Templates will not be appropriate for every study and should be adapted to fit your research. Feel free to cut and paste from any example in this document.

This broad consent form should be used in addition, and secondarily, to a consent form that details information about the full research study; this form only provides information about including participant data in a data repository or keeping it for future unspecified research. This broad consent form can be provided to participants for consideration alongside the study's main consent form (and prior to their participation), or it may be presented after the conclusion of their participation in the study.

The language presented in the broad consent form should be easily understood by participants. The REB recommends a grade 8 reading level in most cases.

The content of this form must be consistent with information presented in the REB application.

DATA SHARING CONSENT FORM

[Template #6: Broad consent for data repository and/or future research]

The following text between the stars (* *) can be omitted if this consent form is presented after the main consent form where this information is already provided.

***Project title:** Insert Title of Project

Lead researcher: Name, title, institutional affiliation and contact information (email, phone number)

Other researchers
Names, institutional affiliations and contact information. Include student supervisor (email and phone number) when applicable.

Funding provided by: If the study is funded, state name and description of the funder here.*

[Versioning: After receiving ethics approval, add the date of approval and the consent form version number in the footer. The first approved version is v1.0. If subsequent amendments to the consent form are requested and approved, the date of approval and version number (e.g. v2.0) must be updated.]

Introduction
Briefly explain what this consent form is for and indicate that consent is optional.
Example: Thank you for agreeing to participate in our research study. We also want to ask for your consent to [share your study data in a data repository] or [keep your data for other research in the future]. A data repository is an online space to store data sets associated with research. You do not have to agree [to put your data into the repository/allow your data to be used in future research] to be able to participate in this research study – it is optional.

Why do we want to share your data?
Explain why data sharing in a repository or storage for future research is desirable.
Example: Sharing your study data allows many researchers to use this data without the need to

recruit more participants for each research project. Research can result in benefits to society in different ways. Shared data can also be used for teaching students.

How and where will we share your data?
Include details regarding the repository – where data will be made available, and the data steward, i.e., the organization responsible (e.g., name, where it is located, and any other relevant information). Include information about who might be able to access the data and why.
Example: If you agree, your study data will be made available in a data repository called [name of repository with weblink if applicable]. This repository is meant to hold data for other researchers and educators to use. While we intend to make your data available for research and teaching only, it is possible that your data could be used for other purposes. We will ask the repository to place limits on how the data can be used, including: [list any conditions that are placed on the data.]

Or: Because the data are "open access" there will be no limitations on how data will be used.

Or: If you agree, your study data will be kept by [name of researcher] in case it could be useful for other similar research studies in the future. Your data will be kept securely [explain where it is kept] and will only be available to [our research team/other researchers who work with us] for research about [topic].

What data about me will be shared?
Explain the information that will be shared. These might include demographic information, health information, photographs, videos, audio recordings, etc. Bullet points may be helpful. Be specific about the information to be included so participants' decision will be fully informed.
Example: If you agree, the following study data will be shared in a data repository:

- [List all demographic information to be included]
- Survey responses
- De-identified interview transcripts

[etc.]

How will my privacy be protected?
Explain the steps you will take to prevent the participant from being identified or re-identified by their data.
Example: To protect your privacy, we will [code/de-identify/anonymize] your data before making it available in the data repository. This means we will remove any information that could directly, or indirectly identify you. [If the data are coded]: The link between this code and your identity will be [deleted or stored securely and will only be accessible to the study team – insert as applicable]. [Describe any other mechanisms used to reduce the privacy risks of particularly sensitive data types listed above, where applicable.].

There is a possibility that someone could identify you using your study data. This risk may change over time as technology improves and new ways of understanding information are developed. For example, there may be new ways of linking information back to you that we cannot foresee now. If you are re-identified, it means that someone else could use the information you provide in this study in ways that may or may not be harmful to you. Nonetheless, we believe the risk of being identified is very low.

For how long will my data be stored?
Tell participants how long their data will be stored and shared on the repository in normal circumstances, or how long you will keep their data (as applicable).
Example: Your study data will be shared on [name the repository] for as long as there are the resources required to host it, possibly forever. In the future, it is possible that the responsibilities

for the stewardship of your data will be transferred to a different organization. This could affect the conditions under which your coded study data can be accessed or used.

Or, I will store the data on [storage location] for [X years]. If I leave Dalhousie before the end of this period, I will [explain what will happen to the data].

How will my data be used?
Explain any conditions or limitations placed on how the data can be used.
Example: Your study data will be available in the data repository for free. [Repository name] policies require that users only use data for research purposes. However, it is not possible to guarantee that everyone will respect these policies, or to monitor how data is used. Therefore, it is possible that your coded study data could be used for unauthorized purposes, including non-research purposes. [Remove or modify to reflect actual repository policy.]

[For open access repositories: Open-access repositories place no restrictions on the use of data. Though many uses of the data are related to research or teaching, it is not possible to restrict how people will use open-access data nor to monitor how the data are used. Therefore, it is possible that your coded study data could be used for non-research purposes.]

[For restricted or mediated access: The data collected in this study may be [used by our research team or other researchers who want to study similar topics].

It is not currently possible to define all the types of research that may be done in the future using your data. The research may be about similar topics to this study, but it also may be used as data for other research projects. Some of the methods or analyses used may not even have been invented yet.

Some researchers, like those who work in Canadian universities and hospitals, will be required to receive approval from a research ethics board (REB) before using your data for future research purposes. However, others may not have to follow the same rules about ethical approval, and may use the data without approval from a research ethics board.

It is possible that your coded study data will be used by commercial organizations, and they may profit from the use of your data.

Or: I will only use the data for research on [X topic]. If I use the data in the future I will need to obtain approval from a research ethics board [only state this if the data do not meet the TCPS2 definition of 'anonymous' data].

Will I benefit from sharing my data?
Usually there are no benefits to participants for sharing their data and this should be stated.
Example: You will not receive any direct benefit from sharing your study data. However, sharing your data may contribute to many different research projects.

Can I change my mind and withdraw my data?
Explain if and how participants can withdraw their data. If it is not possible to do so, state this and explain why.
Example: It is your choice whether or not to let researchers [share/keep] your study data for future research. If you say "yes" now, you can still change your mind until *[state the time frame after which you will not be able to identify individual data for the purposes of withdrawal. This should align with the withdrawal limitations of the main study*.] If you say "no," you can still fully participate in this study.

Or: It is your choice whether or not to let researchers [share/keep] your study data for future research. If you change your mind later, I won't be able to remove your data because [it will be de-identified/anonymized] and I won't know which data are yours.

Other
See TCPS2 2 Article 3.2 for additional suggested consent form items that may need to be addressed for your particular study, such as conflict of interest, commercialization, and not waiving legal rights.

Whom should I contact if I have questions or concerns?
Explain who participants should contact if they have questions.
Example: If you have any questions, you should discuss them with the study team. You should take as much time as you want to make an informed decision about whether you wish to [include your data in the data repository/allow the researcher to keep your data for future research projects]. If you have questions about sharing data in an open-access data repository, you should talk to [name and contact information]. Remember, this is optional and will not impact your participation in the research study itself.

If you have any ethical concerns about your rights as a participant or about ethical issues related to the data sharing topics in this document, you may contact Research Ethics, Dalhousie University at (902) 494-3423, or by email at ethics@dal.ca and reference REB file # 20XX-XXXX [insert REB file number].

Signature
Not all informed consent processes require a signature. The TCPS2 requires researchers to document consent (Article 3.12). If a signature is obtained, it should be on a separate page and not on the back side of the study information. This allows researchers to collect the signature pages but leave the detailed study information, and contact information, with participants.

Signature page

Project Title: Insert study title

Lead Researcher: Insert name, affiliation, and contact information

If written consent is being obtained, the signature page should be signed and dated by the research participant or by the person authorized to sign on behalf of the research participant (e.g., a parent or caregiver). In the latter instance, the participant's name must also be clearly indicated.

Example: I have read the explanation about the request to [store my research data in a data repository/allow the researcher(s) to store my data for future research]. I have had the opportunity to ask questions, and they have been answered to my satisfaction. I understand that my [coded/deidentified/anonymized] study data will be shared in a data repository that anyone can access/ will be kept by the researcher for [x years], and that the risk of re-identifying my study data is low, however, there remains a possibility that someone could identify me. I understand that if I choose not to share my study data, I can still participate in the research study.

☐ Yes - I agree to have my data included in a data repository / saved by the researcher for future research.
☐ No – I do not agree to have my data included in a data repository / saved by the researcher for future research.

Name: Signature: Date: