Guide to COVID-19 Rapid Response Data Sharing and Deposit for Canadian Researchers

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Guide to COVID-19 Rapid Response Data Sharing and Deposit

Canadian researchers are faced with an unprecedented urgency to share COVID-19 research outputs via data repositories and open access publishers. Many Canadian funding agencies, including the Tri-Agencies (SSHRC, NSERC, and CIHR), have signed the Joint statement on sharing research data and findings relevant to the novel coronavirus (nCoV) and will require funded projects to share their research data widely and rapidly. The World Health Organisation (WHO) also released a statement on "Data sharing for novel coronavirus (COVID-19)", making it clear that timely sharing of preliminary results and research data is needed. In response, this resource was created by the Portage Network COVID-19 Working Group to enable researchers in Canada to follow international data sharing guidelines for pandemic-related research.

This guide is based on the Research Data Alliance (RDA)³ COVID-19 Working Group <u>Recommendations and Guidelines for Data Sharing</u>,⁴ which were designed to:

- help researchers follow best practices for data sharing in their discipline, and
- help researchers maximize the impact of their work.

The guidance provided here has been streamlined to make it as straightforward as possible. Follow the links provided for more in-depth information and reach out to librarians at your institution to see if further support is available. Many Canadian universities have dedicated research data librarians who can help you to better understand these guidelines.

¹ "Sharing Research Data and Findings Relevant to the Novel Coronavirus (COVID-19) Outbreak," Wellcome Trust, last modified January 31, 2020, https://wellcome.ac.uk/coronavirus-covid-19/open-data.

² Vasee Moorthy, Ana Maria Henao Restrepo, Marie-Pierre Preziosi, and Soumya Swaminathan, "Data sharing for Novel Coronavirus (COVID-19)," *Bulletin of the World Health Organization* 98. no. 3 (March 2020): 150. http://dx.doi.org/10.2471/BLT.20.251561.

³ RDA is an inclusive international collaboration, engaging data producers, users and stewards, with the goal of building the social and technical infrastructure to enable open sharing and re-use of data. See "RDA | Research Data Sharing without barriers," RDA, last accessed August 17, 2020, https://www.rd-alliance.org.

⁴ RDA COVID-19 Working Group. "RDA COVID-19 Recommendations and Guidelines on Data Sharing," June 30, 2020. https://doi.org/10.15497/rda00052.

How do I Prepare Research Data for Sharing and Deposit?

Plan to Share

RDA Guidance: Researchers should create a Data Management Plan (DMP) at the beginning of the research process so that it can be included in the work plan and the budget (2.2.4 Data Management Planning, p. 17).

How to:

- Create a Data Management Plan (DMP) at the start of your project and update it as the project evolves. Use one of the templates available in the <u>Portage DMP Assistant</u> to get started.⁵
- Looking at DMPs published by others may also be helpful in developing your own. The <u>Digital</u> <u>Curation Centre's Example DMPs and Guidance</u> is a good place to start.⁶

⁵ "Portage DMP Assistant," Portage Network, accessed August 24, 2020, https://assistant.portagenetwork.ca/?locale=en

https://assistant.portagenetwork.ca/?locale=en

6 "Example DMPs and guidance," Digital Curation Centre, last accessed August 5, 2020, https://www.dcc.ac.uk/resources/data-management-plans/guidance-examples.

Make Your Data Understandable

RDA Guidance: Research outputs need to be documented, which includes documentation of methodologies used to define and construct data, data cleaning, data imputation, data provenance and so on. Software should provide documentation that describes at least the libraries, algorithms, assumptions and parameters used (2.2.6 Documentation, p. 19).

How to:

- Organize your files using well-documented file naming conventions.
 - Check out <u>UBC's guidance on organizing research data</u> for examples of simple file naming strategies.⁷
- Provide documentation and supporting information, which may include describing your data workflow and methodologies in a codebook or README file.
 - Learn more about preparing appropriate research data documentation with <u>Portage's</u>
 <u>Documentation and Supporting Materials Required for Deposit.</u>⁸
- Identify and properly cite any secondary data used in your research.

⁷ "Research Data Management: Organize," The University of British Columbia Library, last modified January 9, 2019, https://researchdata.library.ubc.ca/plan/organize-your-data/.

⁸ Portage COVID-19 Working Group, "Documentation and Supporting Materials Required for Deposit." September 25, 2020, https://doi.org/10.5281/zenodo.4042034.

Make Your Data Open and FAIR

RDA Guidance: Research outputs should align with the **FAIR principles,** meaning that data, software, models and other outputs should be Findable, Accessible, Interoperable and Reusable (2.2.3 FAIR and Timely, p. 17).

How to:

- Familiarize yourself with the FAIR principles with this checklist: How FAIR are your data?⁹
- Get permission to share:
 - o If your data were originally generated or collected by a third party, do you have permission and the rights to redistribute them?
 - Be aware that data collected from Indigenous participants, or on Indigenous lands, can only be deposited after consultation with community leaders.¹⁰
 - Understand that data from human participants must be de-identified prior to deposit if respondents were promised confidentiality, and consent must be obtained. Share only what participants have agreed to share. (Need help figuring out what you can share? Jump to the next section on Protecting the Privacy of Research Participants.)
- Share your data using an open license:
 - Use the <u>Open COVID License</u>, or choose a <u>Creative Commons</u> license such as <u>CC-BY 4.0</u> for your data.¹¹
 - o For open source software license options, check out the Open Source Initiative. 12

Making your data FAIR can be a big undertaking. It may be useful to hire a research assistant or train someone on your team to manage permissions and licenses. If you have questions about licensing your data, you may also want to contact your institution's copyright officer.

⁹ Sarah Jones and Marjan Grootveld, "How FAIR are your data?" November 24, 2017, http://doi.org/10.5281/zenodo.1065991.

¹⁰ "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018)," Government of Canada, last modified February 19, 2020. https://ethics.gc.ca/eng/policy-politique tcps2-eptc2 2018.html.

¹¹ Open COVID Pledge Steering Committee, "Open COVID-19 Licences (OCL-Standard)," accessed August 5, 2020, https://opencovidpledge.org/licenses/. See also, "About the Licenses: The Licenses," Creative Commons, accessed August 5, 2020, https://creativecommons.org/licenses/.

¹² "Licenses & Standards," Open Source Initiative, accessed August 5, 2020, https://opensource.org/licenses.

Protect the Privacy of Research Participants

RDA Guidance: Access to individual participant data and trial documents should be as open as possible and as closed as necessary, to **protect participant privacy and reduce the risk of data misuse.** [Executive Summary, p. 7].

How to:

Although the FAIR principles above outline an ideal of openness, research with human participants may require you to hold back some data or edit it before sharing. The following guidance documents will help you understand how to prepare your data to share.

- Prepare consent forms that describe what data will be shared. The ICPSR has some helpful tips for developing consent form language in their <u>Recommended Informed Consent Language for Data Sharing</u>.
- How does your consent form control what data you can share? Do you understand what your consent form language allows or prohibits? We recommend starting with this decision tree: <u>Can I Share My Data?</u>¹⁴
- If there may be restrictions on what you can share, follow <u>Portage's De-identification Guidance</u> to protect the privacy of research participants and reduce the risk of harm. ¹⁵

https://www.icpsr.umich.edu/web/pages/datamanagement/confidentiality/conf-language.html.

¹³ "Recommended Informed Consent Language for Data Sharing," Inter-university Consortium for Political and Social Research (ICPSR), accessed August 5, 2020,

¹⁴ Portage COVID-19 Working Group, "Can I Share My Data?" September 25, 2020,

https://doi.org/10.5281/zenodo.4041661.

¹⁵ Portage COVID-19 Working Group, "De-identification Guidance." September 25, 2020, https://doi.org/10.5281/zenodo.4042023.

Help Others Discover and Use Your Data

RDA Guidance: Data should be deposited in data repositories... widely used disciplinary repositories are recommended for maximum accessibility and assessability of the data, followed by general or institutional repositories... By providing persistent identifiers, demanding preferred formats, rich metadata, etc., certified trustworthy repositories already guarantee a baseline FAIRness of and sustained access to the data, as well as citation (2.2.7 Use of Trustworthy Data Repositories, p. 19).

How to:

- Describe your data using a metadata standard that works best for your discipline. Check out this list put together by the Digital Curation Centre.¹⁶
- Save your data in appropriate data formats for preservation. Consult <u>OpenAIRE's Guides for Researchers: Data Formats for Preservation</u>. ¹⁷
- Deposit your data and all associated documentation in a recognized repository. Consult <u>Portage's</u>
 Recommended Repositories for COVID-19 Research Data.¹⁸

¹⁶ "List of Metadata Standards," Digital Curation Centre, accessed August 5, 2020, https://www.dcc.ac.uk/guidance/standards/metadata/list.

¹⁷ "Guides for Researchers: Data Formats for Preservation," OpenAIRE, accessed August 5, 2020, https://www.openaire.eu/data-formats-preservation-guide.

¹⁸ Portage COVID-19 Working Group, "Recommended Repositories," September 25, 2020. https://doi.org/10.5281/zenodo.4042037.

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