safeguard the privacy and confidentiality of the information that these participants provide. Any secondary analysis that you perform must also maintain the confidential nature of the data.

All data is stripped of identifiers that could permit a direct relation to be established between data holdings and specific respondents. Direct and indirect identifiers such as name, specific geographic location, etc. have been deleted from the analytic file. Successful applicants will receive only subsets of the data, consisting of the groups and variables required for their particular analyses.

As mentioned above, all researchers must sign an agreement with PHDR and the owners of the data in order to access data. As part of this process you agree not to disclose or knowingly cause to be disclosed any information that relates the particulars obtained from any individual return to any identifiable individual person, business or organization. Material to be presented or published must be examined carefully to make sure it does not disclose such information.

### 1.3. **Security provisions**

As a requestor of data, you will be required to provide at the outset a statement of the data security provisions for the computer on which the requested data subset will reside.

PHDR data sets must be stored in a password protected location on your computer.

Other researchers (beyond those specified in the application) must not be given access to data sets without permission from the PHDR and the owner(s) of the data. You must not carry out analyses for colleagues or other researchers who do not have approved research projects.

### 1.4. **Ethics clearance**

Ethics clearance must be obtained from the principal investigator's institution for the proposed secondary data analysis. This is to ensure institutional review of the conditions under which access to the data are granted.

## 2. **Obtaining access to data held in the PHDR**

- 2.1. **Project Proposal** - To be granted access to data housed in the PHDR, researchers are required to submit a project proposal to the ICE Tools, Resources and Structures Group. After this initial review, successful proposals will be sent to the owner(s) of the data for their approval. The results of the review will generally be communicated to the principal investigator as soon as is feasible, normally within two weeks of the date of application.

It is important to note that you will only have access to the data specified in your approved research project and only for the purpose of completing the project. You must submit a proposal for any research project in which you wish to use PHDR data. A separate proposal is required if you wish to answer a different question using the same or different data.

- 2.2. **Obtaining new data and/or carrying out a different research project** – To obtain access to different data or to conduct further analysis of the same data, you must complete another proposal. You must provide reasons for your request, how the new data will fit with your original research project, how its use may affect your schedule, and how it may affect the output you foresee producing.
- 2.3. **Submission and Review** – Research proposals can be submitted electronically by accessing the application form on the ICE website ([www.ice-rci.org](http://www.ice-rci.org)). The application can be sent directly to the PHDR. Receipt of the submission will initiate the review process. Proposals can also be sent by surface mail or fax.

The formal review process will be co-ordinated by the Population Health Research Group at the University of Waterloo. Each proposal will be evaluated by the owner of the data.

The applicant will be advised of the results. The rationale for the decision will be included in a short report. No appeal will be granted but researchers can revise and resubmit their proposal.

Once the project has been approved, the researcher(s) will only be sent the specific requested data in their preferred statistical package format. Operational and ethical issues that need to be considered when working with the PHDR as well as other documentation covering the basic criteria that must be taken into account to avoid disclosure of confidential data will accompany the requested data. The user agreement may specify further conditions that are required for use of the data.

**2.4. Proposed Criteria for Evaluation** – The proposed research project will be assessed by the owner(s) of the data who are encouraged to consider the following criteria:

- Clarity of objectives and statement of the research question
- The extent to which the proposed research will advance understanding in the area of tobacco control
- The extent to which the proposed questions are new, without undue overlap with those already being addressed or those proposed by the owner(s)
- The sustainability of the proposed statistical/research methodology, including software requirements
- The resources and capacity of the research team to accomplish the goals
- Potential conflict of interest

The proposed project will also be reviewed to ensure that issues of confidentiality and disclosure avoidance have been addressed.

**2.5. Project Acceptance and Data Agreement** – Once the project has been approved, the license agreement must be signed. The agreement will be between the PHDR, the owner(s) of the data, and you and your research team.

### **3. Reporting to the PHDR and the owner(s) of the data**

**3.1. Reporting created variables** – Users of data stored in the PHDR are required to share any created variables and coding used in the analysis of data sets upon completion of the analysis.

**3.2. Progress reports** – Periodically the PHDR may ask for brief progress reports on the research.