

## RDC RESEARCH AND RESEARCH ETHICS REVIEWS

### Purpose

This document is intended to guide RDC users in deciding whether or not to submit their academic project for research ethics board (REB) approval at their university. Based on the arguments set out in this document, it is generally felt that data available to researchers at the RDCs across Canada meet the standards set out by the Articles in the TCPS2 for exemption from REB review. Given the variety of policies in place at universities across the country, the CRDCN cannot definitively state that you do not need to submit your RDC project for review. It is anticipated that the vast majority of institutions will not require an ethics review for research conducted in the RDC. This document can also be used as reference material for ethics statements required for some journals (particularly in health fields) or as reference material in a submission to a university or any other research ethics board. An annex that provides some further background and RDC-specific context to those pursuing research that relates to Indigenous Peoples appears at the end of this document.

### Background – Tri-Council Statement: Ethical Conduct for Research Involving Humans

In universities across Canada, the principles guiding REBs are primarily derived from the [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#) (TCPS2). This statement provides both a framework for how to create and govern research ethics boards as well as guidelines for the types of projects that should be exempt from these reviews. We cite the relevant portions of the TCPS2 here.

#### Research Requiring Ethics Board Review – Article 2.1

Generally, per the TCPS2, the following types of research should be subject to approval by an REB:

- A. those involving living human participants;
- B. those involving human biological materials, as well as human embryos, fetuses, fetal tissue, reproductive materials and stem cells. This applies to materials derived from living and deceased individuals.

This would generally include data from living human participants, such as those in the RDC, but for two exceptions outlined in Chapter 2.

#### Research Exempt from Research Ethics Board Review – Article 2.2

Research does not require REB review when it relies exclusively on information that is:

- A. publicly available through a mechanism set out by legislation or regulation and that is protected by law; or
- B. in the public domain and the individuals to whom the information refers have no reasonable expectation of privacy.

The Application Section for this article provides the following rationale:

“Exemption from REB review for research involving information that is legally accessible to the public is based on the presence of a legally designated custodian/steward who protects its privacy and proprietary interests (e.g., an access to information and privacy coordinator or a guardian of Canadian census data).”

#### Research Exempt from Research Ethics Board Review – Article 2.4

REB review is not required for research that relies exclusively on secondary use of anonymous information, or anonymous human biological materials, so long as the process of data linkage or recording or dissemination of results does not generate identifiable information.

### **TCPS2 and the RDC Program**

The key parts of the TCPS2 upon which we focus are Article 2.2 (part a) and Article 2.4. In brief, the collection of data by Statistics Canada is governed by *the Statistics Act* and disseminated by Microdata Access Division through the RDCs at universities across Canada. Furthermore, all RDC data are, by their very nature, secondary from the researchers' perspective, and in addition to the removal of all names and identification numbers from the data before the researcher ever accesses the data, protocols are in place to prevent disclosure of personally identifying information.

### **Legislation**

The *Statistics Act* (1985) prescribes the mandate of Statistics Canada, its role in the federal government, its powers and responsibilities, and its operating structure. Central to the *Act's* provisions is an implicit social contract with respondents, under which Statistics Canada may burden respondents with requests for information, and in some cases demand response, in order to provide information that is clearly of broad public benefit, but with an absolute undertaking to protect the confidentiality of identifiable individual responses.

Any disclosure of information that identifies an individual, business or organization is a punishable offense.

The confidentiality provisions of the *Statistics Act* are not affected by either the *Access to Information Act* or any other legislation.

The *Privacy Act* (1983) applies not only to the activities of Statistics Canada but to all federal government organizations. The *Privacy Act* requires that personal information must only be collected if it "relates to an operating program or activity of the institution". In the case of Statistics Canada, this would include surveys collected under the provisions of the *Statistics Act*. The *Privacy Act* requires that the individual be informed of the purpose for which the personal information is being collected. It includes the right for an individual to know of, and have access to, their personal information. Informed consent is not a component of the *Privacy Act*.

However, informed consent is utilized by Statistics Canada as part of certain activities. With the exception of the Census of Population and the Labour Force Survey, all Statistics Canada household surveys are voluntary. Participation in a voluntary survey requires implicit consent. Respondents are informed of the voluntary nature of the survey through a notice prior to the start of the data collection, such as the one below. Interviewers are also instructed to permit respondents to refuse to answer any question or to terminate an interview at any time.

Respondents to voluntary surveys are prompted as follows: "Your answers will be kept strictly confidential and used only for statistical purposes. While participation is voluntary, your cooperation is important to ensure that the information collected in this survey is as accurate and as comprehensive as possible."

### **Prevention of disclosure of personally identifying information**

Two types of data are commonly available to RDC researchers: Records from surveys conducted by Statistics Canada, and administrative data files either collected by Statistics Canada (such as the vital statistics data) or for which Statistics Canada is serving as custodian for another agency (such as the Ontario Social Assistance Case Records). As noted above, all of Statistics Canada's activities are governed by the *Statistics Act*. Therefore, the following is true of all datasets made available through the RDC program:

- Any microdata accessed by a researcher will have all personal identifiers, such as name, address, SIN, and personal health number removed from the records.
- Researchers may only access those data that are required for their particular project.
- The majority of the datasets collected by Statistics Canada use sampling frames in which households are randomly sampled. Within selected households, sometimes all persons are requested to participate in the survey. In many cases, a random selection of a person within the household is done by the interviewer. This randomization of participants makes identifying specific individuals more difficult.

#### **Procedures to access data**

- As required by the Government of Canada Treasury Board Policy on Government Security, researchers must obtain Reliability Status from Statistics Canada Departmental Security before having access to the data in the RDC. Security checks are conducted by the RCMP for each researcher accessing data in the RDC.
- As required by the Statistics Act, each researcher accessing data in the RDCs has deemed employee status and swears a legally binding oath to protect the confidentiality of Statistics Canada data utilized in the RDC. This oath is binding for life.
- Each researcher is required to attend an orientation session during which a Statistics Canada site employee explains the researchers' legal responsibilities to protect the confidentiality of the data, as well as all the security measures in place within the RDC.
- A Statistics Canada employee on site ensures that the above measures are clearly understood and adhered to by all researchers participating in the RDC program.

#### **Procedures to protect data**

- Each RDC is a secure physical environment where the only people permitted entry are researchers working on active approved projects, IT support people, and Statistics Canada staff.
- Doors to the facility are opened with secure swipe cards assigned to each researcher.
- Researchers are prohibited from operating any electronic communication and storage devices, such as laptops, tablets, E-readers, PDAs or cell phones in the vicinity of (secure) computer workstations.
- The computing environment inside an RDC cannot be linked externally, particularly to the internet.
- The file structures and permissions are created to ensure that researchers have access only to the data for which they have received permission.

#### **Control of released results**

- The RDC Analyst is the only person who can release analytical output from an RDC.
- All analytical output, including programs and compiled results, are vetted for potential confidentiality breaches using rules developed by Statistics Canada methodologists.
- These rules are created to protect individuals' data being released, either directly, or through reconstruction using multiple releases.

Where confidentiality is at risk, the researcher and Analyst work together to eliminate the risk of disclosure and release the necessary information to answer the research question while ensuring the confidentiality of respondent data.

### **Conclusion**

It is our position, based on the arguments set out in this document, that the data available to researchers in the RDCs across Canada meet the standards set out by the Articles in the TCPS2 for exemption from review by an REB. RDC researchers should consider the information set out in this document and their own institutions in deciding whether to submit their projects to their REB. It is important that researchers also consider any other data from human participants involved in their research projects, whether that data is brought into the RDC for analysis or if they are meant to complement the RDC work in a separate analysis.

## Annex 1 – Aboriginal People’s Survey and other Aboriginal research in the RDC

As the issue of Indigenous research principles – including OCAP<sup>1</sup>, Partnership, Empowerment, Equity and Informed Consent – is particularly important, the topic merits a special note in this document. The Secretariat on Responsible Conduct of Research has interpreted the TCPS2 in relation to the use of aboriginal identifiers as follows:

“Based on the most current version of TCPS, when conducting research that relies exclusively on data under the control of a legally designated custodian such as Statistics Canada, there is no restriction on using the aboriginal identifiers within those data sets. This type of research does not require review by a Research Ethics Board and does not require community engagement, a term defined in Section A of Chapter 9.

However, where the information can be identified as originating from a specific community or a segment of the Aboriginal community at large, Article 9.21 in Chapter 9 suggests that researchers ‘seek culturally informed advice before the use of such data to determine if harms may result and if other considerations, such as sharing of the research results, should be explored with the original source community.’”

In addition, it is important to remember that, if the researcher decides to link the data with other data sources outside of Statistics Canada’s custody, or to collect additional information from individuals or communities, then REB review would be required. In this case, community engagement is also likely to be warranted, if not required. In addition to Article 2.2 (part a), cited above (Background), we cite Chapter 9 (specifically items related to Articles 9.2 and 9.21) of the TCPS2 here.

### Nature and Extent of Community Engagement – Article 9.2

The Application section in chapter 9, indicates that REB review is not required in the following situation:

“Research based only on publicly available information that is protected by law or on information that is in the public domain with no expectation of privacy as defined by this Policy, does not involve the collection of data from communities directly, or from living persons. As indicated in Chapter 2, REB review for this type of research is not required. Community engagement is not required. Examples are historical or genealogical research or statistical analysis.”

This Article notes that it may be advisable to seek culturally informed advice when the information can be identified as originating from a specific community. The document goes on to say the following:

“In these cases, researchers may not have any direct relationship with communities, but their findings may, nevertheless, have an impact on the identity or heritage of persons or communities.

In order to minimize any harm, researchers should seek culturally informed advice before the use of such data to determine if harms may result and if other considerations, such as sharing of the research results, should be explored with the original source community (Article 9.15).”

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<sup>1</sup> Ownership Control, Access and Possession: A First Nation Community retains ownership and control over Aboriginal Knowledge and its interpretation. A community will have full access to any documents and research that includes its Aboriginal knowledge. *First Nations Ethics Guide on Research and Aboriginal Traditional Knowledge*. Assembly of First Nations. Accessed on August 11, 2017. [https://www.afn.ca/uploads/files/fn\\_ethics\\_guide\\_on\\_research\\_and\\_atk.pdf](https://www.afn.ca/uploads/files/fn_ethics_guide_on_research_and_atk.pdf)