**Baycrest Academy REB: Template data sharing wording**

# Notes

* Some text may not be relevant for all studies or may need editing, such as the text in red. Further editing will be needed if data is collected anonymously (vs. de-identified or anonymized data).
* Recommended this is included as a separate section, either within or at the end of the ICF

# DATA SHARING FOR OTHER RESEARCH

Baycrest Academy is a member of the Tanenbaum Open Science Institute whose goal is to support the practice of “Open Science”. Open Science refers to the sharing of data, tools, and research results, and the removal of barriers for researchers to collaborate and work together. Through Open Science, we expect to make more rapid advances in solving the most challenging problems in brain science, and contribute to identifying solutions that benefit people affected by neurological disorders and mental health conditions worldwide [or substitute with other relevant research focus if not neuroscience].

In keeping with the principles of Open Science, we wish to share data collected in this study with other researchers at Baycrest or around the world for future research projects. Any personal information that could identify you will be removed or changed before the data are shared. Data that is shared will be “de-identified” [or “anonymized” if applicable] and identified by a study ID only. De-identified data from this study may be combined with data collected from other studies, or it may be saved in an online database that is accessible by other researchers. We do not know what the future research may be yet, but we expect it will be related to aging, brain health, or cognition [or substitute with other relevant focus]. We will not be able to inform you about or share results of these future studies with you.

You will not directly benefit from these future studies, but it is hoped that the research may help other people in the future.

De-identified data that is shared will be kept indefinitely. If you withdraw your consent, it may not be possible to delete your data that has already been shared. Your de-identified data may be shared with researchers outside of Canada. The privacy laws outside of Canada are different and may not be as strict. Despite removing personal identifying information from your data, there is a small risk that someone could trace the information to you. Please talk to the research team if you have questions or concerns about future use of your data.

[Example language for studies with audiovisual or other data that cannot be fully de-identified] Any portions of your data that cannot be fully de-identified (e.g., video and audio recordings) will never be included in an online database that is freely accessible without your explicit consent. Any researchers who wish to access these data for future research will be required to sign a Confidentiality Agreement, and/or obtain permission of the Baycrest Research Ethics Board.

If you prefer to opt out of sharing your de-identified data with other researchers, please complete the following:

* I do not agree to share my de-identified data in accordance with the principles of Open Science.

**Template approved by Baycrest REB (23-May-2023)**