

THE MANITOBA TOMORROW PROJECT

FREQUENTLY ASKED QUESTIONS (FAQ)

I. ABOUT THE MANITOBA TOMORROW PROJECT

1. What is the Manitoba Tomorrow Project?

The Manitoba Tomorrow Project (MTP) is a long-term research study that aims to learn more about the causes of cancer and other chronic diseases, by following the health of 10,000 Manitobans over several decades.

This MTP is part of a larger Canada-wide initiative called the Canadian Partnership for Tomorrow Health (CanPath) (formerly The Canadian Partnership for Tomorrow Project (CPTP)). CanPath is the largest health research project in Canada, and has enrolled over 330,000 Canadians across the country. The purpose of CanPath is to better understand the causes of cancer and other chronic diseases, such as heart disease, stroke, multiple sclerosis, diabetes, Alzheimer's disease, and other health conditions. CanPath and the MTP are being created as a resource for researchers to study how different factors - like environment, genes, illness, diet, exercise and lifestyle- interact with one another to influence risk for cancer and other chronic health conditions. Results from these studies will help us over time to better understand why some people develop cancer and other chronic diseases while others do not, leading to improvements in health for Canadians.

2. Why is the Manitoba Tomorrow project important? What are the benefits for me and/or for society?

For many chronic diseases, the causes are still unknown, or not well understood. We know that our genetics, environment, lifestyle, behavior and social factors all play a part in our health, but we still have a lot more to learn about how and why. Studying how health changes over a long time in a large group of people can help us to better understand the causes of chronic diseases. This knowledge could lead to better treatments, new tools to detect diseases earlier (when they may be easier to treat), and strategies to prevent diseases altogether.

While we do not anticipate any direct benefits to you for participating, your involvement is an opportunity to pay it forward for the benefit of future generations of Canadians, by contributing to a better understanding of what influences health and illness for many Manitobans.

3. How long will the Manitoba tomorrow project last?

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The study will follow the health of our participants for up to 50 years, so it depends on how old you are when you sign up! We will likely actively follow-up with our participants up to 85 years of age.

Cancer and chronic diseases like diabetes and cardiovascular disease can take a long time to develop. By analyzing information provided over a substantial time period, researchers may be able to determine why some people develop certain cancers and chronic diseases and others do not. In addition, it can be difficult to remember what you did 1, 5 or 10 years ago. Longitudinal (long term) data collection from the same people over time helps researchers learn more about how lifestyle, behaviour, environmental exposures, genetics and social factors contribute to disease risk.

4. How is the Manitoba Tomorrow Project funded?

Manitoba Tomorrow Project is funded by the Canadian Partnership Against Cancer (CPAC), with in-kind support from CancerCare Manitoba (CCMB).

5. What risks are involved?

A small blood sample will be taken. Blood collection performed by a professional can sometimes cause bruising, pain or fainting. There is also a small risk of infection associated with blood draws. Some of the questions in the questionnaire(s) might be stressful or upsetting to you. Every caution will be taken to protect the confidentiality of the biological samples and information you provide.

6. Will it cost me anything?

There are NO costs to you for participating in the project. Any parking fees related to your visit to a Manitoba Tomorrow Project study center will be reimbursed.

II. TAKING PART

1. Who can participate?

You may choose to join this project if you:

- Live in Manitoba
- Are between 30-74 years of age

2. Can I still sign up for the Manitoba Tomorrow Project?

Yes! We are actively recruiting participants, until March 31, 2022.

3. What do I need to do if I want to sign up?

Get in touch with us!

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- Complete the contact form on our website to receive your study package in the mail: <https://www.cancercare.mb.ca/Research/contact-form>
- or Call us toll free: 1-855-588-0658
- or send us an email: CCMBTomorrow@cancercare.mb.ca

4. I received a study package in the mail a while ago? Is it too late to complete it?

IT IS NOT TOO LATE!

We will be accepting new volunteers until our planned close date of **March 31, 2022**.

5. I received an invitation letter in the mail asking for my participation. How was I selected to receive this invitation?

The invitation letter was sent by Manitoba Health. We requested assistance from Manitoba Health to help us recruit volunteers for our study. Manitoba Health has an administrative database with a record of the contact information for every Manitoba resident who has a provincial health card. After excluding folks that were too old or too young to participate in our study, invitation letters were sent to a random selection of individuals. We have no knowledge of who receives the letters.

6. I submitted my study package and haven't heard back from you. What's the next step?

You are going to be contacted and invited to an optional 45-minute visit to our study center.

****As of March 14, 2020 – PRESENT**** Note that our “optional” in-person study appointments are on hold due to the COVID-19 situation, until further notice.

7. What happens during the study center visit?

The visit will take approximately 45 minutes in total. Our trained staff will answer your concerns and will clarify some questions from the completed core questionnaire. Our staff will verify your Personal Health Identification Number (PHIN); found on your Manitoba health card. Also, we will ask you to bring your prescription drugs with you or the list of your drugs (you could bring the medication records or list from your pharmacy) or take a picture of your current medications. The purpose of checking your prescription medications is to confirm DINs. We will ask you a few more questions before taking some simple measurements, and before sending you to the lab to make sure there are no contraindications.

During the optional visit to our study center you may:

- i. Have some simple body measurements taken-

A trained staff member will take some or all of the following measurements:

- Blood pressure and heart rate
- Waist and hip circumference

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- Standing and sitting height
- Weight and body composition

You can choose to not have any or all of the measurements if you do not feel comfortable being measured. If you so choose, we can share the results from these measurements with you. If we find abnormal results from these tests, for example if your blood pressure is very high, we are obliged to share these results with you. It is important for you to know that this assessment does not amount to a medical checkup by a qualified physician.

- ii. Donate a small amount of blood and urine:

On the day of your appointment, a trained staff member will ask you some questions to determine if it is safe to take a blood sample from you. If it is, and you agree, they will take about 40mL (2-3 tablespoons) of blood from a vein in your arm. During your visit, you will be directed to a washroom and asked to provide about 20mL of urine as well. You can eat and drink normally on the day of your appointment.

8. What kinds of tests are being done with my biological samples?

Blood is a source of genetic information (DNA). Changes in DNA can give rise to diseases, but it is not always clear why or how these changes occur. Levels of hormones, vitamins and other environmental factors can be measured in blood and urine.

A small portion of your blood sample may be analyzed at a lab right after your study center visit, by performing a test called a Complete Blood Count (CBC). A health professional associated with the MTP will contact you by telephone to inform you if the analysis of your CBC reveals very serious results that may require additional tests. The rest of your biological samples will be frozen so that researchers can use some of it in the future.

Your biological samples and information will be coded (i.e. your name will be replaced by a code) and stored in a highly secure, protected site at the Manitoba Tumor Bank of CancerCare Manitoba for future use in health research studies.

9. Will I receive results from research done using my biological samples?

Researchers who use Manitoba tomorrow project biological samples and information for research studies in the future might discover something unexpected that could significantly affect a participant's health (known as an 'incidental research finding'). A researcher could uncover something that could be life-threatening, or reveal a serious condition that could be treated or prevented. In the event of this occurring, the researcher, the Research Ethics Board, and the Manitoba Tomorrow Project will work together on a case-by-case basis to reach a decision about whether or not the incidental research finding should be communicated to the participant.

If your biological samples are used by researchers in the future, individual results from the research will not be communicated to you, unless incidental research findings are uncovered, as described above.

10. What if I'm not interested in taking part in the study visit?

The visit to our study center is “**optional**”, which means that you don't have to agree to that to be part of the study. If you prefer to participate by mail only, that is perfectly fine. We are grateful for your participation either way!

11. Could I refuse to give my biological samples (urine and/or blood sample)?

All of the parts of the study visit are optional. You can choose to not to donate blood and/or urine sample, if you do not feel comfortable doing so, and/or are unable to.

12. How often will I be contacted for follow ups in the future?

The Manitoba Tomorrow Project will continue for up to 50 years, and one of the goals of the Study is to collect information about your health at multiple times throughout your life. You will be contacted again in the future to complete additional questionnaires, and may be asked to provide additional samples and measurements. We estimate this will be roughly once every 3-5 years. The Study will also send you updates about the progress the Manitoba Tomorrow Project is making - and information about new planned study initiatives -through regular newsletters, roughly once per year.

13. How do I update the Project with major changes to my health?

We contact our participants every couple of years to obtain updated health and lifestyle information using follow-up questionnaires, which are designed to be snapshots of participants' health over a long period of time. By giving us your permission to link to your administrative health data, changes will also be captured via administrative and medical databases such as Manitoba Health Insurance Registry and the Manitoba Cancer Registry.

14. What happens if I move out of Manitoba? Can I still participate?

Yes! We want to keep you in Manitoba Tomorrow Project even if you move to another province, or to another country. To change your name, address or phone numbers please [contact us](#) by calling toll-free **1-855-588-0658**, or email us at CCMBTomorrow@cancercare.mb.ca.

15. If I join the study now, could I withdraw later?

You may withdraw from the project at any time, and you do not have to say why. If you choose to withdraw, simply contact us and let us know in what way you would like to withdraw . Please check the Consent and Withdrawing from the study in the Privacy and Confidentiality section for detailed information.

III. PRIVACY AND CONFIDENTIALITY

1. How will my privacy be protected?

Your privacy is very important to us, and we will make every effort to protect it. When we receive your biological samples and information, we will remove the personal identifying information (your name, address, and health card number) from them and replace it with a unique code. Replacing your personal information with a unique code will allow us to share biological samples and information with researchers while keeping your identity confidential. Researchers will only be given access to coded information that cannot be used to identify you or anyone else in the project.

2. Who will have access to my personal information?

Your personal identifying information (name, address, and health card number) will only be accessible by authorized personnel from the *Manitoba Tomorrow Project* under controlled conditions. This access will be only for the purposes of contacting you for additional information. Any disclosure of your personal identifying information will be in compliance with the Personal Health Information Act (PHIA) of Manitoba.

3. Why do you require my Manitoba health card number?

We will ask you to provide us with your Personal Health Identification Number (PHIN; found on your Manitoba health card), so that we can access your past, present and future health information, and link it with the biological samples and information you provide to the project. Databases that may be used by the project include the Manitoba Cancer Registry and the Manitoba Health Insurance Registry.

4. What steps are being taken to ensure that the study is performed ethically?

All researchers who apply to access the *Manitoba Tomorrow Project* data for their research projects will be required to have their project plans reviewed and approved by a Research Ethics Board. Research Ethics Boards look after research projects that involve humans (including biological samples and information collected from humans) for the purpose of research, to ensure that the proposed research will be carried out according to the highest ethical and scientific standards.

5. Will I be paid to participate in this project?

You will not receive any payment for participating in this project. Should you experience expenses related to the project (i.e., loss of wages/travel) you will not be compensated. Parking charges for your visit to the CancerCare Manitoba study center will be reimbursed up to a maximum of 2 hours.

6. Will the project lead to any commercialization?

Research using your biological samples and information could in the future lead to commercialization of a medical test or product- some researchers may also benefit financially from any future commercialization. If a commercial product is developed as a result of research conducted through accessing your biological samples and information, you will not receive any personal financial benefit.

7. Will my insurance company or employer find out my results?

Your family members, friends, employers and insurance companies will not be able to access any information about you that has been collected from the Manitoba Tomorrow Project.

8. Consent and Withdrawing from the study

a) I've changed my mind and longer want to take part?

How do I withdraw from the study?

Your decision to take part in this project is totally voluntary. You may withdraw from the project at any time, and you do not have to say why. If you choose to withdraw, simply contact us and let us know in what way you would like to withdraw.

There are three 'levels' of withdrawal:

No further contact: The *Manitoba Tomorrow Project* will no longer contact you, or ask you to participate in any follow-up activities, like completing follow-up questionnaires. We will still have your permission to store and use the biological samples and information you have provided, and to access information in your health records.

No further access: The *Manitoba Tomorrow Project* will no longer contact you, or ask you to participate in any follow-up activities. We will still have your permission to store and use the biological samples and information you have provided, but we will **NOT** access any further information about you from your health records in the future, from the time of your withdrawal onwards.

No further use: The *Manitoba Tomorrow Project* will no longer contact you, or ask you to participate in any follow-up activities. We will not access any more information about you, the information you provided us will be removed from our databases, the information we accessed from your health records will be removed from our databases, and your biological samples will

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be destroyed. However, we **CANNOT** remove or destroy biological samples and information that have already been granted to approved researchers before your decision to withdraw.

b) Do I have to agree to everything in the consent form to participate in the study?

To participate in this study, you have to consent to: complete a questionnaire about health and lifestyle; provide my personal health information number (PHIN) for linkage of health records about your past, current and future health; and be re-contacted in the future to follow-up research.

The visit to our study center is optional, which means that you don't have to agree to that to be part of the study.

9. What happens to my information if I die?

Biological samples and information collected by the *Manitoba Tomorrow Project* may be used for research purposes after you pass away or are unable to make decisions on your own, unless you tell us differently while you are still alive.

For questions about your rights as a research participant or about ethical issues related to this project, you may contact someone who is not directly involved in the project. That person is:

The University of Manitoba
Health Research Ethics Board (HREB)
Research Ethics Board Coordinator
Telephone Number: (204) 789-3389

IV. ADDITIONAL QUESTIONS

Do you have an additional questions you could not find the answer to here?

Please connect with us. We're always happy to speak with you!

- Call us toll free: 1-855-588-0658
- Call our direct line: 1-204-787-8890
- Send us an email: CCMBTomorrow@cancercare.mb.ca