

2024

DATA MANAGEMENT FRAMEWORK*



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*In the event of any differences in translations or interpretations, the French version shall prevail.

Table of contents

1	<i>Preamble</i>	4
2	<i>Description of the BALSAC database</i>	4
2.1	Contents	4
2.2	Vocation	4
2.3	Data ownership	5
3	<i>Administrative management</i>	5
3.1	Managers	5
3.2	Management structure	5
3.3	Data retention and durability	6
3.4	Installations and equipment	6
4	<i>Data management</i>	6
4.1	Data processing	6
4.2	Access to raw data	6
4.3	Chance discoveries	6
5	<i>Access procedures for research purposes</i>	7
5.1	Access to data for research purposes	7
5.2	Access to vital statistics 100 years or older	7
5.3	Request management	7
5.3.1	Request for access by several researchers	7
5.3.2	Student access request.....	7
5.3.3	Request for access to confidential data.....	7
5.3.4	Request for access to non-confidential data	8
5.3.5	Access request involving a genealogical reconstruction option.....	8
5.3.6	Dataset definition	8
5.3.7	Data transfer.....	9
5.3.8	Follow-up with the researcher.....	9
5.3.9	Pricing	9
5.4	Data use by researchers	9
5.4.1	Responsibility of the principal investigator	9
5.4.2	Use of data by the research team.....	9
5.4.3	Data use period.....	9
5.4.4	Mention of data use	10
5.4.5	Modification of initial access request.....	10

5.4.6	Failure to comply with initial access request.....	10
5.5	Handling complaints and infringements	10
5.5.1	Handling complaints	10
5.5.2	Handling infringements	10
6	<i>Ethical follow-up.....</i>	10
7	<i>Review</i>	11
	<i>Appendix 1: List of peripheral files.....</i>	12
	<i>Appendix 2: BALSAC database access request form</i>	13
	<i>Appendix 3: Project modification form for the BALSAC database</i>	18
	<i>Appendix 4: Commitment form for access to BALSAC database data.....</i>	21
	<i>Appendix 5: Commitment form for Balsac Project staff concerning access to data in the BALSAC database</i>	22
	<i>Appendix 6: Sample information and consent form for the genealogical component of a research project</i>	23
	<i>Appendix 7: Sample genealogical questionnaire.....</i>	25

1 Preamble

The BALSAC (pronounced “Balzac”) population database is a demographic database of the Quebec population. It has been under development since 1972 at the Université du Québec à Chicoutimi (UQAC). The database is managed by the BALSAC Project, a research infrastructure that coordinates all work relating to the operation, development, exploitation and enhancement of the BALSAC database.

As stipulated in *the BALSAC Project Agreement*, signed in April 2011, the BALSAC Project management is mandated to implement all procedures for the protection of personal information and access to data contained in the BALSAC database¹.

The purpose of this data management framework is to inform file users and BALSAC Project staff of the principles and rules governing the management of and access to BALSAC database data, including privacy issues.

Persons granted access to BALSAC data are responsible for complying with their commitments, as well as with the conditions and directives attached to the access they have been granted.

2 Description of the BALSAC database

2.1 Contents

This management framework covers all the data making up the BALSAC database, *i.e.* the computerized database operated using the BalNet interface, the peripheral files (see [Appendix 1: List of Peripheral Files](#)) and the archives, which include all the paper documents linked to the historical construction of the BALSAC database.

The data in the BALSAC database comes mainly from Quebec civil registry records. These records have been computerized and linked together using a nominative data matching methodology, enabling the automatic reconstitution of individual and family biographies, as well as genealogical lineages. The file is built on a relational database model, linking data by a unique identifier principle. The temporal scope of the data is consistent with the record of deeds from the settlement of the first Europeans in New France in the 17^e century, to the present day. The file also contains genealogical data collected as part of research projects. These data were provided by project participants or found in sources other than the Quebec civil registry.

So-called peripheral files are also included in the BALSAC database. These peripheral files contain socio-cultural and economic data on the population of the Saguenay-Lac-Saint-Jean region, compiled in the early decades of the BALSAC database. These files are not all digitized, but are subject to the same management, conservation and loan procedures as the rest of the BALSAC data (see [Appendix 1: List of peripheral files](#)).

The main data contained in the BALSAC database are nominal (surnames, first names, professions, places, etc.), numerical (dates, ages, etc.) or geographical (coordinates linked to places of registration of deeds and declared residences). Some of this data is confidential, and access to it is governed by specific measures described in section [5.3.6 Dataset definition](#).

2.2 Vocation

The use and exploitation of the file is aimed at the production and enhancement of scientific knowledge. Access to the data in the file is reserved for individuals working in a scientific research context, carried out in an ethical and disinterested framework, without any consequence of interference in the private lives

¹ I-C-242 BALSAC 2011 framework agreement - Clauses 5.1.4 and 5.2.1

of others, and without any interest in commercial, personal or abusive use of the information. Under no circumstances may the BALSAC database be used for commercial purposes. Similarly, no participant or subject may profit from the integration of his or her genealogical information within the BALSAC database as part of a research project.

If a change of vocation is envisaged, an amendment to the present Management Framework will be produced and submitted to the CER-UQAC for approval. The application must provide a detailed explanation of the proposed changes and the reasons for them.

2.3 Data ownership

Ownership of the BALSAC data is shared by three universities: Université Laval, Université de Montréal and Université du Québec à Chicoutimi. It is governed by the *Entente interuniversitaire relative au Projet BALSAC*².

3 Administrative management

3.1 Managers

UQAC oversees the day-to-day management of the file through the BALSAC Project Management, as mandated by the *Entente interuniversitaire relative au Projet BALSAC*³.

The BALSAC Project is managed by its director, who is responsible for preserving, developing, promoting and exploiting the BALSAC database. The director's duties and responsibilities are defined in the *Entente interuniversitaire relative au Projet BALSAC*⁴.

3.2 Management structure

The management is supported in the execution of the various components of its mandate by a steering committee. The composition of the committee, comprising at least one DSHS professor and at least one DSF professor, is as follows:

- BALSAC director;
- the BALSAC Project coordinator;
- two to four UQAC professors.

The BALSAC Project management mandates the data access committee to evaluate requests for access to the file, monitor approved projects and accredit staff and researchers who have been granted access. The data access committee is made up of the following members:

- a representative of the steering committee;
- the person in charge of the BALSAC Project's Researchers service;
- a member appointed by the University's research ethics board (CER-UQAC);
- two to four UQAC professors from at least two different departments (may be a member of the steering committee).

Members of both committees are appointed by BALSAC management. In Quebec, committee members act in the same way as a trustee with respect to the data held by the committee.

² I-C-242 Entente cadre universités partenaires BALSAC 2011- Clauses 4

³ I-C-242 Entente cadre universités partenaires BALSAC 2011 - Clauses 5.1.3 and 5.1.4

⁴ I-C-242 Entente cadre universités partenaires BALSAC 2011 - Clauses 5.1.4

3.3 Data retention and durability

The duration of data retention is relative to the proper functioning and long-term management of the host infrastructure. Should the BALSAC Project no longer be able to fulfill this mandate, a continuity plan will be implemented by UQAC, in accordance with the CER-UQAC, so that another body can take over.

3.4 Installations and equipment

The facilities and equipment of the BALSAC database are housed within UQAC's IT infrastructure. The security of the file's data is ensured by several physical, IT and structural measures. Physical access to the archives and computer equipment of the BALSAC Project is governed by all security measures applicable to UQAC buildings.

4 Data management

4.1 Data processing

Data processing is carried out by staff employed by the BALSAC Project. The work consists of adding, verifying or correcting data, as well as matching nominative data or genealogical reconstructions. Any other related operation carried out with the aim of preserving or improving the integrity of the information contained in the file may also be considered.

Any exceptional or unprecedented correction operation involving the deletion of data or the permanent transformation of the structure or information contained in the file must be authorized in advance by the steering committee.

4.2 Access to raw data

Access to the BALSAC database, i.e. to the raw data and the file's IT infrastructure, is restricted to BALSAC staff and members of the Steering Committee. Access conditions vary according to the responsibilities of each employee, as detailed in the document *Gestion interne du projet BALSAC*⁵. At all times, these procedures respect the confidentiality of the data and the purpose of the BALSAC database. BALSAC Project staff and steering committee members are required to sign the confidentiality commitment form presented in [Appendix 5: BALSAC Project staff commitment form concerning access to BALSAC database data](#).

Researchers and other professionals are not authorized to access raw data, except in the case of exceptions related to the development of the file and with the authorization of the steering committee.

4.3 Accidental discoveries

Any accidental discovery made by BALSAC Project staff while preparing a dataset will be communicated to the principal investigator registered on the access request. In return, any discovery allowing a correction of the data in the BALSAC database, made within the framework of a data loan, should be communicated, by the principal investigator, to the person responsible for the BALSAC Project researcher service.

⁵ Internal management of the BALSAC project (working title)

5 Access procedures for research purposes

5.1 Access to data for research purposes

Researchers may be granted access to data for research purposes if their request is consistent with the purpose of the file, as described in section [2.2 Vocation](#). It is up to the data access committee, as named in section [3.2 Management structure](#), to determine whether access is admissible and relevant.

This access takes the form of a loan of a set of data extracted from the file and sent to the principal investigator via the Researchers service. No researcher has direct access to the BALSAC database.

5.2 Access to vital statistics 100 years or older

An access request that concerns only vital statistics data 100 years old or more will first be redirected to the *Infrastructure intégrée des microdonnées historiques de la population du Québec* (IMPQ)⁶, which contains data from the BALSAC database going back 100 years or more. If the IMPQ portal is unable to respond to the access request, it will be treated as a request for access to the BALSAC database, as described in section [5.3.3 Request for access to non-confidential data](#).

5.3 Request management

The BALSAC Project Researchers service is responsible for managing and processing requests for access to BALSAC data. A request for access must be submitted to the Researchers service using the access request form, presented in [Appendix 2: BALSAC database access request form](#), available on the BALSAC Project website. The request must clearly name the project's principal investigator and, if applicable, the team member(s) who will be in charge of communicating with BALSAC's Researchers service. The request for access must contain a description of the project concerned and meet the admissibility criteria presented on [the BALSAC Project website](#).

Each request for access to BALSAC data is examined by the members of the data access committee, as mentioned in point [5.1 Access to data for research purposes](#). The committee may approve or refuse access. It also has the power to grant access subject to certain modifications to the initial access request.

Each request must be formally approved by members of the data access committee before the data can be forwarded to the principal investigator.

5.3.1 Request for access by several researchers

A request for access may be made by a team of researchers, but it must specify the member acting as the project's principal investigator. The principal investigator signs all documents and acts as the project's ethical and scientific leader.

5.3.2 Student access request

A request for access may be submitted by a student, but it must be overseen by a research supervisor affiliated with the student's home institution. This person is considered the researcher responsible for the request for access. He or she signs all documents and acts as the project's ethical and scientific manager.

5.3.3 Request for access to confidential data

Confidential data is information enabling the re-identification of individuals linked to events that took place less than 100 years ago. Any request for access to confidential data must be accompanied by approval from the research ethics committee of the principal investigator's institution.

⁶ [Infrastructure intégrée des microdonnées historiques de la population du Québec \(cieq.ca\)](#)

The person in charge of Researchers service is responsible for verifying that this certificate has been obtained before submitting the access request to the data access committee. The committee reserves the right to consult CER-UQAC if it has any questions concerning the decision rendered by the ethics committee of the researcher's home institution. In all cases, the decision must comply with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans⁷.

5.3.4 Request for access to non-confidential data

Non-confidential data is information about individuals linked to events that took place 100 years ago or more. Information on individuals linked to events that took place less than 100 years ago, but which does not allow these individuals to be re-identified, also constitutes non-confidential data.

Any request for access to non-confidential data must specify the period covered and the variables requested, so that the data access committee can ensure that the confidentiality of the data and the non-traceability of the individuals concerned are respected.

5.3.5 Access request involving a genealogical reconstruction option

Access requests involving a genealogical reconstruction option presuppose a list of proposers (starting points for genealogies). When this list of recruited proposers concerns contemporary individuals, for example as part of a medical or genetic research project, the principal investigator is responsible for demonstrating that they have obtained the informed consent of the participants to the genealogical reconstruction option of their research protocol. This consent must specify that the genealogical information collected from participants will be definitively integrated into the BALSAC database and will be managed, in the future, in the same way as all other data in the file, as governed by this Management Framework. The person in charge of Researchers service may refer the principal investigator to a suggested wording for inclusion in the consent form, as presented in [Appendix 6: Sample information and consent form for the genealogical component of a research project](#). It is also advisable to use the computerized genealogical form, as proposed in [Appendix 7: Model genealogical questionnaire](#), to collect genealogical data from participants.

Requests for access that do not concern a list of contemporary proposers, or concern only non-confidential data, do not need to be accompanied by a consent form.

5.3.6 Dataset definition

The dataset consists of a defined selection of individuals and variables that meet the objectives of the project described in the access request approved by the data access committee. When defining the dataset, the Committee is responsible for specifying the measures to be applied in preparing the dataset to ensure the protection of personal information included in the BALSAC database.

These measures can be a restrictive selection of the variables making up the dataset, a reduction in the level of precision of the variables, anonymization of the data or recoding of the identifiers. The strategy employed, which may include one or more of these measures, depends on the research project and must be chosen with a view to striking a balance between protecting the confidential nature of certain data and developing scientific knowledge. The confidentiality measures governing loans of data from the file are determined in such a way as to meet the requirements prescribed by the *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels* (L.R.Q., c. A-2.1)⁸ and the

⁷ [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS 2 \(2022\)](#)

⁸ [A-2.1 - Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels \(gouv.qc.ca\)](#)

Loi sur les archives (L.R.Q., c. A-21.1)⁹ ; as well as the *Politique d'éthique de la recherche avec des êtres humains de l'Université*¹⁰. In case of doubt, the data access committee may refer to CER-UQAC.

5.3.7 Data transfer

All data transfer procedures are discussed between the person in charge of Researchers service and the project's principal investigator, to accommodate all parties. At all times, the chosen transfer medium and format must ensure the integrity and confidentiality of the transferred data. The dataset is extracted from the BALSAC database and processed as required, as described in the previous section. A copy of this dataset is kept in the Researchers service files for future reference.

5.3.8 Follow-up with the researcher

Any follow-up with the principal investigator must be carried out by e-mail exchange via the investigator's institutional address, enabling the exchange to be followed up and archived permanently in the BALSAC databases.

5.3.9 Pricing

A fee is charged for each loan of data. The current rates are available on [the BALSAC website](#).

5.4 Data use by researchers

5.4.1 Responsibility of the principal investigator

The data, once extracted and transmitted to the principal investigator, is the latter's ethical and legal responsibility. The principal investigator is also responsible for ensuring data integrity and confidentiality. The principal investigator must complete the researcher's commitment Form, which sets out the rights and responsibilities to which he or she is committed (see [Appendix 4: Commitment Form for access to BALSAC data](#)).

5.4.2 Use of data by the research team

The principal investigator is morally and ethically responsible for the use of the data by all members of his or her research team and individuals who will have access to the data while carrying out the research project. The principal investigator is also responsible for controlling access to the data, and for limiting its use to the purposes for which access was initially granted by the BALSAC data access committee.

5.4.3 Data use period

The period of data use is five years from the date the dataset is sent to the principal investigator. This period may be extended indefinitely for a maximum of five years at a time, provided that a formal request is made to the Researchers service, accompanied by a renewal of the project's ethics approval if applicable. Requests for extension are approved by the data access committee.

If the person in charge of Researchers service is unable to contact the researcher, or that his or her attempts at communication go unanswered, he or she reserves the right to close the researcher's file with BALSAC and consider it closed. In this case, the file will be forwarded to the person in charge of responsible conduct in research (PCCRR de l'UQAC) in accordance with the *Politique relative à la conduite responsable en recherche et en création de l'UQAC*¹¹.

⁹ [A-21.1 - Loi sur les archives \(gouv.qc.ca\)](#)

¹⁰ [Politique d'éthique de la recherche avec des êtres humains | Manuel de gestion \(uqac.ca\)](#)

¹¹ [Politique relative à la conduite responsable en recherche et en création | Manuel de gestion \(uqac.ca\)](#)

5.4.4 Mention of data use

The principal investigator and his/her research team must mention the use of the BALSAC database in their publications or presentations as presented on the [BALSAC Project website](#). Research results resulting from the use of BALSAC data, excluding the data itself, remain the property of the researcher.

In addition, the principal investigator must send the BALSAC Project a list of publications and communications based on data in the BALSAC database. Whenever possible, researchers are encouraged to provide the BALSAC Project with a computerized copy of their published article.

5.4.5 Modification of initial access request

Once a request has been accepted by the data access committee, any modification to a project must be the subject of a modification request. This request must be made by filling in the appropriate form (see [Appendix 3: BALSAC project modification form](#)) and sending it by e-mail to the head of Researchers service by the project's principal researcher. It must indicate which elements of the initial access request have changed and, where applicable, must be accompanied by the approval of the REB of the principal investigator's institution approving these modifications. These requests are managed by Researchers service and must be approved by the data access committee. The committee reserves the right to refuse any modifications to the initial access request.

5.4.6 Failure to comply with initial access request

In the event of a breach or non-compliance with the terms and conditions of data use, particularly regarding confidentiality, the principal investigator's file will be communicated to the UQAC person in charge of responsible conduct in research (PCCRR) in accordance with the *Politique relative à la conduite responsable en recherche et en création de l'UQAC*¹².

5.5 Handling complaints and infringements

5.5.1 Handling complaints

Any complaint from a researcher concerning a problem related to data access or quality must first be addressed in writing to the person in charge of the BALSAC Project Researchers service. The complaint will be handled by the data access committee, which will act if necessary.

5.5.2 Handling infringements

Anyone aware of a breach of the rules and policies relating to the development, operation and use of the BALSAC database should inform the data access committee. The committee will forward the file to the person in charge of responsible conduct in research (PCCRR de l'UQAC) in accordance with the *Politique relative à la conduite responsable en recherche et en création de l'UQAC*.¹³

6 Ethical follow-up

CER-UQAC has approved this Management Framework and is monitoring its implementation. This version of the Management Framework takes effect on the date of approval. Thereafter, all modifications to this Framework will take effect on the date of approval by CER-UQAC.

To ensure follow-up following approval of this management framework, those responsible for the file undertake to inform CER-UQAC in writing, as soon as possible, of the following situations should they arise:

- Any changes to the Management Framework, as approved, prior to implementation.

¹² [Politique relative à la conduite responsable en recherche et en création | Manuel de gestion \(uqac.ca\)](#)

¹³ [Politique relative à la conduite responsable en recherche et en création | Manuel de gestion \(uqac.ca\)](#)

- Any unforeseen and serious event occurring during activities related to this Management Framework and affecting the fulfillment of commitments to participants, or in the case of a breach of confidentiality.
- Any change in the purpose of the file or its managers.
- Any change in the list of people with privileged access to raw genealogical data.

The annual renewal of ethical certification will be presented to CER-UQAC.

7 Review

A revision of the Management Framework is undertaken as required, or at least every 5 years. If no revision is made within the allotted time, the last version approved by the CER-UQAC remains in force.

Appendix 1: List of peripheral files

Computerized files

- The religious of Saguenay
- ALCAN workers (Arvida)
- Immigrant Place of Origin File
- Employees of Compagnie Price
- Adoption records, Saguenay (1945-1971)
- Pionniers du Saguenay (memoirs of SHS/ANQ)
- Interviews on social and professional mobility
- Property assessment rolls (1879-1949)
- Wedding contracts
- Notarial deeds relating to indebtedness (1846-1950)
- Students of the Petit Séminaire de Chicoutimi
- Local socio-political elites (1874-1947)
- Proceedings of the Bureau de la Statistique du Québec, Saguenay (1971-1986)

Non-computerized files

- Saguenay Criminals
- Deeds of donation
- Family transmission (urban areas)

Appendix 2: BALSAC database access request form

1. GENERAL INFORMATION				
Project title				
Data access schedule				
Start date				
End date				
Project principal investigator				
Status: <input type="checkbox"/> PROFESSOR <input type="checkbox"/> POSTDOCTORAL FELLOW <input type="checkbox"/> GRADUATE STUDENT				
Last name, First name				
Establishment				
Phone				
E-mail				
Responsible researcher <i>(For requests from postdoctoral fellows or students)</i>				
Last name, First name				
Establishment				
Phone				
E-mail				
Research team members <i>(List all people who will have access to the data, including students)</i>				
Last name, First name	Role	E-mail	Establishment	Contact
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input checked="" type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
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				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO

2. RESEARCH PROJECT DESCRIPTION

Project summary

Include hypothesis and objectives, human subjects to be researched and methodology employed.

3. RESEARCH PROJECT FUNDING

Confirmed	
Requested	

4. DATA REQUESTED FROM THE BALSAC DATABASE

Basic genealogical file
It includes the following variables: *Individual ID; Individual gender; Individual father ID; Individual mother ID; Parents' place of marriage; Parents' date of marriage; Migration status; Place of origin; Proposer identification key.*

Personalized genealogical file
A brief justification must accompany the request for each variable requested. To be attached to the request.

Additional variables:

- Individual's date of birth
- Date of first marriage
- Individual's date of death
- Individual's place of birth
- Place of first marriage
- Individual's place of death

Variables calculated on a genealogical corpus:

- Number of genealogies in which the individual appears
- Number of occurrences of the individual
- Individual's total genetic contribution
- Minimum generation in which the individual appears
- Maximum generation in which the individual appears
- Average generation where the individual appears

Custom dataset(s)
Enter a list of requested variables. A brief justification must accompany the request for each variable requested. To be attached to the request.
(The list of variables available in the BALSAC database can be found at the following Internet address: <https://balsac.uqac.ca>)

Would you like to receive the BALSAC genealogy questionnaire template?
 YES (*Excel format*) YES (*RedCap format*) NO

5. USE OF DATA EXTERNAL TO THE BALSAC DATABASE

As part of your research project, do you intend to use data from a cohort or database other than the BALSAC database? YES NO

Specify cohort or database:

- CARTaGENE
- Quebec Regional Reference Sample (ERRQ)
- Other :

Specify the nature of the data to which you have access:

Have you already obtained approval to work with this cohort or dataset?
 YES NO (*If yes, include confirmation as an attachment to your application.*)

6. DOCUMENT TO ENCLOSE WITH APPLICATION

Ethical certification

Your access request must be accompanied by an approval from your current institutional REB if it concerns confidential data.

Genealogical questionnaires and consent form

In the case of genealogical reconstruction, your request must be accompanied by the genealogical questionnaire template used to collect data from study participants, as well as the consent form presented to them authorizing the integration of their genealogical data into the BALSAC database.

Justification of requested variables

Justification is required for genealogical files and customized datasets.

Confirmation of access to a cohort or dataset other than BALSAC database data

If your research project uses data from a cohort or database other than the BALSAC database, include your authorization to access the data with this request.

Signature of principal investigator

Date

Signature of responsible researcher

(for requests from postdoctoral fellows and students)

Date

Appendix 3: Project modification form for the BALSAC database

7. GENERAL INFORMATION	
Project title	
Modification request date	
8. REASONS FOR PROJECT MODIFICATION	
<input type="checkbox"/> Data access extension → Complete section 2.1	
<input type="checkbox"/> Modification of the project's principal investigator → Complete section 2.2	
<input type="checkbox"/> Add member(s) to research team → Complete section 2.3	
<input type="checkbox"/> Modification of team members authorized to communicate with the BALSAC Project. → Complete section 2.3	
<input type="checkbox"/> Adding new variables or modalities → Complete section 2.4	
<input type="checkbox"/> Adding new proposers or a new population cohort → Complete section 2.5	
<input type="checkbox"/> Renewal of ethics certificate → Attach certification	
<input type="checkbox"/> Other reason for modification: → Complete section 2.6	
2.1 Data access schedule	
Previous end date :	
New end date :	
2.2 Senior researcher	
Former senior researcher	
Last name, First name	
Establishment	
Phone / E-mail	
New principal investigator	
Status: <input type="checkbox"/> PROFESSOR <input type="checkbox"/> POSTDOCTORAL FELLOW <input type="checkbox"/> GRADUATE STUDENT	
Last name, First name	
Establishment	
Phone / E-mail	
Responsible researcher <i>(For requests from postdoctoral fellows and students)</i>	
Last name, First name	
Establishment	
Phone / E-mail	

2.3 Changes to the research team				
Last name, First name	Role	E-mail	Establishment	Contact
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO
				<input type="checkbox"/> YES <input type="checkbox"/> NO

2.4 Adding variables	
<input type="checkbox"/> Adding variables to a genealogical file <i>(A brief justification is requested for additional variables. To be attached to the request)</i>	
Additional variables: <input type="checkbox"/> Individual's date of birth <input type="checkbox"/> Date of first marriage <input type="checkbox"/> Individual's date of death <input type="checkbox"/> Individual's place of birth <input type="checkbox"/> Place of first marriage <input type="checkbox"/> Individual's place of death	Variables calculated on a genealogical corpus: <input type="checkbox"/> Number of genealogies in which the individual appears <input type="checkbox"/> Number of occurrences of the individual <input type="checkbox"/> Individual's total genetic contribution <input type="checkbox"/> Minimum generation in which the individual appears <input type="checkbox"/> Maximum generation in which the individual appears <input type="checkbox"/> Average generation where the individual appears
<input type="checkbox"/> Adding variables to a personalized dataset <i>Enter a list of requested variables. A brief justification must accompany the request for each variable requested. To be attached to the request.</i> <i>(The list of variables available in the BALSAC database can be found at the following Internet address: https://balsac.uqac.ca)</i>	

2.5 Adding new proposers or a new cohort	
<i>Attach a list of all proposers to be included in your dataset, including former proposers. The file must contain the following information: Nominator identification key; Pedigree or family identification key (where applicable); New nominator or original cohort nominator.</i>	
If these proposers come from an existing cohort, do you have permission to use this data? <input type="checkbox"/> YES <input type="checkbox"/> NO <i>(If yes, attach confirmation to this application.)</i>	
Name of cohort	
Institution / Person responsible for the cohort	
Contact	

2.6 Reason for modification other
<i>Explanation of reason and justification for change request</i>

9. DOCUMENT TO ENCLOSE WITH APPLICATION

Ethical certification renewed and compliant with the modifications presented in this form.

A request for access to confidential data must be accompanied by approval from your institutional REB.

Genealogical questionnaires and consent form

In the case of genealogical reconstruction, your request must be accompanied by the genealogical questionnaire template used to collect data from study participants, as well as the consent form presented to them authorizing the integration of their genealogical data into Fichier BALSAC.

Justification of requested variables

Justification is required for custom genealogy files and custom datasets.

Authorization to use a proposer cohort

For the use of proposers from a biobank, a patient cohort or a reference sample that has already been composed, please attach to this request the authorization of the institution or person responsible for these data.

Signature of principal investigator

Date

Signature of initial principal investigator
(for requests concerning a change of principal investigator)

Date

Signature of responsible researcher
(for applications from postdoctoral fellows and students)

Date

Appendix 4: Commitment form for access to BALSAC database data

Principal investigator : _____

Project title : _____

As principal investigator, I declare that I have read the BALSAC database management framework and agree to comply with it. I also undertake to :

- Keep a list of those who use the data and provide them with the information they need to comply with this commitment;
- Do not claim intellectual property rights on data extracted from the BALSAC database.
- To use the data exclusively for the realization of the project that I have submitted and that has been approved by the BALSAC Project data access committee;
- Not to redistribute the data provided to me under this agreement;
- Acknowledge the use of data from the BALSAC database in any activity involving the dissemination of results resulting from analyses made using data from this file, in accordance with the appropriate citation model presented on our website at <https://balsac.uqac.ca/citer-balsac/>.)
- Inform the BALSAC Project of any production resulting from the data received (scientific articles, book chapters, research reports, posters, communications, writings for the popularization of science and the transfer of knowledge, dissertations or theses).
- Destroy the data covered by this agreement no later than five years after the signing of this commitment or submit a request for an extension.

In witness whereof, I have signed at _____ this _____
20__.

Signature of principal investigator: _____

Signature of responsible researcher: _____
(for applications from postdoctoral fellows and students)

Appendix 5: Commitment form for Balsac Project staff concerning access to data in the BALSAC database

Name of employee: _____

Job title: _____

As an employee of the BALSAC Project, I declare that I have read the BALSAC database management framework and that I will comply with it. I also undertake to :

- Respect the confidentiality of the information in the BALSAC database to which I have access;
- Not to divulge, reproduce or use, in any way whatsoever, the information in the BALSAC database to which I have access other than for the professional purposes for which it was communicated to me;

In witness whereof, I have signed at _____ this _____
20 .

Signature : _____

Appendix 6: Sample information and consent form for the genealogical component of a research project

Information and consent form for the genealogical component of the project entitled [project title].

Description of the BALSAC Project and data use

As part of this study, it may be necessary to reconstitute your genealogy, and to do this, we will be asking for the collaboration of the BALSAC Project. BALSAC is a computerized file based on Quebec civil status records. It enables the automatic reconstitution of genealogies throughout Quebec, tracing ancestors back to the early 17th century. It has been used for scientific research for over 50 years and was developed at the Université du Québec à Chicoutimi, in partnership with Université Laval and Université de Montréal.

Based on the information you provide in the genealogical questionnaire, BALSAC Project staff will reconstruct your genealogy and compare it with that of other participants or witnesses. Your reconstructed genealogy, in anonymized form, will be forwarded to the person responsible for this research, where it will be treated in the strictest confidence.

Confidentiality principles of the BALSAC Project

Your genealogical questionnaire will only be accessible to authorized BALSAC Project personnel and will be treated in the strictest confidence. At Projet BALSAC, physical and computer security measures are in place to protect the confidentiality of personal information.

Your personal information will never be shared with the general public, insurers, bank managers, other credit institutions or employers, in accordance with the BALSAC database Management Framework.

No medical or genetic data about you will be passed on to the BALSAC Project.

For more information about the BALSAC Project, please visit our website: <http://balsac.uqac.ca/>

Voluntary participation and withdrawal

Your participation in the genealogical component of this project is entirely voluntary. If you decide to participate, you may withdraw at any time by contacting *** *to be completed by researcher* *** to request the destruction of your genealogical questionnaire held at the BALSAC Project.

It is understood that once your genealogy has been reconstituted, it will become an integral part of the BALSAC database. Your individual data may be removed from the BALSAC database, but the data concerning your ancestors will remain in the file. It will then be governed by the current Management Framework governing the BALSAC database, which authorizes the use of the file's data for other research projects duly authorized by the data access Committee.

Disadvantages and benefits

The main disadvantage of participating in the genealogical component is the time required to complete the genealogical questionnaire.

You will not derive any direct benefit from participating in the genealogical aspect of this research. However, your participation may contribute to a better understanding **** to be completed by the researcher ****.

Consent clauses

- I have read and understood the information concerning the genealogical aspect of the research;
- I had the opportunity to ask all the questions I needed to understand my participation in the genealogical section and to obtain answers to my satisfaction;
- I've taken enough time to reflect and make a decision about my participation in the genealogy section;
- I agree to transmit my genealogical questionnaire to the BALSAC Project at the Université du Québec à Chicoutimi to enable the reconstitution of my genealogy;
- I understand that my genealogy reconstructed by BALSAC Project staff will be used for scientific research purposes in accordance with the BALSAC database Management Framework.

Appendix 7: Sample genealogical questionnaire

Excel format, see: "Sample Genealogy Questionnaire.xlsm".

Or

RedCap format, see: "RedCap genealogical questionnaire".