

What About My Privacy and Confidentiality?

Who will have access to my contact information?

Nova Scotia Health Research Team

- This is the lead research team.

University of Waterloo Statistical Consulting and Survey Research Unit

- The interview data are being collected by the Statistical Consulting and Survey Research Unit at the University of Waterloo, on behalf of the researchers at NS Health.

University of Manitoba Research Team

- Your contact information may also be shared with the research team at the University of Manitoba, our saliva storage site, if you need support providing your saliva sample.

How will my contact information be shared?

The information will be shared using a password-protected and secure method.

Access to your health records

- If you decide to participate in this study, the research team will **not** access your health records during this study.

Access to your personal health information

- Personal health information will be collected from you directly.
- Study personnel will collect only the information needed for this study.
- *“Personal health information” is health information about you that could identify you because it includes information such as your name, telephone number, date of birth, information from the study interviews, and results of genetic testing.*
- **Once we take your saliva sample, we will assign it a code number. We will separate your name and any other information that points to you from your sample. We will keep files that link your name to the code number in a secure place away from your sample.**

Access to Research Records

Other people may need to look at the personal *health* information you shared to make sure the study followed the required laws and guidelines. These people might include:

- The Canadian Institutes of Health Research
- The Nova Scotia Health Research Ethics Board (NS Health REB) and people working for or with the NS Health REB because they oversee the ethical conduct of research studies within Nova Scotia Health

- The Committee for Harmonized Health Impact, Privacy, and Ethics Review (CHIPER) and people working for CHIPER because they oversee the ethical conduct of health research studies in Manitoba
- Authorized Representatives of Queen's University, its affiliated hospitals and/or Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB)

Privacy

- Protecting your privacy is an important part of this study.
- **Every effort to protect your privacy will be made.** If the results of this study are presented to the public, nobody will be able to tell that you were in the study.
- However, complete privacy cannot be guaranteed. For example, the principal investigator may be required by law to allow access to research records.

Use of Your Study Information

- The interview data, with no personal identifiers, collected from this study will be maintained on a password-protected computer database in a restricted access area of the University of Waterloo. The data will be electronically archived after completion of the study and retained for seven years.
- A copy of the data will be securely shared with the NS Health Research team and securely stored on NS Health servers.
- Sharing study data with other researchers is important.
- Sharing study data can let other researchers answer new questions without making study participants go through the process again. It also lowers research costs.
- We want to use the data and samples from this study for future research projects, not just the one you are part of now. Those future projects can focus on any topic. Those projects might be unrelated to the goals of this study. We would also like to make the study data and samples available to other researchers who may do unique analyses that we do not do at our study sites.
- These other researchers may be at Nova Scotia Health or at other research centres around the world. Researchers will need to be approved to access the data by a Research Ethics Board and the principal investigators of this study.
- **Data access will be time-limited.**
- **Any study data sent outside of Nova Scotia Health will have a code and will not contain your name, email, or address, or any information that directly identifies you.**
- The research team and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be eliminated.



- The research team will keep any personal health information about you in a secure and confidential location for **20 years**. Your study data may be destroyed after this time based on the advice of an ethics board. Your personal *health* information will not be shared with others without your permission.
- The REB and people working for or with the REB may also contact you personally for quality assurance purposes.
- Please be aware that once your de-identified data is sent outside of Canada it may be accessed by regulatory authorities in other countries who may not have the same privacy laws as we do. All information sent outside of Canada will be transferred in compliance with all relevant Canadian privacy laws.
- **You do not need to agree to sharing data outside the research team to participate.**

Use of Your Personal Email

- If you prefer not to use your personal email for study-related communication, the research team can help you set up a separate email account (e.g., a generic Gmail address) to be used for the study. This helps reduce the amount of personal information shared with third-party platforms or study partners.