

Can I Share My Data?

Prepared by the Portage Network, COVID-19 Working Group on behalf of the Canadian Association of Research Libraries (CARL)

Nick Rochlin (University of British Columbia)

Felicity Tayler (University of Ottawa)

Chantal Ripp (University of Ottawa)

Jane Fry (Carleton University)

Minglu Wang (York University)

Kristi Thompson (Western University)

Lucia Costanzo (University of Guelph)

Kathy Szigeti (University of Waterloo)

Qian Zhang (University of Waterloo)

Rebecca Dickson (COPPUL)

Roger Reka (University of Windsor)

Mark Leggott (RDC)

Erin Clary (Portage)

Beth Knazook (Portage)

Melanie Parlette-Stewart (Portage)

SEPTEMBER 2020

Portage Network

Canadian Association of Research Libraries

portage@carl-abrc.ca

www.carl-abrc.ca

portage

SERVICES PARTAGÉS POUR LES DONNÉES DE RECHERCHE
SHARED STEWARDSHIP OF RESEARCH DATA

CARL ABRC
CANADIAN ASSOCIATION OF RESEARCH LIBRARIES
ASSOCIATION DES BIBLIOTHÈQUES DE RECHERCHE DU CANADA

Table of Contents

Can I Share My Data?.....	2
Do you have a consent form that contains a statement about sharing data after the study’s completion? .3	
YES → <i>What type of data can be made public as specified in your consent form?</i>	3
NO → <i>What type of data do you have?</i>	4
<i>Explanation of Articles Referenced from TCPS 2 (2018)</i>	5
References	6

Can I Share My Data?

This decision tree is designed to help alert you to situations where research data collected in Canada and derived from human participants either may not be shared publicly or may require some modification before sharing. It relies heavily on the Canadian [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS 2 \(2018\)](#) which addresses consent and secondary use of information for research purposes.¹

For help understanding any terms used in this document, please see Portage's [Glossary of Terms for Sensitive Data Used for Research Purposes](#).² You may also wish to review Portage's [Human Participant Research Data Risk Matrix](#) for more information.³

¹ Government of Canada (Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council). "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018)." Last modified February 19, 2020. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html.

² Portage Sensitive Data Working Group, "Sensitive Data Toolkit for Researchers Part 1: Glossary of Terms for Sensitive Data used for Research Purposes," September 30, 2020, <https://doi.org/10.5281/zenodo.4060158>.

³ Portage Sensitive Data Working Group, "Sensitive Data Toolkit for Researchers Part 2: Human Participant Research Data Risk Matrix," October 1, 2020, <https://doi.org/10.5281/zenodo.4060448>.

Do you have a consent form that contains a statement about sharing data after the study's completion?

For examples of informed consent language that allows for data sharing, or precludes it, please see Portage's [Research Data Management Language for Informed Consent](#) or the ICPSR's [Recommended Informed Consent Language for Data Sharing](#).⁴

YES → What type of data can be made public as specified in your consent form?

→ Identified / potentially identifiable

→ Human participant data that is identifiable cannot normally be shared unless approval was given in a consent form, and even then, the sharing must follow the format indicated in the consent form. You can share your data if these conditions are met.

→ Anonymized / de-identified

→ Your data can be shared once stripped of direct identifiers, provided any ID codes or links to key files are removed and not made public, and risk of re-identification from indirect identifiers remains low. Use Portage's [De-identification Guidance](#) to find out how to strip direct identifiers from your data.⁵ You can also learn more about data confidentiality here: [ICPSR Data Confidentiality](#).⁶

→ Anonymous

→ Your data can be shared as long as it was collected anonymously and it *never had identifiers associated with it*. If you used the word "anonymous" in your consent form and the data can't be completely anonymized (stripped of both direct and indirect identifiers), refer to article [5.5A/B](#) in TCPS 2 and consult with your institution's Research Ethics Board.⁷ Learn more about direct and indirect identifiers, and how to remove them, in Portage's [De-identification Guidance](#).⁸

⁴ Portage Sensitive Data Working Group, "Sensitive Data Toolkit for Researchers Part 3: Research Data Management Language for Informed Consent," October 1, 2020, <https://doi.org/10.5281/zenodo.4060460>, and Inter-university Consortium for Political and Social Research (ICPSR). "Recommended Informed Consent Language for Data Sharing," accessed August 5, 2020, <https://www.icpsr.umich.edu/web/pages/datamanagement/confidentiality/conf-language.html>.

⁵ Portage COVID-19 Working Group, "De-identification Guidance," September 25, 2020, <https://doi.org/10.5281/zenodo.4042022>.

⁶ Inter-university Consortium for Political and Social Research (ICPSR), "Recommended Informed Consent Language for Data Sharing," accessed August 5, 2020. <https://www.icpsr.umich.edu/web/pages/datamanagement/confidentiality/index.html>

⁷ Government of Canada, "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018)," last modified February 19, 2020. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html.

⁸ Portage COVID-19 Working Group, "De-identification Guidance."

NO → What type of data do you have?

→ Human biological material and data, including materials related to human reproduction

→ Article [12.3A/B](#) in TCPS 2 addresses the secondary use of human biological materials, while sections [5.5A/B](#) and [5.6](#) provide more information about managing the identifying data collected to describe these materials.⁹ Review these articles and consult with your local Research Ethics Board.

→ Human biological material and data originating from Indigenous communities or peoples

→ Refer to article [9.20/9.21](#) for more information about the use of data and human biological materials identifiable as originating from an Indigenous community or peoples (and [5.5A/B](#) and [5.6](#) for information about identifying data collected to describe these materials) in TCPS 2 and consult with your local Research Ethics Board.¹⁰

→ Other

→ Refer to article [5.5A/B](#) in TCPS 2 and consult with your local Research Ethics Board.¹¹

⁹ Government of Canada, “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018).”

¹⁰ “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018).”

¹¹ “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018).”

Explanation of Articles Referenced from TCPS 2 (2018)

Human Biological Materials

12.3A - Provides criteria to be met for researchers who have not obtained consent from participants for secondary use of **identifiable** human biological materials.

12.3B - States that researchers shall seek REB review, but not participant consent, for the secondary use of **non-identifiable** human biological materials.

Information or Human Biological Materials Identifiable as Originating from Indigenous Communities or People

9.20 - Provides criteria for when a researcher must engage with an Indigenous community when dealing with secondary use of data and human biological material identifiable as originating from an Indigenous community or peoples.

9.21 - Provides recommendations when dealing with publicly available information that is protected by law, or information in the public domain.

General

5.5A - Provides criteria to be met for researchers who have not obtained consent from participants for secondary use of **identifiable information**.

5.5B - States that researchers shall seek REB review, but not participant consent, for the secondary use of **non-identifiable information**.

5.6 - States that researchers shall seek REB approval to contact participants in circumstances where secondary use of identifiable information without the requirement to seek consent has been approved under 5.5A, but the researchers wish to contact the participants anyway.

References

1. Government of Canada (Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council). "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018)." Last modified February 19, 2020. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html.
2. Inter-university Consortium for Political and Social Research (ICPSR). "Recommended Informed Consent Language for Data Sharing." Accessed August 5, 2020. <https://www.icpsr.umich.edu/web/pages/datamanagement/confidentiality/conf-language.html>.
3. Inter-university Consortium for Political and Social Research (ICPSR). "Recommended Informed Consent Language for Data Sharing." Accessed August 5, 2020. <https://www.icpsr.umich.edu/web/pages/datamanagement/confidentiality/index.html>
4. Portage COVID-19 Working Group. "De-identification Guidance." September 25, 2020. <https://doi.org/10.5281/zenodo.4042022>.
5. Portage Sensitive Data Working Group. "Sensitive Data Toolkit for Researchers Part 1: Glossary of Terms for Sensitive Data used for Research Purposes." September 30, 2020. <https://doi.org/10.5281/zenodo.4060158>.
6. Portage Sensitive Data Working Group. "Sensitive Data Toolkit for Researchers Part 2: Human Participant Research Data Risk Matrix." October 1, 2020. <https://doi.org/10.5281/zenodo.4060448>.
7. Portage Sensitive Data Working Group. "Sensitive Data Toolkit for Researchers Part 3: Research Data Management Language for Informed Consent." October 1, 2020. <https://doi.org/10.5281/zenodo.4060460>.