



Family No.:

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Growing Up in Québec Study – 2022-2023 Sweep Consent Form



**Growing Up
in Québec**

Québec Longitudinal Study
of Child Development, 2nd edition

Study partners

Lucie and André Chagnon Foundation, Ministère de la Famille, Ministère de la Santé et des Services sociaux, Ministère de l'Éducation, Ministère du Travail, de l'Emploi et de la Solidarité sociale, Conseil de gestion de l'assurance parentale, and Institut de la statistique du Québec (Statistique Québec).

1. The study and its objective

This consent form relates to the *Growing Up in Québec* study conducted by Statistique Québec. The overall objective of this study is to collect data that will help us better understand the development and well-being of children until they reach adulthood (longitudinal study).

2. By participating in this study, I understand that:

- 2.1. The data collected in this study will be treated as CONFIDENTIAL in accordance with the *Act respecting the Institut de la statistique du Québec* (CQLR, chapter I-13.011) and the *Act respecting Access to documents held by public bodies and the Protection of personal information*;
- 2.2. My participation and that of my child are voluntary. We are therefore free to participate or not in the study, and we can withdraw at any time without penalty to us in any way;
- 2.3. If I withdraw from the study, all the data collected in the study will be kept in databanks, unless written notice to the contrary is submitted by me to Statistique Québec;
- 2.4. Data collection for this year includes:
 - 2.4.1. two paper questionnaires that take about 15 minutes each to complete, one about my child's language and communication development, and another about my child's overall development;
 - 2.4.2. a self-administered questionnaire to be completed online (or on paper) by each parent. This questionnaire takes about 30 minutes to complete. The questions will cover topics such as our health, some of our lifestyle habits, and our experience as parents;
 - 2.4.3. a computerized questionnaire lasting about 1 hour and 15 minutes that will be completed by a Statistique Québec interviewer during an interview (at home or remotely). The questions will focus on my selected child's development and environment (family, dwelling, childcare setting, etc.);
 - 2.4.4. weighing and measuring my child (only if the interview takes place at home);
- 2.5. My family will contribute to a better understanding of the processes underlying children's development, thus enabling more children to reach their full potential. The only drawback to my participation is the time spent answering the questionnaires.

3. By signing this form, I authorize Statistique Québec to:

- 3.1. **Invite me to participate** in each round of data collection, for the duration of the study or until I give notice to Statistique Québec that I am withdrawing from the study;
- 3.2. **Send the data** that has been collected as part of this study, without any identifying information (i.e., not revealing any name, address or telephone number), to the partners and collaborating researchers who will have committed to respecting Statistique Québec's data security and privacy standards (the list of researchers collaborating on the study can be provided to me upon request);
- 3.3. **Collect additional information from departments and agencies in order to keep in touch** with me and my child, that is obtain our contact information, including information that can facilitate communication, from departments and agencies holding this information, such as Retraite Québec, the Régie de l'assurance maladie du Québec, and the Ministère de l'Éducation;

- 3.4. **Collect additional information from departments and agencies in order to carry out statistical work** related to the study's overall objective, that is obtain administrative or survey data about me or my child in various areas, such as:
- health (e.g. Régie de l'assurance maladie du Québec, Ministère de la Santé et des Services sociaux, Québec Vaccination Registry)
 - education (e.g. Ministère de l'Éducation, school service centres, school boards)
 - government services (e.g. Québec Parental Insurance Plan, childcare, Family Allowance)
 - income (e.g. Revenu Québec)
- 3.5. Send information that can identify me or my child (e.g. first name, last name, sex, date of birth) to certain departments and agencies **only to obtain the data referred to in 3.3 and 3.4**. This information will only be used to obtain administrative data about me and my child. Once identification is complete, the information will be destroyed by these departments and agencies.
- 3.6. Match all of the de-identified information collected in the study in order to carry out statistical and research work. This work must be related to the study's overall objective.
4. **I hereby certify that I have read and understood this consent form. All my questions have been answered, and I have been given enough time to make my own decision. Consequently, by signing this form, I consent to participating in the study.**

CHILD

Child's first name (in capital letters)	Child's last name (in capital letters)

PARENT 1

Respondent's first name (in capital letters)	Respondent's last name (in capital letters)	
Relationship to the child:		
<input type="checkbox"/> Biological or legal mother	<input type="checkbox"/> Biological or legal father	<input type="checkbox"/> Legal representative
<input type="checkbox"/> Other (specify) _____		
	YYYY / MM / DD	
Respondent's signature	Date	

PARENT 2

Respondent's first name (in capital letters)	Respondent's last name (in capital letters)	
Relationship to the child:		
<input type="checkbox"/> Biological or legal mother	<input type="checkbox"/> Biological or legal father	<input type="checkbox"/> Legal representative
<input type="checkbox"/> Other (specify) _____		
	YYYY / MM / DD	
Signature	Date	



Family No.:

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Optional complementary round

Conservation of blood samples collected as part of the
Québec Neonatal Blood Screening Program

Your participation in *Growing Up in Québec* does not oblige you to take part in this round, which is **optional**.



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When your child was born, if you provided your consent, blood samples were collected from your child's heel to be screened for certain rare diseases as part of the Québec Neonatal Blood Screening Program (QNBSP). Statistique Québec is currently studying the possibility of recovering these samples. If the project goes ahead, we will require your consent for the storage and analysis of the samples. **No new blood samples will be collected as part of this complementary round.**

If the project goes ahead, I authorize Statistique Québec to:

- 4.1. **Provide** information that can identify my child to the Centre hospitalier universitaire de Québec, which keeps the blood samples collected when my child was born as part of the QNBSP;
- 4.2. **Store** the blood samples used in QNBSP for 25 years and use them for secondary research purposes;
- 4.3. **Make these samples available to researchers** for further laboratory analyses, solely for the purpose of conducting research relevant to the overall objective of the study. The researchers' projects will have to be submitted to and reviewed by Statistique Québec's ethics committee. This secondary use of the samples is not part of QNBSP;
- 4.4. **Match** the biological data resulting from the analysis of these blood samples with other information collected in the study. This data matching will be done solely to carry out analyses relevant to the overall objective of the study;
- 4.5. **Send** the matched data without any identifying information (i.e., not revealing any name, address or telephone number) to partners and researchers who will have committed to respecting Statistique Québec's standards regarding the security and confidentiality of information. The biological data will be treated as CONFIDENTIAL, in accordance with the *Act respecting the Institut de la statistique du Québec* (CQLR, chapter I-13.011) and the *Act respecting Access to documents held by public bodies and the Protection of personal information*.

I agree

I refuse

CHILD

<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Child's first name (in capital letters)</p>	<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Child's last name (in capital letters)</p>
<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Name of birthplace (in capital letters) (e.g. name of hospital or birthing center)</p>	<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">City of birthplace (in capital letters)</p>

PARENT

<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Parent or legal representative's first name (in capital letters)</p>	<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Parent or legal representative's last name (in capital letters)</p>
<p>Relationship to the child:</p> <p> <input type="checkbox"/> Biological or legal mother <input type="checkbox"/> Biological or legal father <input type="checkbox"/> Legal representative </p>	
<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">Signature</p>	<div style="border: 1px solid black; height: 20px; margin-bottom: 5px;"></div> <p style="text-align: center; margin: 0;">YYYY / MM / DD Date</p>

If you have any questions, please contact us by e-mail (growingupinquebec@stat.gouv.qc.ca) or by telephone (1-866-433-7828).