



University of British Columbia – Children's & Women's Research Ethics Board

**UBC C&W Research Ethics Board**

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## Open Access and Future Use of Research Data Consent Guidance

If there is the potential for future use of data, it should be clearly disclosed in the consent form. There is an increasing trend in research requiring researchers to make their data publicly available at the time of publication. This trend is both from the funder, e.g., Tri-Councils, and journals, who are refusing to publish papers unless the data is publicly accessible. Researchers should carefully consider whether their research data could be made available in the future and in what form (de-identified or otherwise) and disclose this information in the consent form. Further considerations around privacy, confidentiality, and data management are required when data is sensitive or when there is future potential that data may be re-linked with other data to create identifiable information. It should be noted that many journals and funders will make exceptions to open access policies when it is not possible to make the data available in a way that protects the confidentiality of the participants or when sharing would erode the participants trust in the researcher.

### **Needed Consent Form Disclosures:**

- A statement about the potential for future use and what that means within the context of the research.
- A statement about the nature of the data that will be publicly available, e.g., de-identified. Ensure terms and definitions are defined in lay terms.
- If any, a discussion of any increased risk to participant, e.g., possibility of re-identification.
- If not already covered in the consent form, a statement that once data is made publicly available, the participant will not be able to withdraw their data.
- If possible, a check box to opt out of future use.

### Suggested wording for public sharing of aggregate data at the time of publication can include:

*“As per insert FUNDER POLICY (if relevant), your de-identified research data (which means your name, birthdate, and other identifiers have been removed) may/will be deposited into a publicly accessible location at the time of publication. This can enhance the transparency of the research data and allows for external validation and fraud control, but it also allows others to access the data for re-analysis of this study or to do other kinds of analyses in the future beyond those you are consenting to in this study. Also, this future use of your data may not be subject to oversight by a research ethics board, and thus the data may be publicly shared and used in currently unknown ways. Once the data are made publicly available, you will not be able to withdraw your data nor will your child have the chance to individual consent to this use at the age of majority. Even though the identifying information will be removed from the data it is possible that others may be able to find out who you are. The chance of this is currently thought to be quite low.”*