

CARTaGENE FOLLOW-UP HEALTH SURVEY

INFORMATION

CARTaGENE is the largest population biobank for health research in Quebec. More than 43,000 men and women have enrolled in CARTaGENE and have provided detailed information on their health and lifestyle to create a resource to help researchers understand the causes of diseases like heart disease, diabetes, cancer and dementia.

CARTaGENE is now conducting the **first health follow-up** of all of its participants using **this newly developed participant portal**. This information is intended for all CARTaGENE participants who wish to take part of this health follow-up.

REGISTRATION ON CARTaGENE'S PARTICIPANT PORTAL

By registering onto the CARTaGENE participant web portal, you will receive invitations to participate in health follow-up surveys and other studies of interest. This web portal (<https://www.participants.cartagene.qc.ca>) allows participants to:

- Complete health questionnaires;
- Update personal information and health data;
- Receive information about CARTaGENE's activities and other projects of interest.

PARTICIPATION IN THE FIRST HEALTH FOLLOW-UP SURVEY

This survey is the first follow-up that will be done using this new participant portal. The health follow-up questionnaire is similar to the initial CARTaGENE health questionnaire containing questions on lifestyle, health status and family history of diseases. This questionnaire required about 45 to 60 minutes to fill out.

RIGHT OF WITHDRAWAL

You are free to participate in follow-up surveys and other studies for which you have been invited. You may at any time **request that your name be removed from the list of registered participants on the portal** without involving the destruction of data and biological samples collected since the beginning of your participation in CARTaGENE. If your name is removed from the participant portal, you will no longer receive invitations from CARTaGENE to participate in health follow-up surveys or any other study of interest.

You may also, at any time, **request the destruction of your data and biological samples collected since the beginning of your participation in CARTaGENE.**

To request a withdrawal, simply contact the Unité-CaG CHUSJ at: 1-877-263-2360 (toll-free).

RISKS AND BENEFITS OF THE PARTICIPATION

The main disadvantage of participating in the CARTaGENE health follow-up survey is the time

required to complete the questionnaire.

Risks: The survey data will be collected, coded and stored in secure servers until the termination of CARTaGENE. Only a limited number of authorized persons selected by CARTaGENE can access the data. Given the measures undertaken by CARTaGENE to protect the confidentiality of the data, the risk to their safety or privacy is minimized.

Benefits: Participation through the web portal and in the first health follow-up survey does not directly benefit the participants other than facilitating communication and ensuring long-term liaison between CARTaGENE and its participants. Moreover, it could help improve knowledge in the field of health through studies with CARTaGENE data and biological samples. Participants who completed the health follow-up questionnaire can view their responses at any time.

ACCESS TO CARTAGENE DATA AND BIOLOGICAL SAMPLES

The policy for requests for data and biological samples by researchers is the same as during your initial participation in CARTaGENE.

PRIVACY AND DATA AND BIOLOGICAL SAMPLE PROTECTION

The commitment to the privacy and protection of the CARTaGENE participants' data remains the same as during your initial participation in CARTaGENE. CARTaGENE complies with policies and security measures that have been duly approved by ethics committees and the *Commission d'Accès à l'Information*. Personal information is always kept separate from health questionnaires data and is never transmitted to researchers.

NOTIFICATION OF RESULTS TO PARTICIPANTS

No individual results will be communicated to participants. You will be informed about the general research findings emerging from the use of the CARTaGENE data and biological samples, which appear on its website or as part of the annual newsletter published by CARTaGENE.

For further information:

- Visit CARTaGENE website : <http://cartagene.qc.ca>
- For questions about CARTaGENE or withdrawal, contact the Unité CaG-CHUSJ :
 - Phone : 1-877-263-2360 (toll-free)
 - Email : unite.cartagene.hsj@ssss.gouv.qc.ca
- Any complaint related to your participation in this research can be addressed to the Commissioner for Complaints and Quality of CHU Sainte-Justine:
 - Phone : (514) 345-4749
 - Mail: Commissaire aux plaintes et à la qualité des services
CHU Sainte-Justine, Office 1102
3175, chemin de la Côte-Sainte-Catherine
Montréal (Québec) H3T 1C5

Thank you for taking the time to think about CARTaGENE!

CONSENT

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Host institution : Centre Hospitalier Universitaire Sainte-Justine

Funding: CARTaGENE is funded by the Canadian Partnership Against Cancer (“CPAC”) and by Génome Québec.

Goal of the CARTaGENE health follow-up: The goal is to update health data collected during the CARTaGENE initial participation, using the web-portal.

By accepting this consent form, I agree to register into the participant portal, and to complete the health follow-up questionnaire, and I declare that:

- I have read and understood the information provided herein. I had the opportunity to ask all the questions I had and obtain answers. I agree to answer a follow-up questionnaire regarding my health and lifestyle.
 - I agree that the data collected from the questionnaire be transmitted, in coded form, to CARTaGENE.
 - I accept that my data, once coded, be used by researchers in Quebec or elsewhere, within a framework of biomedical research that have received the necessary approvals from scientific and research ethics committees.
 - I understand that I will not receive any personal financial benefit from any possible commercialization of a test or product developed thanks to my participation in CARTaGENE.
 - I understand that I will never have access to my data stored in CARTaGENE banks.
 - I understand that after my death, my data and biological samples will not be withdrawn from CARTaGENE, unless clear instructions to that effect figure in my testament or any document with legal value.
 - I understand that my participation is completely free and voluntary and that I can withdraw at any moment without giving a specific reason by calling (toll-free): 1-877-263-2360.
- I consent to register on the participant portal and participate in the Health Follow-up Survey.