

Health Information Privacy Committee

Requirements for the Collection and Use of PHINs for Research Purposes

A Personal Health Identification Number (PHIN) is often used in research to link information about a single individual across different administrative datasets or to link administrative data with information collected directly from individuals (e.g. survey responses). The collection of PHINs for research can occur in either of the following situations:

- 1) During a single research project, for use in that same project; or
- 2) During the first research project, for use in a subsequent research project.

For situation #1 above, in accordance with sections 24 and 26 of *The Personal Health Information Act*, PHINs can only be collected and used once the researcher has obtained approval from either the Health Information Privacy Committee (if the PHINs will be linked with data held by the Manitoba government or a government agency) or an Institutional Research Review Committee (if the PHINs will be linked with another trustee's data). Once the research project has been approved, there are two ways that a researcher can go about collecting PHINs:

- Directly from individuals participating in the research project, or
- Indirectly from the trustee that maintains the PHINs, when it is unreasonable or impractical for the researcher to obtain consent directly from the individuals the PHINs are assigned to.

Approval process for obtaining PHINs for use in a future research project

For situation #2 above, the Health Information Privacy Committee, in collaboration with Manitoba Health, Seniors and Active Living, has set out the following requirements that must be addressed before the PHINs can be collected in a research project for the purpose of linking them with Manitoba government administrative data in a second, not-yet approved research project*:

1. The second research project is definitely planned at the time the first research project application is submitted.

At a minimum, an application for the first research project must be submitted to the appropriate University or Manitoba Research Ethics Board indicating that PHINs will be collected for the purpose of linking the research project data to administrative data held by the Manitoba government in a future research project. This will ensure that the collection of PHINs has a defined purpose and is not merely speculative.

2. There is no opportunity to collect the PHINs during the second research project.

The researcher must make the case that the first research project is the last or only time that PHINs can reasonably be collected for use in the second research project.

3. The PHINs are necessary to carry out the second research project

The PHINs must be required to link the research project data with certainty to government administrative data that will be requested through an application to the Health Information Privacy Committee at a later date for the second research project.

4. The researcher will obtain informed consent from the participants or trustee approval before collecting PHINs.

This means that either informed consent will be obtained from the individual participants when the PHINs are collected directly, or approval will be received from the trustee when PHINs are collected indirectly (e.g. in chart reviews).

*This process is only for projects that wish to collect PHINs with the intention of linking them to administrative data maintained by the Manitoba government or agencies. If PHINs will be collected to link to data maintained by trustees outside of the government, those trustees must be consulted.

- 5. The researcher has protocols in place to ensure the confidential destruction of the PHINs if the second research project is not carried out.**

If, for any reason, the second research project is not carried out, the researcher must immediately and confidentially destroy the PHINs that were collected for this purpose.

Example Wording for Requesting Consent to Collect PHINs from Individual Participants

Below is a template for requesting consent to collect and use PHINs obtained directly from participants. This wording is meant to be used as part of the consent form and never on its own. More details are required to inform participants about the specific research project that is being conducted including their rights whether they choose to participate or not, the safeguards that will be in place to protect their information, and when/how their information will be destroyed.

Consent for Data Linkage to Manitoba Government Records

“Data will be collected for this research project over the next _____ years with data analysis projected to be completed approximately _____ years following data collection.

The information gathered from you will be linked to information available from <identify the government trustee(s): e.g. Manitoba Health, Seniors & Active Living; Vital Statistics, etc.>.

This will include information about your <describe specific types of information: e.g. immunization records, doctor visits, hospital stays, prescriptions filled, vital statistics, social services use, childcare use, education records, etc.>.

This information will be used to <describe the reason that the linkage to government information is required>.

We ask that you provide us with your 9-digit Personal Health Identification Number (PHIN) and 6-digit family member number on your Manitoba Health Card to assist us in linking this information. In addition, we also request that you provide your name, gender, birth date, and postal code, as this will help to validate your PHIN and ensure that your information can be linked correctly.”

Participant printed name: _____

9-digit PHIN: _____

6-digit Family Number: _____

Gender: _____

Date of birth (day/month/year): _____

Postal code: _____

Participant signature: _____

Date _____
(day/month/year)