

Participant Information and Consent Form

Study Title: Healthy Future Sask - Healthy Eating and Supportive Environments (HEAL) Study

Local Principal Investigator: Megan Vanstone, Director of Research Development & Strategy, Saskatchewan Cancer Agency

National Principal Investigator: Dr. Rachel Murphy, School of Population and Public Health, University of British Columbia

Sponsor: Canadian Institutes of Health Research

You are being invited to participate in this study because you are a participant in **Healthy Future Sask (HFS)**. In addition to HFS, participants in other regional Canadian Partnership for Tomorrow's Health (CanPath) cohorts are being asked to provide the same information.

The HEAL study involves completing online questionnaires and your participation is entirely voluntary. The information provided in this form explains what is involved in this study, what you will be asked to do, privacy and confidentiality, and any potential benefits or risks of participating.

Introduction

This is an invitation for HFS participants to participate in the **Healthy Eating and Supportive Environments (HEAL) study**.

Poor diet and physical inactivity are among the top risk factors for cancer in Canada. There is strong evidence that structural factors such as the environment where you live influence what people eat and how active they are. To date, studies have been limited to select areas in Canada, select populations and a small number of foods and activities. This national study is being done to address the knowledge gap and understand how to best inform policies to support healthy eating and physical activity in Canada.

The HEAL study will leverage four linked national resources ([Canadian Partnership for Tomorrow's Health \(CanPath\)](#), including HFS, [NutriQuébec](#), [the Canadian Urban Environmental Health Research Consortium \(CANUE\)](#), and the [Canadian Food Environment Dataset \(Can-FED\)](#)) to collect diet and physical activity data from approximately 130,000 participants across ten provinces. Linking the information from the HEAL study to other health and environmental factors will help provide a more complete picture of the factors

that shape dietary intake and physical activity of Canadians, and the subsequent impacts on health.

Purpose

This study seeks to understand how neighbourhood factors shape dietary intake and physical activity of Canadians. You will be asked to provide information on health and lifestyle, and to report your dietary intake and physical activity over the past 24-hours at two separate timepoints. Finally, you will be asked to report your dietary intake and physical activity over the past year to capture seasonal changes and special events.

The information collected will be used to assess aspects of the food environment that impact dietary intake, such as the types of stores in your neighbourhood, and how these aspects differ across Canada. The data will also be used to study how dietary intake and food environments, together, are influenced by other factors like the walkability of your neighbourhood and your physical activity. In the future, this data will help us understand the relationships between diet and physical activity and health outcomes like chronic disease and cancer.

Who can participate?

For this study, all participants enrolled in HFS will be invited to participate. While participants in other regional CanPath cohorts will also be asked to provide the same information on health, lifestyle, diet and physical activity to contribute to this national study, participants from cohorts outside of HFS will be managed by other regional research teams.

Participating in this study is completely voluntary. Your continued participation in HFS will not be affected based on whether or not you participate in the HEAL study. If, for any reason, you no longer wish to participate in the study, you may end your participation at any time. You can do this by contacting HFS by email or phone. You will remain a valued participant in HFS going forward, even if you withdraw from HEAL.

If you wish to participate in this study, you will be asked to sign this form. Please take time to read the following information carefully.

What is involved?

If you agree to take part in this study, you will be asked to complete online questionnaires over one year. Over the course of the year, the study will be divided into several steps.

Step One: The first questionnaire will take approximately 30-45 minutes to collect demographic and lifestyle questions, as well as information about your health, dietary intake, and physical activity.

Step Two: Within two weeks, you will be asked to provide information on what you ate and drank and your activities (e.g., sleep, household and leisure activities) over the past 24-hours. This will be repeated in 1-2 weeks. These questionnaires asking about what you ate and your activities in the past 24-hours can be completed all at once or you may save your answers and return to them within 36 hours of starting the questionnaire. Each questionnaire will take approximately 20-30 minutes to complete.

Step Three: Finally, about eleven months later, you will be asked to report on dietary intake and activity over the past year which will take approximately 45-60 minutes to complete.

The questionnaires can be completed on a computer, phone or tablet.

What are the possible harms of participating?

You may find some of the questions may make you uncomfortable. You can choose to decline to answer any question.

Possible harm from participating in this study could be related to accidental disclosure of your personal health information stored in the database. However, the local Principal Investigator has taken precautions to minimize this risk, like restricting access to the database, forcing authorized staff to update their password every 90 days, and only using coded information to identify your data when it leaves the database for use in research projects. However, we will maintain identifiable information in a specific file to allow us to link the information from HEAL to other health data collected from other sources (like HFS) and to make sure we do not incorrectly link someone else's health information to your record. The risks of accidental disclosure are low, and every precaution will be taken to protect your privacy and the confidentiality of your information.

What are the benefits of participating?

At the end of the study, participants will receive a report summarizing the diet and physical activity information they provided. The dietary report will highlight key details such as your intake of key nutrients and food groups, how your reported intake compares to healthy eating recommendations, and tips for supporting healthy eating. The physical activity report will outline key information such as the types and amounts of physical activity you reported, how this compares to national guidelines, and suggestions for maintaining or improving your activity levels. You are not likely to benefit personally from participating in this study. This study may contribute to a better understanding about how neighbourhoods across Canada shape diet and physical activity to help prevent cancer and other chronic diseases. The study's results will be shared by HFS, other regional cohorts, and CanPath through their websites, newsletters, publications, presentations, and social media by 31 December 2028.

Can I stop taking part in this study?

If you wish to end your participation in this study at any time before 29 February 2028, all information collected for the HEAL study will be destroyed. If withdrawal from the study is requested after this date, however, it may not be possible to destroy records already used in study analyses, or shared with other researchers as part of this study before your withdrawal. Your participation, choice not to participate, or withdrawal from this study will not affect your present or future participation in HFS.

Will my participation be kept confidential?

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. All findings will be reported in aggregated or summarized form, ensuring that individuals cannot be identified.

Federal and provincial privacy laws require safeguards for privacy, security, and authorized access to information. We will not give information that identifies you to anyone without your permission, except as required by law. We will keep the information you provide on secure computers and servers that have many levels of protection until 2072 when the Healthy Future Sask study ends. Your information will be collected, coded, and stored at highly secure and protected sites at HFS. Only authorized personnel will have access to them under controlled conditions. Personal identifiers such as your name and address will be removed and replaced by a unique code. A master list connecting your identifiers (name, email, etc.) will be stored separately from your unique code on the secure, password-protected SCA server, accessible only to authorized HFS staff until the end of the Healthy Future Sask study. However, despite only sharing coded information, the possibility of someone identifying you can never be completely eliminated.

The dietary and physical activity recall questionnaires completed in Steps Two and Three are hosted by Westat and the National Cancer Institute (NCI), respectively, in the United States. The past-year dietary questionnaire is hosted by Information Management Services (IMS), a company also based in the United States. Your online responses about your food intake and physical activity will be temporarily stored by Westat, IMS and the NCI before being transferred to the Saskatchewan Cancer Agency servers. These companies do not use the data for investigative purposes and will not provide the data to other researchers. The data may be used for internal quality control checks, to identify needed updates to the questionnaires, and to audit the functionality of the questionnaires (for example, to assess how long the average participant takes to complete the questionnaires). Upon project completion, HFS staff will delete records held by Westat, IMS and NCI. They will never be given your name, and they will not receive any information that identifies you. They will only have unique login information used to access the questionnaires, which HFS will provide to you via a personalized weblink. Once HFS retrieves a copy of the data, we will use a unique identifier and your login information to link the dietary and physical activity questionnaire information back to your data in our secure Saskatchewan Cancer Agency servers.

Who will have access to my study-related data?

Only authorized HFS personnel will have access to your HFS - HEAL related data under strict controlled conditions.

HEAL study data collected by HFS will be combined with data donated by people taking part in HEAL throughout the other regional cohorts of CanPath (BC Generations Project, Alberta's Tomorrow Project, Healthy Future Sask, the Manitoba Tomorrow Project, Ontario Health Study, and CARTaGENE), and will be managed by CanPath. When the HFS data is transferred to CanPath, strict conditions for transfer will be in place. Administrators of data sent to CanPath will only be given access to coded information that cannot be used to identify you or anyone else in the project.

Researchers from Canada and other countries can request access to the data collected through the HEAL study. This includes researchers from universities, the government, and industry. All researchers applying for data access will be required to submit details of their project and will always have a duty to protect your privacy and to keep your information as confidential as possible. CanPath and HFS have established data access application processes that require a formal review process, as well as approval from a Research Ethics Board. Researchers will only be given access to coded information that cannot be used to identify you or any other participants. Any researcher requesting access to information will also be required to sign an agreement restricting data use only to the approved project and confirming they will not try to determine your, or any other participants' identity.

Your family members, friends, employers, and insurance companies will not be able to access any information about you that has been collected by HFS, including your HEAL study data. In addition, no information or records that disclose your identity will be published, nor will any information or records that disclose your identity be removed or released without your consent, unless required by law.

Your information will be collected and stored securely using trusted, research-approved platforms. Each platform we use has its own safeguards to protect your data:

- **Healthy Future Sask (HFS)** data is hosted by the **Saskatchewan Cancer Agency (SCA)** on secure, firewall-protected servers located in Saskatchewan, **Canada**. Access is limited to authorized study staff.
- **Research Electronic Data Capture (REDCap)** is used for collecting and managing study data. REDCap is hosted on secure servers at SCA located in Regina, **Canada**.
- **ASA24 (Automated Self-Administered 24-Hour Dietary Assessment Tool)**, **ACT24 (Activities Completed over Time in 24 hours)**, and **The Diet History Questionnaire III (DHQ-III - Canadian version CDHQ-III)** are online questionnaires developed by the U.S. National Cancer Institute. These platforms are hosted on secure servers located in the **United States**. Non-personally identifying data collected through these platforms are

encrypted during transfer and will be stored temporarily on their servers before being securely transferred to HFS/SCA servers in Canada.

For all platforms, data are encrypted in transit and at rest, and each requires unique logins with secure authentication.

The platforms hosting the dietary intake and physical activity surveys (ASA24, ACT24, and CDHQ-III) and their privacy policy statements can be found below:

National Cancer Institute: <https://www.cancer.gov/policies/privacy-security>

Westat: <https://www.westat.com/privacy-policy/>

Information Management Services: <https://www.imsweb.com/privacy.policy.html>

Costs, reimbursement and compensation

There will be no cost to you for completing questionnaires for this study. Your participation in the study is strictly voluntary, and you will receive no compensation.

Who can I contact if I have questions?

If you have any concerns about any aspect of the study at any time or if you wish to receive a summary of the findings, you can contact HFS at 1-833-701-0089 or info@healthyfuturesask.ca. Alternatively, you can write a letter to Healthy Future Sask at 1804 McOrmond Drive, Saskatoon, Saskatchewan S7S 0A6.

For privacy-related questions or questions about your rights as a research participant, you can contact the University of Saskatchewan Research Ethics Board at 306-966-2975 (out-of-town calls 1-888-966-2975). Please reference the study number BEH 5794 when contacting Research Ethics so the staff can better assist you.

By signing this form, you do not give up any of your legal rights and you do not release the sponsor, principal investigator, participating institutions, or anyone else from their legal and professional duties.

If you have questions relating to this study, please do not proceed with completing the questionnaire until you've reached out to the HFS-HEAL study team and feel that your questions have been answered to your satisfaction.

PARTICIPANT CONSENT TO PARTICIPATE:**My signature on this consent form means**

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free to refuse to participate or to withdraw from this study at any time.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I agree to complete the questionnaires as described above.
- I agree to my questionnaire data being linked to other relevant health-related data sources (e.g., HFS, CanFED, CANUE).

Please select:

I consent to participate in the Healthy Future Sask - HEALthy Eating and Supportive Environments (HEAL) study and to have my data stored as part of the Healthy Future Sask research platform for future research (required to proceed to the first survey)

I decline to participate in the HEAL study (stops consent, does not proceed to first survey)

I consent to participate in this study.

Participant's Name

Participant's Email

Date

Please press 'Submit' to complete your form.