



The world within you



Information Brochure for Participants

TABLE OF CONTENTS

INTRODUCTION	1
WHAT IS CARTaGENE?	2
PARTICIPATING IN CARTaGENE	
How are participants selected?	3
What does participating in CARTaGENE involve?	3
Access to data and samples	6
Collaboration between biobanks and researchers	7
Possible risks and benefits of participation	8
Compensation	9
Communication of results to participants	10
Participant's right to withdraw	10
Options regarding participation	11
CONFIDENTIALITY AND PROTECTION OF DATA	13
MONITORING AND GOVERNANCE	14
CARTaGENE PROJECT	
Consent form (specimen)	17
THE CARTaGENE TEAM	19
FOR MORE INFORMATION ON CARTaGENE	20
FLOW CHART OF A PARTICIPANT IN CARTaGENE	21

INTRODUCTION

CARTaGENE is a scientific project of the Université de Montréal whose goal is to establish a health information database and a biobank of biological samples for research in health and genomics. Genomics is the study of the functioning of the genome, i.e. the biological information contained in DNA.

CARTaGENE is a research infrastructure that aims to further our knowledge in genetics. In the long term, this could lead to better prevention, diagnosis and treatments of diseases, and thus, to the improvement of Quebec's healthcare system.

Participation in CARTaGENE is completely voluntary. Before taking a decision, it is important that participants have a clear understanding of the project and its implications. Participants must take the time to read this brochure carefully. Feel free to discuss it with others.

The Régie de l'assurance maladie du Québec (RAMQ) (Quebec Health Insurance Board) has set up a team dedicated to the CARTaGENE Project. This team will be referred to as the CARTaGENE Service of the Régie de l'assurance maladie du Québec (CaG-RAMQ Service). It is in charge of both contacting participants as well as storing their personal information. The appointment with the participant for the collection of data and samples is the responsibility of the recruitment sites involved in the project.

Participants may also ask questions when the personnel of CaG-RAMQ Service call to schedule an appointment.

Cette brochure est aussi disponible en français.

For more information on CARTaGENE:

- visit CARTaGENE's website at: www.cartagene.qc.ca
- contact the CaG-RAMQ Service:
 1. by phone (toll-free) at 1 877 263-2360
**(Monday through Thursday, from 8:30 a.m. to 8 p.m.,
Friday, from 8:30 a.m. to 5 p.m. and Saturday, from 10 a.m. to 4 p.m.);**
 2. write to: CaG-RAMQ Service, C.P. 14 500, Québec (QC) G1K 0B9;
 3. send an e-mail to: service.cartagene@ramq.gouv.qc.ca

WHAT IS CARTaGENE?

More and more, researchers wish to have a better understanding of how genes interact with each other, with the environment and with the lifestyle of an individual. CARTaGENE's goal is to establish a public resource for future research on health and genomics. This resource will consist of a databank and a biobank of biological samples (blood and urine). In the long run, CARTaGENE could contribute to the development of better diagnostic tools, treatment and prevention programs for diseases such as heart disease, diabetes, cancer or Alzheimer's disease.

Participants in CARTaGENE accept that data and samples collected from them will be used for health and genomic studies in the future. **Collected data and samples will be coded in order to guarantee confidentiality.**

CARTaGENE is funded by public funds and managed by the Université de Montréal who is in charge of the project, including certain particular aspects such as data and sample security.

Two hundred and twenty three Quebecers have already participated in CARTaGENE during the pilot phase in January and February of 2008. Their participation enabled us to test, validate and adjust the tools and methods of collection. Phase A will start in summer 2009 and aims to recruit 20 000 additional participants.

CARTaGENE will end its activities by December 31st 2058, unless the body responsible for the ethical evaluation and monitoring decides otherwise, or if its funding ends prematurely. When CARTaGENE ends its activities, it will ensure that the data and samples are destroyed, unless the body responsible for the ethical evaluation and monitoring decides otherwise.

PARTICIPATING IN CARTaGENE

How are participants selected?

Potential participants are randomly selected from the files of the RAMQ. They include persons 40 to 69 years of age residing in certain metropolitan areas of Quebec selected in order to obtain a representative sample of this age group. They will receive an invitation letter, an information brochure including a specimen of the consent form, a reminder and a CARTaGENE leaflet.

What does participating in CARTaGENE involve?

Meeting with the nurse or interviewer

Within 7 to 10 days after receiving the CARTaGENE documents by mail, individuals will be contacted by telephone by a member of the CaG-RAMQ Service in order to explain the project. An appointment lasting approximately two and a half hours will be set up with a qualified nurse and/or interviewer. This appointment will take place within an establishment of Quebec's healthcare system.

At the beginning of the appointment, the nurse or interviewer will answer the participant's questions concerning CARTaGENE and will have the participant sign the consent form. A copy of the form is available at the end of this information brochure. Those who agree to participate in the project will then have to sign the consent form.

A snack will be served. It is suggested that participants with allergies bring their own snack.

During the appointment:

- The nurse or interviewer will fill out a health and lifestyle questionnaire with the participant. A certain part of the questionnaire (about 1/3) will be completed by the participant. The nurse will always be available to assist the participant when necessary.

- The nurse will take certain physical measurements: height, weight, sitting height, waistline and hip measurements, cognitive functions, arterial pressure, muscle strength, respiratory volume, bioimpedance (percentage of body fat), arterial stiffness (to verify the condition of the arteries), bone density and partial electrocardiogram (for cardiac rate).
- The nurse will take a blood sample (approximately 7 tablespoons) and a urine sample.

All measurements, tests and blood and urine samples will be done by a qualified nurse.

A person designated by CARTaGENE may observe, with the participant's consent, part of the interview in order to ensure the quality of the process. This person will be bound by a confidentiality agreement.

Storage of participants' data and samples

Data and samples collected from participants will be stored for the next 50 years in two banks (database and biobank) for future research. These samples and data will be coded (**see Confidentiality and Protection of Data**).

■ Consent form

The consent form is the only document with the participant's name on it that will be stored. It will be electronically signed by the participant and a signed copy of the consent form will be given to the participant during the appointment. The electronic version of the consent form will be stored in the CaG-RAMQ Service's secure database until the end of CARTaGENE's activities. Researchers and members of CARTaGENE will never have access to this document.

■ Data collected during the interview

The results of the health questionnaire, as well as the physical measurements (blood pressure, height, weight and others) and biochemical analyses will be **coded** and transmitted electronically to CARTaGENE's database at the Université de Montréal, where they will be stored until the end of CARTaGENE's activities.

■ Samples

Blood and urine samples will be taken during the appointment with the nurse and will then be coded. Certain analyses will be done on some of the samples of the participants at a laboratory designated by CARTaGENE and located in a facility of the healthcare system of Quebec. The results of these analyses will be transmitted to CARTaGENE in **coded** form.

The collected samples will then be sent to the *Biobanque Génome Québec Centre hospitalier affilié universitaire régional de* (GQ-CAURC Biobank). DNA will be extracted from part of the collected blood samples. The DNA, blood by-products and urine samples will then be stored in the GQ-CAURC Biobank for future analyses. DNA analyses will include genome sequencing¹. Cell lines² may be established for research projects on the functioning of the genome and , if necessary, to produce extra DNA in case of a shortage of the DNA already extracted. The samples will be kept until the end of CARTaGENE's activities.

¹ Sequencing is a technique to determine the order of units that build the DNA and consists of the bases C, T, A and G. DNA is the genetic material that underlies heritability and is found in all cells of almost all living organisms.

² An immortalised cell culture is a group of cells to which has been added a component enabling them to reproduce (to divide themselves) indefinitely.

Access to data and samples

Access by researchers

The data and samples will be used for research on health and genomics. It is impossible to predict all the studies that could use the blood and urine samples over the course of the next 50 years. They will be used, among other biomedical projects, for research on the structure and the functioning of the genome.

Researchers with projects that have been approved by research ethics committees or any other competent authority can ask to use certain samples and data stored in CARTaGENE, as well as data stored in government databases (see below). In this situation, ethics committees will evaluate the research projects submitted and the scientific validity of these studies will be examined by a committee on data and sample access independent of CARTaGENE.

CARTaGENE will only grant authorized researchers access to data and samples. It will not allow access to insurance companies and employers.

Quality control and the production of aggregate data

CARTaGENE will be able to use the collected data to perform quality control tests and to produce aggregate data.

Quality control tests are performed to ensure the quality of the collected data and their use in future scientific research. Aggregate data are general data that enables CARTaGENE to describe the contents of its biobank. For example, aggregate data can indicate the number of female/male participants in the biobank, the number of smokers, the number of participants with certain types of diseases, the number of participants by age group, etc. This type of data does not lead to identification of participants.

Governmental health databases

Researchers will be able to request access to participant's data stored in the Quebec government administrative health databases (about thirty) by obtaining the approval of *Commission d'accès à l'information*. These administrative governmental data going back as far as 1998, and are accessible notably through the *Régie de l'assurance maladie*

du Québec (RAMQ), or via the *Institut national de santé publique du Québec* (INSPQ). While it is not possible to provide a complete list, these databases may concern, for example, hospitalizations, causes of death, types of cancer, and, medications purchased and covered by the public health insurance regime³.

Governmental data sent to CARTaGENE for approved research projects will not contain any personal information because they will be transmitted in coded form. CARTaGENE will never access the medical records of participants.

Collaboration between biobanks and researchers

Sharing of data and samples makes it possible to increase the statistical power of studies so as to both gain a better understanding of complex genetic diseases and foster the transfer of knowledge throughout the healthcare system. Such data and samples (always coded) can be shared with researchers from other countries if their research projects respect the measures put in place to protect CARTaGENE participants.

National collaboration

Currently, other biobank initiatives, like CARTaGENE, are taking place in other Canadian provinces. To facilitate access to data and samples collected by the different Canadian biobanks, the Canadian Partnership Against Cancer (CPAC) recently financed the Canadian Partnership for Tomorrow Project (CPTP) which includes five provincial biobanks. CARTaGENE is pleased to be the Quebec partner in this important project. CPTP's goal is to harmonise and coordinate the different provincial biobanks to create a national research platform. This platform will allow the sharing of data and samples of 300,000 Canadians, including the 20,223 CARTaGENE participants. CPTP's objective is to reduce the number of new cancer cases and of other chronic diseases in Canada while improving their quality of life. To achieve these objectives, the research platform will serve to identify risk factors and harmonise prevention methods and diagnoses of diseases.

³ For a list of these databases : www.ramq.gouv.qc.ca/en/statistiques/banques/vuedensemble.shtml

International collaboration

International researchers who wish to use the CARTaGENE resource will have to follow the ethical and legal norms that apply to researchers from Quebec and obtain approval from CARTaGENE's independent Sample and Data Access Committee and from an Ethics Committee designated by Université de Montréal.

Like CARTaGENE, international projects are often part of an international research consortium in population genomics called the Public Population Project in Genomics (P³G).

P³G is a nonprofit consortium with headquarters in Montreal. It was created to facilitate collaboration between researchers and projects in the area of population genomics. Its goal is to harmonise and coordinate the practices and tools for research in genetic epidemiology worldwide. Each research project keeps control over its own data and samples.⁴

Possible risks and benefits of participation

The main inconvenience related to participating in CARTaGENE is the time needed for the appointment with the nurse or the interviewer. Furthermore, it is possible that a participant might feel discomfort with regard to certain measurements taken (e.g. weight), or with certain personal questions asked. All tests will be performed by a qualified healthcare professional.

Risks

- Blood collection sometimes causes bruising, pain or, in rare cases, fainting;
- The pulmonary test can sometimes cause fatigue that may lead to dizziness or, in rare cases, fainting. This test is not recommended for participants who are suffering from a cold, the flu or bronchitis;
- The bone density test is not recommended for participants with open sores or lesions on the feet.

The other measures taken during the appointment with the nurse are known to be without physical risks. However, pregnant participants or participants using a pacemaker should not take part in the bioimpedance measures (for body fat percentage).

⁴ For more information on the consortium, see www.p3g.org.

Data and samples will be collected, coded and stored in a secure and protected installation. Only the authorized staff of CARTaGENE will have access. Considering the great care taken for the protection and confidentiality of participants' data and samples, security risks and possible breach of confidentiality are minimized.

The risks mentioned above are the most probable ones. All the research projects that will use CARTaGENE's data or samples will be evaluated by both scientific and ethics committees in order to make sure that the risks related to these projects are minimised for participants.

Benefits

Participation in the CARTaGENE project will not bring any direct benefit to the participants. It may lead to better medical knowledge due to studies conducted with the data and samples of CARTaGENE.

During the appointment with the nurse, participants can obtain the following results from the physical measurements: height, weight, waist to hips ratio, handgrip strength, sitting height, percentage of body fat and body mass index, blood pressure, bone density and lung function. **These results do not amount to a full medical check-up by a qualified physician**, but they may be useful to evaluate the participant's state of health.

Since the partial electrocardiogram and the sphygmocor (apparatus to evaluate the arterial stiffness) are research tests, these results will not be communicated to participants.

Compensation

During the appointment, the participant will receive an amount of forty-five dollars (\$45) as compensation for collaboration in CARTaGENE.

Communication of results to participants

Only the results of the physical measures will be given to participants. These results do not amount to a medical diagnosis.

However, if any of the results of the physical measurements of a participant are not within the generally acceptable range, the nurse will inform the participant and recommend that (s)he consults a medical professional. If the result is such that it requires immediate intervention, the participant will be referred to an on-call doctor at the healthcare facility where the appointment is taking place.

After the appointment, if the laboratory results of the analyses of the samples from a participant are not within the generally accepted range and reveal a life-threatening condition for the participant, these results will be communicated to the coordinator responsible for the CARTaGENE Project at the healthcare facility where the appointment took place. A physician of the healthcare facility where the participant has taken his appointment will then communicate with the participant to inform him of the results and to give the necessary explanations. This will be done within seven (7) days of the appointment.

No results from future research projects using data or samples will be communicated to participants by CARTaGENE.

Information on research projects using CARTaGENE

A yearly information bulletin for the public on research projects using CARTaGENE will be published on CARTaGENE's website (www.cartagene.qc.ca).

Withdrawal by participants

Participants are free to withdraw from CARTaGENE at any moment. To withdraw, participants can simply contact the CaG-RAMQ Service. CARTaGENE will be informed of the withdrawal in coded form. In this situation, data and biological samples from the participant will be destroyed in CARTaGENE. However, data and samples that have already been used by researchers cannot be withdrawn from current or completed projects.

The death of a participant does not cause his withdrawal from CARTaGENE, unless the participant has so indicated in his will. The participant's data and samples will continue to be part of CARTaGENE's resource and can be used for research.

Options regarding participation

1) To be recontacted for other research projects linked to CARTaGENE

During the appointment with the nurse or interviewer, participants will be offered the possibility to be contacted again in the future for updates or for new research projects linked to CARTaGENE which will have been previously evaluated both scientifically and ethically.

When a participant consents to be contacted again, (s)he authorizes the CaG-RAMQ Service to update his contact address. Should (s)he wish, the participant contacted again by the CaG-RAMQ Service can consent to an update of the health questionnaire, other physical measurements and/or provide new samples. The participant will be completely free to accept or refuse to participate in such updates or in new proposed research projects.

Research projects using the stored data and samples of CARTaGENE will not always need to recontact participants. Data and samples already collected will often be sufficient for the researcher's needs. Authorization to recontact participants will only be given if it is necessary for updates of CARTaGENE or for a research project that has previously received the required ethical approval and a scientific evaluation.

Participants can withdraw from this option (recontact) at any time by calling the CaG-RAMQ Service at: 1 877 263-2360 (toll-free) (Monday to Thursday, from 8:30 a.m. to 8 p.m., Friday, from 8:30 a.m. to 5 p.m., and Saturday, from 10 a.m. to 4 p.m.)

2) To participate in the genealogical option of CARTaGENE

■ How?

The nurse or interviewer will give instructions, an information brochure, a consent form and a genealogical questionnaire to participants at the end of the appointment. Participants can fill out these documents at home and send them by mail to the BALSAC Project (Université du Québec à Chicoutim) if they so choose. Genealogies will then be constructed only if a researcher requests it and will be transmitted to him in a coded form. Participants will not receive a copy of the genealogy.

Participants are completely free to participate or not in this genealogical option.

■ What is BALSAC?

The BALSAC population register is a computerized database that permits the automatic construction of family histories and ascending or descending genealogies from the beginning of the province of Quebec in the 17th century up until now. Data for this register is principally taken from official acts and documents (births, marriages, deaths). Any personal information in the BALSAC register is protected by both physical and electronic security measures.

This information is useful to researchers in order to understand the demographic and historical factors that have shaped Quebec's genetic heritage. If participants do not have any ancestors in Quebec, the genealogical questionnaire would still be useful to collect information for certain types of research.

For more information, see the documentation on BALSAC available during the appointment or on the website www.cartagene.qc.ca, or visit the BALSAC website: www.uqac.ca/balsac/ang/index.php

Participants can withdraw from this genealogical option at any moment by contacting the CaG-RAMQ Service at: 1 877 263-2360 (toll-free) (Monday to Thursday, from 8:30 a.m. to 8 p.m., Friday, from 8:30 a.m. to 5 p.m., and Saturday, from 10 a.m. to 4 p.m.)

CONFIDENTIALITY AND PROTECTION OF DATA

Only the CaG-RAMQ Service will have personal information on participants

Only the CaG-RAMQ Service is in charge of recruitment, storing the consent forms, recontact, and any other activity requiring communication with participants or use of personal information. The CaG-RAMQ Service has a legal obligation to ensure confidentiality of the information that it possesses and uses. All personal information supplied to the CaG-RAMQ Service will be treated and protected according to the laws and policies of the RAMQ and the *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels*.

Identifying information used by the healthcare centres to schedule appointments will never be communicated to CARTaGENE and will be destroyed a few days after the appointment with the participant.

Personal information will be kept separated from data and samples

Personal information and consent forms will be stored at the CaG-RAMQ Service. The CaG-RAMQ Service will not obtain any information contained in the health questionnaire or from the results of physical tests. This information will be transmitted to CARTaGENE in coded form. **CARTaGENE will not have access to any personal information on participants**, such as their name, address or telephone number. Personal information will thus always be kept separate from the data and samples that they are linked to.

Furthermore, CARTaGENE will never have access to the medical records of participants.

Strict security measures have been put into place

The installations of the CaG-RAMQ Service and CARTaGENE are protected by strict physical and electronic security measures, in particular by regulations with regard to access, encryption of data and coding, confidentiality agreements and by the training of the staff.

Data and samples will be coded

All data and samples will be coded before transmission to CARTaGENE. Codes will be modified by CARTaGENE before the storage of data and samples. Furthermore, before transmitting data and samples to a researcher, they will once again be coded. This way, neither CARTaGENE nor the researchers will be able to identify participants. In the same way, the CaG-RAMQ Service that holds identifying information on participants will not be able to establish links between this information and the data and samples held by CARTaGENE.

MONITORING AND GOVERNANCE

Public and expert surveys

A public consultation (focus groups and a survey) has been carried out to identify the concerns of the population regarding CARTaGENE. Workshops with ethics and legal professionals as well as policy decisionmakers were held. CARTaGENE has taken the results of these activities into account.

Ethical oversight of CARTaGENE

The Research Ethics Committee of the Faculty of Medicine of the Université de Montréal is responsible for the ethical evaluation and monitoring of CARTaGENE. This committee is independent from CARTaGENE. Its goal is to protect the interests of participants and the public.

CARTaGENE and the Université de Montréal follow the ethical norms applicable to research in Quebec and Canada.

The ethical evaluation and monitoring of the project will also be done by the ethics committees of the healthcare facilities participating in the recruitment of participants in CARTaGENE within the multicentre process put in place by the *ministère de la Santé et des Services sociaux du Québec*. Thus, the Research Ethics Committee of the *Centre hospitalier de l'Université de Montréal* (CHUM) will act as the Principal Committee and the ethics committees of other healthcare facilities receiving participants for CARTaGENE will act as local committees.

The ethics committees of the healthcare facilities are independent from CARTaGENE and report to the *ministre de la Santé et des Services sociaux du Québec*. The mandate of all ethics committees is to ensure the protection of the participants and the public.

Commission d'accès à l'information (Access Commission)

Personal data obtained by CARTaGENE are subject to supervision by the *Commission d'accès à l'information* (CAI) (Access Commission) governed by the *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels*. The CAI is an organization who has among its goals the protection of personal information held by public or private organizations.

For CARTaGENE, the CAI will authorize the CaG-RAMQ Service to use the names and addresses of participants for potential recruitment and recontact. The CAI will evaluate requests by researchers using CARTaGENE when they wish to obtain government data regarding participants.

The CAI also has the authority to undertake investigations and audits in order to verify that the collection, use, communication and storage of personal information are in conformity with the law.

Knowledge transfer

Results obtained by researchers using data and samples from CARTaGENE will be returned to the database in order to improve it. General results of research projects will be published in scientific journals and will be available on CARTaGENE's website. It will be impossible to identify participants in these publications.

Commercialization

The CARTaGENE resource is not for profit. However, it could someday enable researchers to develop new tests or commercial products. Should this be the case, participants will not receive any financial benefit from such commercialization.

For more information on CARTaGENE:

- visit CARTaGENE's website at: www.cartagene.qc.ca
- contact the CaG-RAMQ Service:
 1. by phone (toll-free) at 1 877 263-2360
**(Monday through Thursday, from 8:30 a.m. to 8 p.m.,
Friday, from 8:30 a.m. to 5 p.m. and Saturday, from 10 a.m. to 4 p.m.);**
 2. write to: CaG-RAMQ Service, C.P. 14 500, Québec (QC) G1K 0B9;
 3. send an e-mail to: service.cartagene@ramq.gouv.qc.ca

Thank you for taking the time to think about CARTaGENE!

CARTaGENE PROJECT

Consent form

CARTaGENE Investigators : Bartha Maria Knoppers, Ph.D. (Professor of Medicine, McGill University; Law, Université de Montréal), Claude Laberge, M.D., Ph.D. (Physician and Geneticist, Professor of Medicine, Université Laval and Université de Montréal), Philip Awadalla, Ph.D., (Population Genomics, Université de Montréal), Daniel Gaudet, M.D., Ph.D. (Professor of Medicine, Université de Montréal), Béatrice Godard, Ph.D. (Sociologist and Professor of Bioethics, Université de Montréal), Isabel Fortier, Ph.D. (Epidemiologist, Université de Montréal).

CARTaGENE Funding: Genome Canada, Génome Québec and the Canadian Partnership Against Cancer.

The goal of CARTaGENE is to establish a database and a biobank of biological samples for research in health and genomics. Your participation in CARTaGENE may help in the advancement of knowledge in genomics and contribute in the long term to better prevention, diagnosis and treatment of disease. *Thank you for reading the information brochure and for asking all the questions you may have about the project.*

By signing this consent form, I agree to participate in CARTaGENE and I declare that:

- I have read and understood the information brochure and that it was explained to me verbally to my satisfaction. I had the opportunity to ask all the questions I had and received satisfactory answers. I was given sufficient time to think and to make an informed decision regarding my participation.
- I agree to meet with a nurse or an interviewer to answer a detailed questionnaire regarding my health and lifestyle, to allow the nurse to take certain basic physical measures and to take a sample of my blood and urine.
- I agree that a representative of CARTaGENE may be present occasionally during this appointment to check the quality of the work done by the nurse or interviewer.
- I agree that my blood and urine samples be analysed by a laboratory designated by CARTaGENE and that the coded results of the analyses be transmitted to CARTaGENE.
- I understand that the results of the physical measures that the nurse will transmit to me at the end of my interview will be the only results that will be given to me. However, if the results of the analyses done on my samples by the healthcare facility where my appointment took place are not within the norms generally accepted such that my life might be in danger, I understand that a doctor will contact me within seven (7) days of the appointment to inform me.
- I understand that I will never have access to my data and samples stored in CARTaGENE.
- I accept that the data and blood and urine samples collected during the appointment be transmitted, in coded form, to CARTaGENE and to the *Biobanque Génome Québec–Centre hospitalier affilié universitaire régional de Chicoutimi* (Biobank GQ-CAUR).
- I accept that personal information about me contained in government databases be transmitted confidentially to CARTaGENE in coded form when needed for research in health and genomics. This information may cover the period from January 1st 1998 to the end of CARTaGENE.
- I agree that the data and samples stored by CARTaGENE be destroyed at the end of its activities on December 31st 2058 or if its funding ends prematurely, unless otherwise specified by the body responsible for ethics review and monitoring.
- I accept that my data and samples, once coded, be used by researchers in Quebec, Canada or other countries within a framework of biomedical research that has 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 by using the data and samples from CARTaGENE.
- I understand that after my death, my data and biological samples will not be withdrawn from CARTaGENE.
- I understand that my participation is completely voluntary and that I can withdraw at any moment without giving a specific reason by calling (toll-free): 1 877 263-2360. I authorize the CaG-RAMQ Service to inform CARTaGENE of the end my participation if I should withdraw.

Option : Check your answer with an X

Do you accept to be contacted again by the CaG-RAMQ Service or any other instance acting on CARTaGENE's behalf in the future for updates of your questionnaires, physical measures and/or samples or for new research projects? If so, you also agree that the CaG-RAMQ Service or any other instance acting on CARTaGENE's behalf obtain confidentially your information in order to be able to contact you. I accept ☐ I refuse ☐

Contact staff

For further information, you can:

- Visit CARTaGENE's website at www.cartagene.qc.ca
- Call the CaG-RAMQ Service:

1. toll-free at 1 877 263-2360; operators will be available Monday through Thursday, from 8:30 a.m. to 8 p.m., Friday, from 8:30 a.m. to 5 p.m., and Saturday, from 10 a.m. to 4 p.m.
2. write to: CaG-RAMQ Service, C.P. 14 500, Québec (QC) G1K 0B9
3. or send an e-mail to: service.cartagene@ramq.gouv.qc.ca

Any complaint regarding your participation in this research project can be addressed to the Ombudsman of the Université de Montréal at 514 343-2100 or by e-mail to ombudsman@umontreal.ca. The Ombudsman accepts collect calls.

By accepting to participate in this project, you do not waive any of your rights nor do you release the researchers or the establishments from their civil and professional responsibility.

Participant's signature

_____ Signature	_____ Date
_____ Last name	_____ First name

Representative from the healthcare facility

I have explained the present consent form to the participant and indicated that (s)he is free to withdraw from CARTaGENE at any moment. I gave a signed copy of the present form to the participant.

_____ Signature	_____ Date
_____ Last name	_____ First name

Accompanying person (where applicable)

I have helped the participant to better understand the information regarding the CARTaGENE project (translator, family member, person who has a special interest).

_____ Signature	_____ Date
_____ Last name	_____ First name

A signed copy of the present form must be given to the participant.

THE CARTaGENE TEAM

Principal Investigators

Bartha Maria Knoppers, Ph.D., Professor of Medicine, McGill University;
Law, Université de Montréal

Claude Laberge, M.D., Ph.D., Professor of Medicine, Physician and Geneticist,
Université Laval and Université de Montréal

Philip Awadalla, Ph.D., Population Genomics, Université de Montréal

Daniel Gaudet, M.D., Ph.D., Professor of Medicine, Université de Montréal

Béatrice Godard, Ph.D., Sociologist and Professor of Bioethics, Université de Montréal

Isabel Fortier, Ph.D., Epidemiologist, Université de Montréal

Partners

The **Université de Montréal** is the host institution for the project that is responsible for the overall project as well as for specific aspects such as data and sample security.

The **Régie de l'assurance maladie du Québec** (RAMQ) is involved in the random selection and recruitment of potential participants through the CARTaGENE-RAMQ Service (CaG-RAMQ Service).

The **Génome Québec-Centre hospitalier affilié universitaire régional de Chicoutimi Biobank** (GQ-CAURC Biobank) in Saguenay will store the blood and urine samples.

CARTaGENE is also part of a Canadian research infrastructure, the **Canadian Partnership for Tomorrow Project (CPTP)**.

Funding

CARTaGENE is financed by **Génome Québec** and **Genome Canada**, two public organisations that provide funding for scientific research in genomics, as well by the **Canadian Partnership Against Cancer (CPAC)**.



FOR MORE INFORMATION ON CARTaGENE:

- visit CARTaGENE's website at www.cartagene.qc.ca
- contact the CaG-RAMQ Service

by phone (toll-free) at 1 877 263-2360

Monday through Thursday, from 8:30 a.m. to 8 p.m.

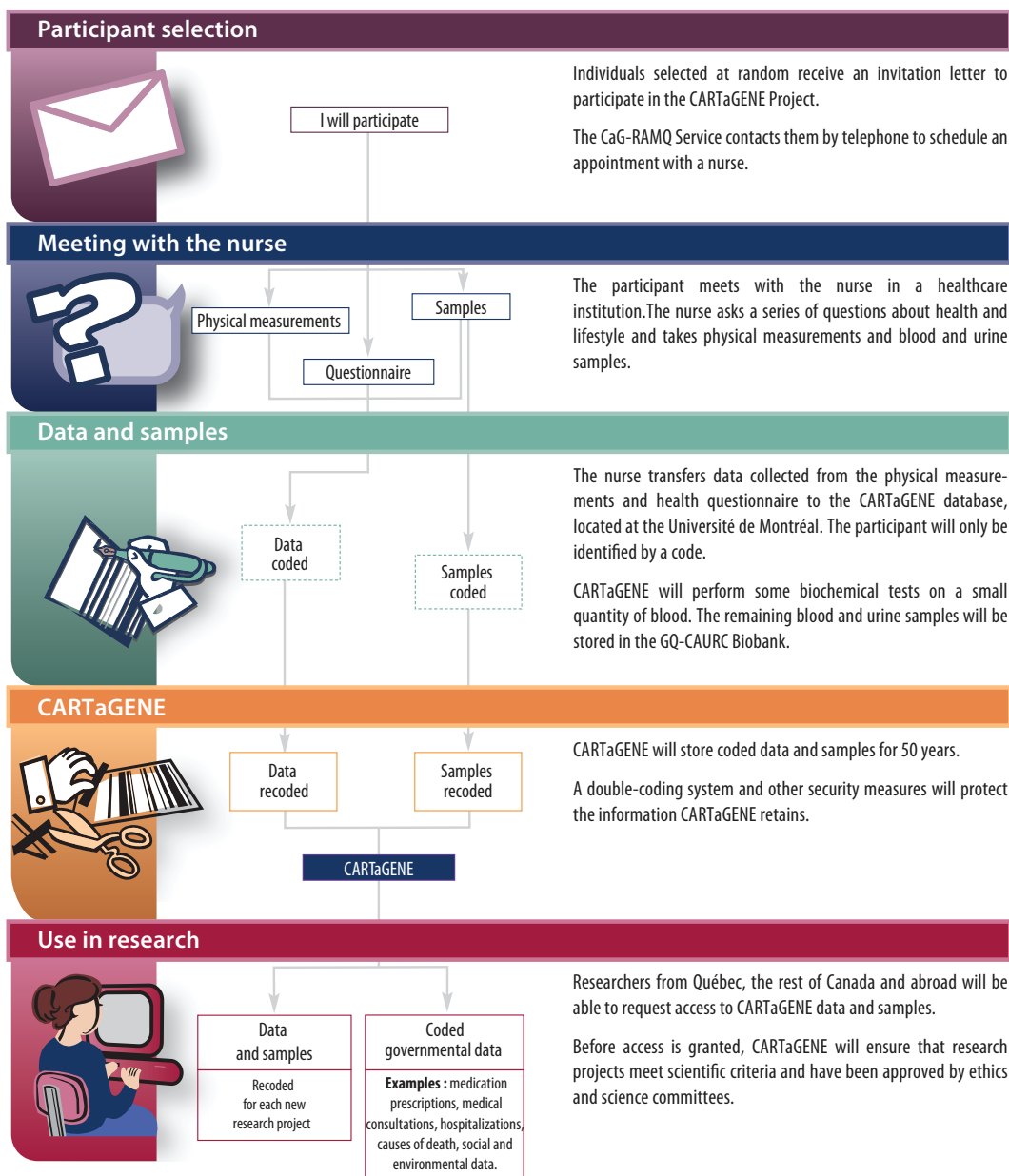
Friday, from 8:30 a.m. to 5 p.m.

Saturday, from 10 a.m. to 4 p.m.

write to: CaG-RAMQ Service, C.P. 14 500, Québec (QC) G1K 0B9.

send **an e-mail to:** service.cartagene@ramq.gouv.qc.ca

Flow chart of a participant in CARTaGENE





www.cartagene.qc.ca
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