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## Opinion of the Comité d'éthique de santé publique

### Qaniuppitaa? How are we? Proposed Health Survey of the Inuit of Nunavik — 2004

June 2004

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**Coordination**

France Filiatrault

**Analysis and writing**

Lynda Bouthillier and France Filiatrault

**Secretariat**

Marie van Vloodorp and Danielle Comtois

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Secrétariat du Comité d'éthique de santé publique  
201, boulevard Crémazie Est  
Bureau RC-03  
Montréal (Québec) H2M 1L2  
Telephone: (514) 873-4622  
Fax: (514) 864-2900

[www.msss.gouv.qc.ca/cesp](http://www.msss.gouv.qc.ca/cesp)

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Given that the population of Nunavik speak Inuktitut and English, the CESP took the initiative, on an exceptional basis, of translating the present opinion into English in order to make it more accessible to the population targeted by the survey.

The Comité d'éthique de santé publique (CESP, Public Health Ethics Committee) is established by the Public Health Act (R.S.Q., chapter S-2.2), which specifies its mandate, composition and certain elements related to its functioning. Sections 19 to 32 on the ethics committee came into effect on February 26, 2003. On the same day, the Government appointed the first members of the CESP.

The Comité d'éthique de santé publique plays a consultative role and its mandate includes two major components. A general component consists in responding to the Minister's requests for an opinion on any ethical question that may arise in the application of the Public Health Act, in particular, on the activities or actions provided for in the national public health program. A specific component consists in systematically examining the proposed surveillance plans or surveys on health and social issues submitted to it by the Minister or public health directors as part of their responsibilities for ongoing surveillance of the health status of the population and of health determinants. In accordance with the Minister's expectations, the requests of the national public health director are considered to be the same as those of the Minister.

The CESP favours providing support to the directors of the projects submitted for its attention in order to foster the integration of an ethical perspective in the updating of public health functions.

### Composition of the Comité d'éthique de santé publique<sup>1</sup>

<b>Éthicist</b>	<b>Mr. Daniel Weinstock</b> , Chair of Committee Professor of Philosophy and Ethics, Université de Montréal Director, Centre de recherche en éthique de l'Université de Montréal (CREUM)
<b>Representatives of the population (3)</b>	<b>Mr. Désiré Brassard</b> , Vice-chair of Committee Retired teacher
	<b>Ms. Ghislaine Cournoyer</b> Retired teacher
	<b>Ms. Catherine Régis</b> Lawyer, LL.M.
<b>Professionals practising in the public health sector, one of whom in public health surveillance (2)</b>	<b>Ms. Aline Émond</b> (professional in surveillance) Department Head, methodological support and evaluation at the Estrie Local Health and Social Services Network Development Agency
	<b>Ms. Suzanne Walsh</b> , Acting Executive Director, Côte-des-Neiges CLSC
<b>Public health director</b>	<b>Dr. Philippe Lessard</b> Director of public health, planning and evaluation at the Chaudière-Appalaches Local Health and Social Services Network Development Agency

### Secretariat of the Comité d'éthique de santé publique

<b>Ms. France Filiatrault</b>	Secretariat Coordinator and Secretary of the Comité d'éthique de santé publique
<b>Ms. Lynda Bouthillier</b>	Research and Socio-Economic Planning Officer
<b>Ms. Marie van Vloodorp</b>	Secretary

1. Based on paragraphs 1 to 4 of Section 23 of the Public Health Act.



## Foreword

The Comité d'éthique de santé publique chooses to carry out its consultative mandate by providing ethics support service to the directors of the projects that are submitted for its opinion. The current project, like the requests made to the CESP during its first year of operation, relates to the component of its mandate that involves the systematic examination of the proposed surveillance plans or surveys for surveillance purposes.

Given that the ethical examination of these projects is a new process, the CESP decided to produce its opinions in such a way that they can be used as a guide for all the tools of the surveillance function.

From a pedagogical perspective and in accordance with the way it sees itself as playing a supportive role, the CESP's opinion reports on the ethical process carried out jointly with the directors of the *Health Survey of the Inuit of Nunavik 2004*. Thus, the CESP not only gives its opinion on the final version of the project submitted to it but also reports on the adjustments made to the project during discussions between the CESP and the survey directors. Thus, certain elements that are no longer in the final version of the survey may be mentioned. We believe that this will enhance our understanding of the issues that mark an ethical process.

This opinion is not intended to mark the end of the ethical process for the project promoters. Rather, as the project is carried out, other issues may arise or continue to exist under new aspects during the stages of analysis and dissemination of results. We therefore hope that the examination process initiated here can be pursued.

The CESP would like to thank the project directors, Ms. Danielle Saint-Laurent, of the INSPQ, and Dr. Serge Déry, Public Health Director of the Nunavik Local Health and Social Services Network Development Agency, who have actively participated in the discussions. Their work has developed based on thoughts shared with the CESP, thoughts that they shared with members of the working groups associated with the survey and members of the Consultative Committee made up of representatives of the Inuit community.

Also thank you to Mr. Nicolas Baltazar from the Nunavik ADRLSSS who kindly accepted to read and comment the English version of this opinion.



Monsieur Daniel Weinstock,  
Président du Comité

Daniel Weinstock  
Committee Chair



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## **A Brief Summary of the Proposed Survey**

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As no information on the general health status of the population has been available since the last major survey conducted in 1992 by Santé Québec, the Public Health Department of the Nunavik Regional Board of Health and Social Services (currently Nunavik Local Health and Social Services Network Development Agency — ADRLSSS<sup>2</sup>) considered it essential to conduct a new general health survey in order to update the health profile of the population, to better assess the evolving situation and adapt its health programs accordingly. The principal elements of the survey presented here are drawn from the Research Design submitted to the CESP<sup>3</sup>.

Numerous partners are collaborating in this project placed under the primary responsibility of the Public Health Department of the Nunavik RBHSS and the Institut national de santé publique (INSPQ), the latter being responsible for the planning, administration and coordination of the survey. The Unité de recherche en santé publique (URSP) of the Centre hospitalier universitaire de Québec (CHUQ) is responsible for the scientific component and fieldwork logistics, and the Institut de la statistique du Québec (ISQ) for the methodological component of the survey<sup>4</sup>. The collected biological samples are analyzed by the Québec Public Health Laboratory (LSPQ) of the INSPQ and the Department of Biochemistry at Hôpital Laval. The laboratory of the McGill Centre for Tropical Diseases and the laboratory of the Montreal General Hospital's Department of Microbiology are collaborating in certain serological analyses. The project is funded by the ministère de la Santé et des Services sociaux (MSSS) and the Nunavik RBHSS.

Lastly, the survey directors have established a consultative committee that includes the Nunavik public health director, three representatives<sup>5</sup> of the Inuit community and four members of the survey preparation team (INSPQ and URSP/CHUQ). This committee assesses the needs expressed in order to enhance the knowledge of the health status of the Inuit population of Nunavik, and to assess the pertinence, validity and admissibility of the tools and means used to conduct the survey (e.g.: questionnaires, contact procedures, consent forms).

Moreover, the proposed Inuit health survey has received the support of the Nunavik Nutrition and Health Committee (NHCC), a committee made up of Inuit community members and considered to be an advisory committee of the Nunavik region.

## **Project Goals and Survey Strategies**

The 2004 Health Survey, whose goal is surveillance of the health status of the Inuit, is a follow up to the 1992 Health Survey among the Inuit. Most of the themes of this earlier survey have been reproduced here, often using the same wording (questions). As in 1992, the 2004 Survey also contains clinical tests and collected biological specimens (blood). It also makes use of the tools developed in other surveys (such as the Canadian Community Health Survey [CCHS]) in order to respond to the needs expressed by the Nunavik ADRLSSS and the Inuit representatives who are members of the Consultative Committee.

This survey provides an opportunity to update the health profile of the Inuit population through the collection of representative data. This exercise should help to monitor the evolution of various health indicators, social

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<sup>2</sup>. The research design and instruments refer to the Nunavik RBHSS; this designation as well as that of the ADRLSSS are both used in the CESP's opinion.

<sup>3</sup>. Qaniuppitaa? How are we? Health Survey of the Inuit of Nunavik – 2004 Research Design, June 18, 2004.

<sup>4</sup>. More particularly, with regard to the development of the survey plan.

<sup>5</sup>. The three individuals from the community who are members of the Consultative Committee are considered as leaders in their communities.

conditions and characteristics of the living environment and the social and physical environment. Finally, this entire process should help to update the programs and interventions intended for the Inuit of Nunavik in addition to facilitating the identification of emerging problems and generating research hypotheses so as to better understand and intervene on certain problems<sup>6</sup>.

A particular aspect of this proposed survey is that it will integrate the participants who consent to it into a circumpolar cohort study (entitled *The Inuit Health in Transition: the Nunavik Study*). The latter study will examine different populations and will bring together researchers from various countries, including those involved in the current survey project. Therefore, the present survey constitutes Year 0 of the cohort study. Only individuals aged 18 or over who have already been approached for the survey will be invited to participate in this research project<sup>7</sup>.

The survey targets the entire population living in Nunavik on a permanent basis,<sup>8</sup> that is, members of Inuit private households who reside in one of the region's 14 municipalities. Thus, based on a sample of 600 Inuit private households (25% more than in 1992), approximately 2 700 Inuit<sup>9</sup> aged 15 or over will be selected to participate in the survey.

Data will be collected on board a ship<sup>10</sup> during August and September 2004, and various collection instruments will be used, given the variety of data to be collected and compared.

Data will first be collected through structured interviews with the individuals in the sample and a self-administered questionnaire. Thus, seven instruments will be used to collect the data: (1) the identification record; (2) the household questionnaire; (3) the individual questionnaire; (4) the confidential questionnaire; (5) the clinical questionnaire; (6) 24-hour food recall; (7) the questionnaire on records of food consumption.

All these questionnaires come from the 1992 Santé Québec Health Survey. However, they were revised and modified several times to allow for a comparison with the Canadian population in general and the Nunavut population in particular. Questions from the CCHS were integrated into the present survey. Moreover, each section of the questionnaires was examined by experts to ensure that the necessary content is valid and certain problems emerging in the region are covered. A last revision will be made with the translator of the questionnaires and the three representatives of the Consultative Committee attached to the survey.

During the clinical session, the physical and physiological measurements of subjects aged 18 or over will be obtained. A nurse will then take the pulse and two blood pressure tests, the body temperature, as well as the following body dimensions: weight, height, waist and hips measurements<sup>11</sup>. Lastly, the bone density of women aged between 35 and 74 will be measured using bone densitometry.

During the clinical session, biological samples will also be collected. First, a blood sample (approximately 45 ml) which will be used to analyze total cholesterol, HDL-cholesterol, LDL-cholesterol, triglycerides, glucose, insulin and the biochemical determinants of anemia. This blood sample will also be used for serological analyses to observe antibodies attesting to previous infections. Lastly, a toenail sample (30 mg) will be taken and analyzed to detect the presence of environmental contaminants.

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<sup>6</sup>. For example, in particular, data from the 1992 Survey have helped to act on the blood-lead level in pregnant women and young children.

<sup>7</sup>. The project's research component was submitted to the Research Ethics Committee (CER) of Université Laval.

<sup>8</sup>. Except for households made up uniquely of persons who are not Inuit and not related to an Inuit; institutionalized persons are those who live full time in a public institution.

<sup>9</sup>. The approximate estimate of 4.5 persons per Inuit private household is used.

<sup>10</sup>. The Amundsen, a Canadian Coast Guard icebreaker, was refitted to accommodate researchers. While providing room and board to the research team, the ship will travel to the region's villages. Participants will then be requested to board the ship where the data collection takes place.

<sup>11</sup>. Pregnant women will be excluded from the body dimension measurements.

The survey will be conducted in English or Inuktitut; all the questionnaires are written in these two languages and the participants will be interviewed in the language of their choice. It is estimated that the administration of the questionnaires will take two hours and the clinical tests for participants aged 18 or over will take from 30 to 40 minutes.

## **Process of Ethical Examination by the CESP**

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This proposed health survey is in line with the updating of the responsibilities entrusted to the public health Director regarding the function of surveillance of the population's health status and health determinants. In particular, under Section 43 of the *Public Health Act (PHA)*, the latter is responsible for submitting the proposed survey to the CESP and for ensuring compliance with rules relating to the confidentiality and protection of personal information<sup>12</sup>.

According to the new legislative safeguards stemming from the *PHA* (related to the updating of the surveillance function on the one hand and the role of the public health ethics committee on the other), since a proposed survey is one of the data sources that provides the information needed for the production of a surveillance plan, it should be directly linked to the latter. However, given that these measures have been implemented recently and work on the proposed survey has already begun, the CESP deemed the project admissible, pursuant to the mandate conferred to it under Section 20 of the *Public Health Act*.

The following documents were submitted to the CESP: the survey research design, the first draft of the questionnaires to be administered in August 2004 and then the revised versions, the information sheets as well as the consent forms intended for young people aged 15-17 and those aged 18 or over respectively.

The project was first discussed in working groups, then in a meeting of the entire CESP. Discussions took place between the CESP's secretary and the project directors as well as members of the CESP. As mentioned in the Foreword, the survey directors reviewed a number of discussions with their working groups and the Consultative Committee so as to follow them up further. The last version of the documents was submitted to the CESP on June 18, 2004. The present opinion was adopted by the CESP at its regular meeting on Monday June 21, 2004.

It should be pointed out that, in its work process, the CESP favours providing support to the project directors in identifying the ethical dimensions of the project, discussing the significance of these elements and, if applicable, identifying the measures likely to improve the project in terms of respect for certain values or the reduction or elimination of undesirable consequences for the targeted individuals or population groups.

Thus, on the basis of the documents initially submitted to the CESP in January 2004 and in light of their evolution until June 18, the CESP's comments and recommendations are presented here.

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<sup>12</sup>. To this end, for example, the survey directors submitted a request for authorization to the Commission d'accès à l'information du Québec (CAIQ) so as to obtain the lists necessary for creating a survey base since they contain nominal information.

## The Project's Ethical Dimensions

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While congratulating the project directors on the work they have accomplished, the CESP recognizes the conceptual, methodological and logistical complexity of the IHS.

The CESP examined the project's context and highlighted three major sets of challenges that marked and influenced the development of the survey.

A first challenge, no doubt the greatest, relates to the cultural adaptability of the project. The Inuit population of Nunavik has its own culture (with its values and points of reference), language and history -- a culture that is shaped by a territory and particular conditions as well as by its historic meeting with the culture of the white people in the South, a culture that serves as a vehicle of meaning, allowing people to belong to a coherent universe. Thus, it is necessary to adapt the approaches and the data collection tools if only to obtain the participation of the targeted communities. This adaptation, which is based on the project architects' sensitivity to the Inuit social and cultural characteristics, makes it possible in return to present a survey process that strikes a chord with and has meaning for the participants.

However, this concern with respecting the characteristics of the Inuit population must meet the feasibility criteria, which are reflected, in particular, in a concern for the comparability of the data to be collected with those produced in other regions (on the same themes), and for the utility of the data in the planning of care and services. Though the latter are given "local colour" in their planning and delivery, they are part of a broader health and social services system established by the culture of the South. These criteria of data comparability and utility should ultimately help to update the value of equity between the different regions of Québec in terms of health care and services needs. This equity is also stated in terms of equivalency of services since needs may vary greatly from region to region.

All the objects of surveillance selected in the survey because they meet the feasibility criteria, among other things, form a kind of prism through which the health status of the Inuit of Nunavik will be observed and documented. However, does the health profile observed through this prism reflect their reality? Are the categories used to report on their health status pertinent? And, especially, do they make sense to the communities involved in the survey? This gives rise to the question of the definition of health and the idea of health and illness as conceived by the Inuit of Nunavik, as compared to the definition underlying the choice of objects included in the survey.

How then can the gaps be reduced between these two definitions of health, which have co-existed for a long time without necessarily overlapping? One of the most appropriate solutions is the IHS directors' decision to create a consultative committee that includes representatives of the population who can facilitate the transcultural process. However, the issue of the criteria of representativeness of "the representatives" remains complex.

Therefore, to implement a survey, the project architects must be sensitive not only to the environmental, but also to the social and cultural context of the targeted populations, since even the most logistical elements are bound to be tinged with local colour. This implies coming to terms with the fact that participants do not undress for the clinical examination, agreeing to the survey being conducted in a very definite period of time, or using local interviewers who speak Inuktitut. All these elements attest to the fact that the Inuit context has been taken into consideration.

This openness nevertheless requires that the survey directors, in conducting the survey, be vigilant about the fact that the means chosen to "reduce the gap between the two cultures" might adversely affect certain

individuals, even families and communities. An example would be the presence of interviewers speaking Inuktitut (thus implying that they are of Inuit extraction) and the fact that these are small communities where “everybody knows everybody else” because they have a cousin in the next village, a friend in another village, etc. To best ensure confidentiality, it was decided that Inuktitut-speaking interviewers should not come from the same villages as the people to be interviewed.

It goes without saying that these challenges give rise to ethical concerns. Thus, the examination of the project’s documents by the CESP highlighted a number of issues that mainly concern the following aspects:

- Consent;
- The balance between the potential benefits and negative effects for the individuals and households participating in the survey as well as for the Inuit community as a whole; and,
- The idea of health / the idea of a community.

The relationship between the experts and the population, and the latter’s participation are also important aspects of the ethical perspective discussed.

## Consent

What courses of action will better achieve the qualities of a free, informed and explicit consent, given the particular context of the *Health Survey of the Inuit of Nunavik — 2004*?

The unique context is due to, among other things, the fact that the IHS constitutes Year 0 of a circumpolar cohort study and therefore serves two purposes: surveillance<sup>13</sup> and research. In addition, the information gathered includes data obtained both through questionnaires and from biological specimens (blood, toenail sample).

Lastly, since this is a vast population survey, the project aims to reach both adults (aged 18 or over) and minors aged 15 to 17 since the latter age category is more regulated legally.

These contextual elements play a role in determining the forms of consent for these participants. Thus, based on this perspective, the following concerns were raised by the CESP.

### **Free consent...**

For consent to be considered free, it must be given without any pressure having been exerted on the individual who is preparing to give consent, thus raising the issue of the individual’s autonomy, integrity and capacity to choose.

In this respect, the CESP questioned the financial compensation<sup>14</sup> granted to survey participants. This compensation practice may be viewed as a means for the survey directors to “facilitate” (even to purchase) consent. This might be an unwarranted pressure on certain more vulnerable individuals who might see it as a way to obtain money even though they are not comfortable with the idea of having to disclose information

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<sup>13</sup>. While the databanks (such as Med-Écho or the Fichier des tumeurs (tumor file)) contribute to surveillance aimed at increasing knowledge of the health status of the population, the survey provides access to information which would be difficult to obtain otherwise, or which could not be correlated either, in particular those related to risk factors such as lifestyles.

<sup>14</sup>. A \$25 financial compensation is provided for adults (an additional \$10 will be offered to the principal respondent who completes the “household questionnaire”) and \$10 for young people aged 15 to 17 who participate in the survey.

about themselves. Given this compensation practice, it is not unreasonable to think that the respondent of a selected household may “coerce” the other members to participate so that the household can take advantage of this amount.

For the survey directors, these possibilities seem to be unlikely. Moreover, this point was not raised in the discussions with the working groups or the Consultative Committee attached to the survey. In fact, as the survey directors explained, financial compensation is a common practice among Inuit people and is part of a “giving-giving” spirit. The issue of the amounts allocated was discussed with the Consultative Committee which considered them to be proportionate to the required participation. Thus the CESP concluded that the suggested compensation appears to be perfectly reasonable.<sup>15</sup>

On the other hand, the CESP questioned whether, in general, free consent could be achieved through the administration of a *household questionnaire* to a principal respondent who provides information on each member of this unit. Potential problems may arise because of the fact that information is provided on each of the household members without them being given the opportunity to consent to it. While the administration of this type of questionnaire<sup>16</sup> is quite common, the question of free consent does not yet appear to have been raised. The questions that are put to the principal respondent about the other persons are those that anybody living with other persons could answer because they are potentially “visible” (for example, the person was the victim of an accident, is suffering from certain ailments, allergies, is a student, is unemployed or employed, etc.). It should be noted that the CESP’s questioning was not fuelled by the type of questions included in the household questionnaire but by the very principle of consenting to providing personal information.

The CESP did not see any problem with this part of the survey being conducted according to the proposed process. One way to reduce the possibility of a confidentiality breach is to identify the household members about whom information was provided by a number and not by any nominal information. The first name of the individuals is recorded in the questionnaire so that the interviewer can administer the questionnaire more effectively. However, this first name is excluded from the data input process. In other surveys, in particular the Santé Québec Survey, the interviewer only gave a number and had a separate sheet on which the number and the first name of the individual involved were matched. This procedure enhances the confidentiality of information.

Furthermore, the examination of the consent of minor participants (youths aged 15 to 17) led the CESP to ask for clarifications about the possibility for a minor to withdraw from the survey. While it is agreed that a minor cannot participate in the survey without parental consent, what about his possible withdrawal from the project at any time, even though he has signed the consent form? In other words, can a young respondent withdraw from the survey on his own initiative, without his parent (or guardian) being informed of it? The directors clarified that the minor respondent can withdraw from the survey at any time without the parents being informed of it, but that a parent can also put an end to the child’s (a minor’s) participation upon request. The last version of the information sheet is sufficiently clear about this matter.

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<sup>15</sup>. However, the CESP members pointed out that, although the financial compensation may exist in certain contexts, it is not systematic; otherwise, it would be very difficult to conduct large-scale population surveys.

<sup>16</sup>. The Santé Québec Survey and other well-known surveys function in this way.

### ***Informed and explicit consent***

For consent to be free, it must first be informed and explicit, that is, the individual who is going to participate in a project (research study, survey, etc.) must be informed of the nature and the purpose of the project, its benefits and risks as well as the scope of his consent. The consent is thus given for specific purposes and for a definite period of time<sup>17</sup>. The participant will have also signed a consent form<sup>18</sup> in which the broad outlines of the project are set out, including the conditions of preservation and use of the data collected about him.

In the *2004 Health Survey of the Inuit*, the data collected have mainly involved biological specimens (blood and toenail samples) that will be used for the following potential purposes:

- The survey (surveillance purposes): the databanks (composed of both data derived from the questionnaires and biological specimens) will not contain any nominal data, and the analyses or types of analyses envisaged are explained in the information sheet;
- The cohort study (research purposes): the data will have to be preserved in a nominal form since the study involves following up the same group of individuals over a period of time and therefore participants will be contacted again periodically (every five to seven years);
- Any other request that might be made to access the data or biological specimens collected by the survey, even made anonymous, for other currently unspecified purposes (for example, research projects that include other types of analyses of the blood samples).

Regarding the possible uses of the biological sample provided by the individual, it is crucial to determine to which purposes the individual has specifically consented<sup>19</sup>. This raises the entire question of the autonomy and the integrity of not only the individual donor but also of all those who are related to that person (common genetic baggage). This is all the more worrying since, in this specific case, the community under study is small to say the least (approximately 9 600 residents in 2001, according to the Research Design, p. 3). The undetermined use of a bank of samples that represents nearly one quarter of the population (the survey directors intend to contact approximately 2 700 people for this study), not counting “relatives,” may certainly give rise to great discoveries and have beneficial effects for the community, but it may also lead to all kinds of blunders. These blunders must be controlled and, among the mechanisms that can be used to do this, the consent of participants becomes an invaluable tool.

Although the CESP was not mandated to examine and comment on the proposed cohort study, it was nevertheless induced to comment on the information provided with a view to obtaining consent to a number of analyses which were contained in the documents initially submitted to it. In fact, some of these analyses serve both the survey and the cohort study. Moreover, the databanks that will be created by the survey, even though made anonymous, will contain all the data to which researchers will want to have access.

More specifically, the CESP wondered for which purposes the collected biological specimens could or would be used, and more generally, to what exactly the participants would be giving consent. Thus, the CESP found “grey areas” in some of the wordings, particularly in the information sheet, which made consent to the future use of the blood samples somewhat similar to a blank cheque since it created the possibility of unspecified uses (for example, the terms “other diseases”) or uses of undetermined scope (the terms “for genetic markers potentially related to prevalent diseases in Nunavik”).

<sup>17</sup>. CEST (Commission de l'éthique de la science et de la technologie), 2003. *Les enjeux des banques d'information génétique : pour un encadrement démocratique et responsable*, Government of Québec, p. 43.

<sup>18</sup>. The consent form referred to also includes the information sheet.

<sup>19</sup>. Thus, the CESP support team has produced a document called *Consentement et conservation des prélèvements biologiques Éléments de réflexion* to assist the CESP and the directors of the proposed survey in their consideration of this issue. The document can be consulted at the CESP website under the heading “autres publications.”

The CESP understands that certain types of analyses (similar to those explained in the information sheet and which help to detect contaminants, for example) will not be available at the time of the survey but could prove to be very useful in the next few years. However, it also considers that it is necessary to clarify and explain further, in the consent form, the uses that might eventually be made so as to ensure a satisfactory level of confidentiality between these medical or public health activities and other types of uses based on, for example, genetic knowledge (genomics, proteomics), gene patenting, and the commercialization of genetic data banks. A solution proposed by the CESP is to proceed with the negative, by specifying in the consent form, what *cannot be done* with the samples collected. This would at least reassure people about the uses that could precisely make them fear the worst. The last version<sup>20</sup> of the documents of the proposed survey shows that this important issue has been taken into consideration. Thus, the research team, aware "that the ethical dimension can, in some communities, take on a community aspect in addition to an individual aspect" (Research Design, p. 22), decided, in accordance with the CESP's expectations, to exclude the possibility of using the blood samples collected during the survey for genetic analyses or by commercial or pharmaceutical companies<sup>21</sup>.

This issue of the conditions for using the collected biological data also gives rise to a corollary issue, namely the length of time and conditions under which they will be preserved. Once the data have been used for the survey purposes, they will be made anonymous, preserved and made available (to researchers) for future analyses which can or will only take place "after the presentation and acceptance of a research protocol that must conform to the criteria of the Nunavik RBHSS (the data banks will remain under its responsibility), the INSPQ, the NNHC and the Research Ethics Committee of Université Laval" (Research Design, p. 22).

The prospect that the data would be preserved for an extended period of time makes the solution of renewing consent with each new use seem quite uncertain. The length of preservation of blood specimens was compared with the scope of this consent, that is, given the speed of techno-scientific development, it is certainly difficult to fully grasp the scope of a consent that allows for analyses in 15 years' time,<sup>22</sup> as stipulated in the information sheet.

Thus, what are the mechanisms that would make it possible to repeat consent periodically when a new use is envisaged, particularly in the case where databanks have been made anonymous (because, for the participants in the cohort study, the fact of being contacted again periodically should allow for the renewal of individual consents)? In reference to the concept of "community consent," the CESP suggests that the following condition be included in the consent form: any subsequent use should be approved by a regional body that includes Inuit representatives. This would allow researchers to come back and consult the population (since these data have a collective scope) on how it wants its biological legacy (both social and environmental)<sup>23</sup> to be used. This suggestion was taken up in the last version of the Research Design submitted to the CESP which indicated that an advisory committee, such as the Nunavik Nutrition and Health Committee (NNHC) would be consulted on the accessibility of nominal or non-nominal data for purposes not specified in this project. However, neither the information sheet nor the consent form deal with this possible access to data for purposes other than the survey. This possibility and the means provided to

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<sup>20</sup>. June 18, 2004 version.

<sup>21</sup>. In the last version of the design, dated June 18, the CESP found that the NNHC Advisory Committee was also opposed to genetic analyses and requested more time to examine this issue before giving an opinion on it.

<sup>22</sup>. According to the survey directors, this is the usual period for preservation of blood specimens.

<sup>23</sup>. According to Arellano, "The native groups feel particularly affected by this new form of appropriation of their wealth [biocolonialism], because they suspect that their genetic baggage is of particular interest to researchers. Some native communities have, moreover, drawn up a protocol for the acquisition of scientific data related to their environment and their social and genetic characteristics, a protocol that allows them to exert better control over the use of these data and the production of scientific knowledge" (translation) (Arellano, Jose Lopez, 2002. *Les représentations véhiculées dans la culture amérindienne du Québec en ce qui a trait à l'alimentation, aux organismes génétiquement modifiés (OGM) et aux transformations que l'humain peut apporter à la nature*, additional document produced for the drafting of the CESP's opinion entitled *Pour une gestion éthique des OGM*, 2003).

deal with it should be made explicit, in compliance with the Design. Following the example of the Comité consultatif national d'éthique, the CESP recommends that the consultative body be considered as a body that can also be questioned by any individual who is concerned by the initial samples and duly informed of this possibility and who wishes to know the destination of the elements and data collected (CCNE 2003<sup>24</sup>).

Another concern raised by the CESP was related to the accuracy of the consent form. The second component of the consent form for people aged 18 or over requests the participant's authorization to share information concerning himself (in an anonymous form) "with the authorized persons." This second authorization did not appear to be precise enough for an informed and explicit consent. The CESP requested that these persons be specified in the consent form. Once again, in the last version of the project presented to the CESP, clarifications were made about information sharing by explicitly identifying the partners in the survey.

Lastly, the CESP underlined that the psychosocial aspects of the survey were difficult to see in the wording used under the heading that describes the information gathered through questionnaires (use of the term "lifestyle") and in the introductory text of the information sheet intended for people aged 18 or over. The survey directors told us that the interviewer would present the examples orally so that the participants can understand this component. The CESP recommended that the following sentence be added to the introductory paragraph presenting the survey, "*It will also be used to help plan programs and services to prevent heart disease, cancer, anemia, diabetes, and other health or social problems (such as suicide, violence), and to improve living habits and nutrition.*"

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<sup>24</sup>. Comité consultatif national d'éthique pour les sciences de la vie et de la santé (France), 2003. *Problèmes éthiques posés par les collections de matériel biologique et les données d'information associées: « biobanques » « biothèques »*, Opinion No. 77.

## Comments and Recommendations of the CESP Regarding Consent

The changes made to the information sheets for both adults and young people aged 15 to 17 were well received by the CESP. The changes of the information on the use of the biological samples clearly indicate the analyses that will be carried out and their purposes. They also exclude certain uses or types of analysis considered to be potentially too risky, for example, uses by commercial or pharmaceutical companies and genetic analyses. The consent form for adults and young people aged 15 to 17 was further clarified so as to better identify who will have access to the information collected for the purposes of the survey. Thus, the form identified all of the organizations that could have access to certain data in order to make their particular contribution to the survey and indicated that the participants could obtain the names of the researchers authorized to have access to certain information.

However, the CESP notes that even with these improvements, it is not explicitly indicated how requests for access to the information collected in the present survey will be managed, in particular, access to the remaining biological specimens. As indicated in the Research Design, the possibility that requests will be made for as yet undetermined projects or purposes (future research projects) is not ruled out. The CESP recommends that this possibility be explicitly stated on the consent form, particularly the form for adults, since this group of respondents (and through them, the Inuit community as a whole) is affected by the use of biological specimens. The CESP therefore recommends that the respondents be asked to authorize (give their consent to) the Nunavik RBHSS to grant future requests for access to the biological specimens for purposes other than those of the survey<sup>25</sup> on the condition that an advisory body that includes representatives of the community is consulted and consents to such use. The CESP also recommends that the consent form should clarify that the population can ask the RBHSS or the advisory body for information on who has requested or been given access to the biological specimens and for what purposes.

Finally, having underlined that the psychosocial aspects of the survey were difficult to see in the wording used under the heading that describes the information gathered through questionnaires (use of the term "lifestyle") and in the introductory text of the information sheet for people aged 18 or over, the CESP recommends that the following terms be added (in bold characters) to the introductory paragraph presenting the survey: "It will also be used to help plan programs and services to prevent heart disease, cancer, anemia, diabetes, and other health or social problems (such as suicide, violence), and to improve living habits and nutrition."

## The Balance Between the Potential Benefits and Negative Effects for the Individuals and Households Participating in the Survey as well as for the Inuit Community as a Whole

Benevolence is a fundamental value of public health, reflecting the duty to take action and intervene for the good of the population. Its corollary principle is non-maleficence, which underlies the moral duty to neither damage nor harm the individuals and populations targeted by public health actions, whether a protective measure, a prevention program or even a survey on health and social issues for surveillance purposes. In short, "good intentions" do not rule out that certain means used to achieve an end may be questionable or have undesirable consequences for the individuals and communities concerned.

<sup>25</sup> And of the circumpolar cohort study, since the CESP hypothesizes that the latter will provide for a consent that conforms to the requirements of a free, informed and explicit consent.

Considering this concern for non-maleficence, to which the survey directors are sensitive, it seems important to consider the potential harmful consequences of an Inuit health survey, not only for certain individuals but for this particular community as a whole, since it is small, circumscribed and culturally different from that of white people in the South. All these elements may make the Inuit population vulnerable and subject it to certain stigmas.

Before examining the elements that were discussed in terms of their potential risk for the individuals and community targeted by the survey, we will first consider the elements identified as benefits in the information sheets accompanying the consent forms for both minors and adults. Apart from the possibility of participants aged 18 or over developing a small bruise as a result of the blood test, the information sheets do not mention any presumed harm. They state that confidentiality is guaranteed and participants are free to withdraw from the survey at any time.

### ***Expected Benefits***

With regard to expected benefits, the information sheets indicate that participation in the survey helps participants to better understand the health risk factors and what can be done to reduce these risks. As a preventive measure against, among other things, anemia, cardiovascular disease and diabetes, undergoing clinical tests will allow participants to check their health status. Thus, participants aged 18 or over with abnormal test results for blood pressure, serum lipids or glycemia, with high levels of antibodies against past infections associated with the presence of fever, or with abnormal hearing test results, and women diagnosed as anemic, will receive a letter encouraging them to consult the director of their community's CLSC in order to receive their results and appropriate follow up.

As a preventive measure, permission is requested on the consent form to transmit any abnormal blood, blood pressure or hearing test results to the CLSC. The last element was added following discussions with the CESP which raised questions about the process through which the respondents would be informed of such results. The information contained in the initial documents suggested that the respondents would be informed directly by letter, rather than by a health professional whom they would have identified, according to the usual clinical information process. The lack of clarity could have also suggested that the information would be transmitted to the CLSC without the participants' consent. The consent form was clarified in order to explain the process for transmitting information on the abnormal results identified above. Individuals who receive such a letter are free to either follow it up or to exercise their right not to know, since consent does not authorize the CLSC to follow up with the participants. Given the organization of services, the statutory identification of the CLSC proves to be the best option and there is no need, in the regional context, to ask participants to indicate to whom the results should be sent.

The possibility of informing all participants of their results, whether or not they are abnormal, was raised during discussions. This information appeared to be a potential benefit as every participant would be aware of his profile as regards the elements tested and these results could also serve as a reference point in their medical record allowing the evolution of these indicators to be monitored (although perhaps not everyone has a medical record at the CLSC or wishes to have one created). It should also be noted that if everyone is sent a letter, the receipt of a letter – which would otherwise be associated with an abnormal result – neither creates worry nor breaches confidentiality (with the method retained, a household member who receives a letter is automatically identified as having an abnormal test result). However, in the opinion of the survey directors, the potential benefits for individuals appear to be limited, compared with the costs (logistics of identifying the type of letter to transmit, sending these letters and results, management of all the results by the CLSC). Not receiving information that confirms that they do not have any abnormal test results is not considered to be harmful for the participants.

Finally, the financial compensation given to the participants (see section above on free consent) is considered not so much as a personal benefit but as a compensation or element to facilitate the effort of participating in the survey, which requires that the participant be available for a few hours and travel to the survey administration site.

Beyond the individual benefits, participation in the survey is more broadly presented to the participants as an opportunity to help build a profile of their community's health.

### ***The Potentially Negative Consequences for Individuals***

Certain potential negative consequences were raised in the section on consent, particularly those related to the unspecified uses of the biological samples (for example, should researchers eventually wish to use the blood samples for genetic tests whose results, if known, could be damaging to individuals or the community).

In this section, we will deal with concerns raised by the CESP regarding certain questions (or themes) dealt with in the survey's questionnaires which are seen as being more sensitive because they refer to aspects of private life that may, in certain individuals, provoke hitherto repressed feelings of hurt. The sections of the confidential questionnaire that deal with well-being (distress), suicide (suicidal thoughts), violence experienced and sexual abuse are all considered by both the CESP and survey directors to be sensitive areas.

The mental or psychosocial health status of individuals should be taken into consideration by activities related to the surveillance of the health status and well-being of the population. However, special sensitivity is required when seeking information from individuals experiencing such situations. This sensitivity is reflected in, among other things, a concern not to add to the suffering of individuals, for example, by increasing their feelings of distress or isolation, or by destabilizing them in a situation with which they are attempting to deal. This sensitivity is also reflected in a concern to relieve suffering. Within the limits of a survey, at a minimum, this may involve expressing our awareness of the suffering associated with certain situations and opening a door to support in the community for those who want it, for example, by identifying available and accessible resources.

Being sensitive to this issue, the survey directors indicated that one or more written documents (existing material) would be made available to the participants at the survey administration site (the ship), informing them of the various physical and psychosocial health services available in their community. Given the scope of the problems addressed by these documents, an individual would not necessarily be associated with a particular problem but would still receive the specific information that meets his needs. The CESP notes that its recommendation that the confidential questionnaire include a note acknowledging that the subjects addressed may be sensitive for respondents and opening the way for individuals to seek help from the resources indicated in the information documents was not retained in the last version of the questionnaire submitted to it.

The survey directors have also indicated that a resource person will also be present to provide support to individuals for whom participation in the survey could provoke an emotional "crisis" — a psychosocial emergency (just as a qualified person will be present to respond to medical emergencies)<sup>26</sup>. The survey directors also wish to ensure that the resource person has the necessary training and is particularly skilled at responding to the possible needs of young people aged 15 to 17.

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<sup>26</sup> However, the last version of the Research Design refers to medical emergency only.

Concerning this group of survey participants aged 15 to 17, the proposed confidential questionnaire was initially intended for both this group and those aged 18 or over. However, the questions concerning sexual abuse were addressed to only participants aged 18 or over because of the legal obligation to report sexual abuse cases referred to by a minor. This constituted a constraint for the survey since confidentiality could no longer be guaranteed to respondents without contravening the law<sup>27</sup>. Thus, while being aware of the block of questions, those aged 15 to 17 were asked to skip over this section. This way of doing things could have had an undesirable consequence by conveying, for example, the message that these situations of abuse do not exist for individuals under 18, or that these situations are unimportant for the purposes of the survey and, consequently, for the purposes of planning services. Discussions led to the creation of a separate questionnaire for each of the two age groups – minors and individuals aged 18 or over.

The ethical dimensions of the section on violence in the confidential questionnaire for participants aged 18 or over were also discussed. Given the sampling structure whereby the members of the households selected are all likely to answer the confidential questionnaire, what could be the possible consequences of questioning the participants on violence (Section 7 of the questionnaire) within the households where a dynamic of conjugal violence already exists? Could this increase the risk of assault? Are there people who are more likely to be vulnerable to such risks? Following discussions both between the CESP and survey directors, and between the latter and the research groups associated with the survey, it was envisaged that there would be two different confidential questionnaires, one for men and one for women, and that only the latter would be asked questions about conjugal violence<sup>28</sup>. This way of doing things would undoubtedly reduce the risk of creating harmful consequences for women in situations of conjugal violence, as they are generally identified as being more at risk in such situations. However, this suggestion was rejected by the survey's Consultative Committee which maintained that family violence involves both men and women and this dual perspective must be transparent in the survey. In the eyes of the Inuit representatives, the risks of violence would not be increased by the administration of the questionnaire. Based on the point of view of the community's members, the original scenario of a single identical questionnaire for men and women was retained.

It should be noted that a methodological approach was explored in order to meet the expectations of the Consultative Committee and to reduce the risk, however low, of provoking an expression of violence. Thus, it was envisaged that one household member – sometimes a woman and sometimes a man -- would be chosen to answer this section, thus taking into account both men and women, but not within the same household. However, given the number of participants, it proved impossible to carry out such an approach and still ensure the statistical value of the results.

Finally, the level of detail initially present in the questions on violence was questioned by the CESP as well as by the survey Consultative Committee. The initial level of detail, by increasing the number of questions on the forms of expression of violence, tended to underline this problem and exacerbate the lack of balance — pointed out by the Consultative Committee — in highlighting the community's problems versus its strengths. The rewording of the final questionnaire resulted in a better balance between the questions while still identifying the essential elements of the issue in the context of a general survey.

### ***The Potentially Negative Consequences for the Community: Idea of Self and the Community***

How can the problems of a community be identified without reducing its image to these problems? Therein lies the challenge of establishing an idea of self (that is, the participant's image of his own community) and

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<sup>27</sup> Sections 38 and 39 of the *Youth Protection Act* (R.S.Q., chapter P-34.1).

<sup>28</sup> This method has been used in the Santé Québec Health Survey.

of the Inuit community through a portrait of health that is not synonymous only with disease and social problems.

Survey questionnaires are much more than simple data collection tools resulting from a rigorous scientific and methodological process. Rather, through the subjects they deal with and the manner in which they are presented, questionnaires, sometimes unbeknownst to those who construct them, convey ideas, images, and even prejudices (both positive and negative) regarding the community concerned. These are all elements that contribute to establishing, from the outset, the main lines of an idea that will be formed about the community and its members. Consequently, there is a potential risk not only that the questionnaire will bring out only a negative image of the community — which may lead to social labelling, or even to stigmatization, but also that the respondent, who is exposed to the image conveyed by the questionnaire, will come to perceive his community in this way, that is, to only view it through its problems. This concern was already expressed by the Consultative Committee and has been reconsidered in the development of certain questionnaires.

### **Comments and Recommendations of the CESP Regarding the Balance Between Potential Benefits and Negative Effects for Individuals Participating in the Survey as well as for the Inuit Community**

First of all, the CESP hails the work of the survey directors and work teams and their concern to best serve the interests of the population targeted by the survey. The decision to establish a Consultative Committee in which community representatives would participate and to refer to the region's advisory committee, the NNHC, reflects their concern with taking into consideration and involving the population. The requirement that all researchers intending to publish based on the information collected in this survey must first submit their publications to the Inuit population or its representatives (Design, p. 23) also attests to this respect for the population. The CESP encourages the researchers to take ethical dimensions into account when analyzing the data and, even more, when disseminating the survey results. Moreover, to demonstrate this, the CESP suggests that this consideration of ethical concerns, which guided the researchers, be explicitly and systematically stated when the results are published.

In examining the potential negative effects, the CESP focused particularly on the confidential questionnaires (addressed, respectively, to individuals aged 15 to 17 and those aged 18 or over). Its recommendation to use a different questionnaire for each of these two survey sub-groups was integrated into the survey's development. Thus, the questions on sexual abuse and violence that participants aged 15 to 17 were not asked to answer are not included in the questionnaire intended for them. Means other than the survey are being used to monitor and report on the evolution of these issues since the inclusion of such questions in the survey could have contravened the *Youth Protection Act* or breached the commitment to confidentiality if such situations were reported by minors.

The section of the confidential questionnaire intended for adults, which deals with conjugal violence, also raised concerns. In a household in which a dynamic of conjugal violence already exists, the CESP feared that the fact of knowing that the victim of assault has answered such questions could increase the individual's risk of being assaulted.

The working groups studied this question and, based on the decision made in the *1992 Santé Québec Health Survey*, proposed that separate questionnaires be created for men and women, the latter being the only ones asked to answer these questions. However, the Consultative Committee rejected this option since it would make it impossible to learn more about violence against men, a situation that exists within the community and, in their opinion, should also be examined. The Consultative Committee members do not

consider the fear that the questionnaire will increase the risks of assault within households to be justified. Moreover, they shared the CESP's view that the level of information initially asked by the questions was unnecessarily detailed; the rewording of this section made it possible to address these comments.

With regard to the concerns raised by the questions on violence or any question of this nature that could provoke suffering with which individuals are trying to deal, the CESP points out the moral duty to be sensitive to the suffering experienced and to offer support. In the context of a survey, this support, at a minimum, consists in informing individuals about the resources available and encouraging them to use these resources. The survey directors informed the CESP that they would make such information available, favoring information on a vast set of resources so that individuals would not be identified as having a particular problem when taking this document home with them. The CESP recommends that the confidential questionnaire, at a minimum, include a message encouraging the respondents who are experiencing problems related to one of the issues addressed, to consult one of the resources suggested in the document available on board the ship. The CESP also asks that the relevance of repeating this message throughout the questionnaire be considered (for example, when questions are asked about sexual abuse or suicide attempts). The CESP believes that it would be preferable to tell respondents that there is an awareness that the questions asked refer to private situations that may be painful. The expression of this sensitivity on the part of the survey directors could be included in the introduction to the questionnaire.

In addition to the effects on individuals, the question of the effects on the Inuit community should be considered. The search for accurate knowledge of health problems, their associated determinants and their evolution may come with negative consequences for the community. The first sign of such consequences may be seen in the inability of the community to recognize itself in a portrait established on the basis of a conception of health that does not correspond to its own conception. The complexity of a definition of health is magnified in a context where a unique cultural tradition is combined with the adoption of an "imported" practice. The fact that the objects of surveillance covered in the survey focus more on problems may also, potentially, reinforce a stereotyped and negative image of the community, which may lead to stigmatization. Moreover, the community's representatives on the survey Consultative Committee pointed out that the survey included very few questions on positive elements.

Finally, having underlined that the psychosocial aspects of the survey were difficult to see in the wording used under the heading that describes the information gathered through questionnaires (use of the term "lifestyle") and in the introductory text of the information sheet for people aged 18 or over, the CESP recommended that the following terms be added (in bold characters) to the introductory paragraph presenting the survey: "It will also be used to help plan programs and services to prevent heart disease, cancer, anemia, diabetes, and other health **or social problems (such as suicide, violence)**, and to improve living habits and nutrition."

## Comments and Recommendations of the CESP Regarding Respect for Confidentiality and Privacy

The CESP underlines that it does not find any ethical problems with regard to the security and confidentiality of the information gathered and finds that the measures provided for to ensure security and confidentiality to be reasonable; in so doing, the CESP is careful not to substitute for the Commission d'accès à l'information du Québec when the latter is asked to give an opinion regarding access to certain information.

### The Idea of Health/the Idea of a Community

The Inuit health survey is part of a process of monitoring the evolution of the health status of this population and helps to construct a portrait of this health status. In so doing, it contributes more broadly to constructing an idea of this community by reporting on, in addition to health problems and social problems, the different features of its lifestyles and behaviours that are linked to this health status.

While the notion of health and well-being has evolved over the years, it is also noted that it can vary from human group to human group (for example, according to socio-cultural links or other affinities) within a single given period.

While the CESP does not claim to have anthropological or special expertise on the Inuit community, it was interested to know if the Inuit population's conception of health was different from the one reflected in the health survey. In other words, is the biomedical model<sup>29</sup> that was retained for the survey and which makes it possible to compare the survey data with the other regions of Québec and even Canada appropriate for bringing out an accurate portrait of the health of the Inuit communities (the more holistic<sup>30</sup> view of health and illness seeming to be more present)?

Although the survey's logistical aspects and instruments have been somewhat adapted to the specificities of the Inuit context, according to the survey directors, it does not seem possible to identify a conception of health that is specific to the Inuit community. It must be said that the process of acculturation is such that the Inuit community shares a large number of referents with white people in the South when it comes to describing its health status and the need for health services. The particularities of the idea of health for the members of this population are thus difficult to identify,<sup>31</sup> and the operationalization of this concern (trans-cultural understanding) is not very evident in the survey.

However, in the opinion of the survey directors, the modes of consultation and the proximity of community representatives suggest that the content of the survey will make it possible to collect information that has meaning in terms of learning about the health status of the Inuit population and that may be useful to the community from the point of view of improving this health status and the factors that influence it. Moreover, the desire expressed by the members of the Consultative Committee to find a balance between the positive

<sup>29</sup> A more linear model of the "determinants: health status: consequences" type which emphasizes individual responsibility in maintaining health; hence the importance attributed to lifestyle (nutrition, alcohol consumption, smoking, physical exercise, etc.) (May Clarkson, "DTIMUUMADSINA ? (Et la santé ça va ?) Méthodologie de l'enquête Santé Québec chez les Cris, 1991," in Trudel, Charest and Breton (eds.), 1995, *La construction de l'anthropologie québécoise, mélanges offerts à Marc-Adélaïde Tremblay*, Chapter 15, Sainte-Foy : PUL.

<sup>30</sup> That is, that health refers to the harmony between the self [as an Inuit] and the physical and social environment (idem.).

<sup>31</sup> This does not prevent certain particularities from being identified or anticipated. Thus, it is underlined (without elaborating) that the notion of time is different (which could influence the answer to questions depending on their wording as regards temporality). The conception or representation of sexuality could also present particularities but the latter are also difficult to assess.

and negative aspects (identification, if not highlighting, of health problems or social problems) is an example of the influence of this consultation.

Although it would be difficult to overlook this dimension of the idea of health in an ethical opinion, it is not reflected in specific findings. Thus, the CESP considers that caution should be exercised in projecting our own categories on the communities which, although they appear to be acculturated, do not necessarily belong to or find themselves in these categories or models. Thus, it will be all the more important, when processing and interpreting the data, to take into account the broader context in which members of the Inuit community are situated and the meaning given to the health determinants observed (lifestyle, environment).

In this regard, the CESP notes that the section on “cultural changes” in the 1992 Survey has been withdrawn from the 2004 version. Since what is involved is the acculturation of Inuit communities, it seems pertinent to ask questions about external cultural influences (for example, the role of television and radio shows from outside, the Internet or even the time spent outside the community by certain household members for work or studies) in relation to the lifestyles examined by the survey. This does not appear to be covered by the survey.

The CESP praises the efforts of the survey directors to involve the community in the development of this project, which it sees as opening the way for consideration of the specificities of the Inuit culture.

### **Comments and Recommendations of the CESP Regarding the Idea of Health Among the Inuit**

The CESP encourages the survey directors and primary users of the results to pursue their processes of consultation and participation of the community in the analysis and interpretation of the survey results and their possible applications while remaining vigilant as regards the expressions of a relationship to health that may differ (relation to body, to factors that allow individuals to feel in harmony with their body, spirit, social and physical environment, etc.).

## Conclusion

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The CESP has identified various elements of the ethical dimension of the *Qaniuppitaa? How are we? Health Survey of the Inuit of Nunavik (2004)* through its examination of the Research Design and survey instruments (questionnaires). Its examination focused particularly on the following aspects:

- Consent;
- The balance between the potential benefits and negative effects for the individuals and households participating in the survey, as well as for the Inuit community as a whole; and,
- The idea of health/the idea of a community.

The relationship of the experts with the population and the latter's participation are also important aspects from the ethical perspective discussed. The comments and recommendations of the CESP are summarized at the end of the present document.

The CESP wishes to reiterate its recognition to the survey directors who, sensitive to the ethical dimensions of their project, participated in the discussions that made it possible not only to bring to light the ethical dimensions of the project submitted to the CESP, but also to search for concrete solutions to improve the project from this perspective. They brought their knowledge of the Inuit community to these discussions, among other things, through the reactions of the proposed surveys Consultative Committee which included representatives of the community. Their openness and involvement in the process will have made it possible to fulfill the goal of support favored by the CESP.

As was noted in the presentation of the project, it serves two purposes – surveillance and research – explicitly expressed by the fact that it constitutes Year 0 of the circumpolar cohort study *The Inuit Health in Transition: the Nunavik Study*. In accordance with the requirements related to the research, the proposed survey was therefore also submitted to the Research Ethics Committee (CER) of Université Laval. Just like the CESP, the CER asked the survey directors to specify as clearly as possible the purposes of the cohort study as opposed to those of the survey so as to distinguish the consent of the participants according to the respective purposes. Except for the development of a different consent form for respondents aged 18 or over who agree to participate in the cohort study, a form excluded from examination by the CESP, it remains difficult to distinguish between surveillance purposes and research purposes. These purposes do not merely co-exist but also overlap since the methods used are often common to both.

Thus, for the moment, it should be retained that the examination of the same project by more than one ethics committee (the CER examined the whole project since it constitutes Year 0 of the research project) cannot bind either of these committees. Thus, while it was informed of the CER's comments and its approval of the project, the CESP is providing its opinion here completely independently from the CER and is asking the directors to improve the project already approved by the CER.

## Summary of Comments and Recommendations by the CESP

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### Regarding Consent

The changes made to the information sheets for both adults and young people aged 15 to 17 were well received by the CESP. The changes of the information on the use of the biological samples clearly indicate the analyses that will be carried out and their purposes. They also exclude certain uses or types of analysis considered to be potentially too risky, for example, uses by commercial or pharmaceutical companies and genetic analyses. The consent form for adults and young people aged 15 to 17 was further clarified so as to better identify who will have access to the information collected for the purposes of the survey. Thus, the form identified all of the organizations that could have access to certain data in order to make their particular contribution to the survey and indicated that the participants could obtain the names of the researchers authorized to have access to certain information.

However, the CESP notes that even with these improvements, it is not explicitly indicated how requests for access to the information collected in the present survey will be managed, in particular, access to the remaining biological specimens. As indicated in the Research Design, the possibility that requests will be made for as yet undetermined projects or purposes (future research projects) is not ruled out. The CESP recommends that this possibility be explicitly stated on the consent form, particularly the form for adults, since this group of respondents (and through them, the Inuit community as a whole) is affected by the use of biological specimens. The CESP therefore recommends that the respondents be asked to authorize (give their consent to) the Nunavik RBHSS to grant future requests for access to the biological specimens for purposes other than those of the survey<sup>32</sup> on the condition that an advisory body that includes representatives of the community is consulted and consents to such use. The CESP also recommends that the consent form should clarify that the population can ask the RBHSS or the advisory body for information on who has requested or been given access to the biological specimens and for what purposes.

Finally, having underlined that the psychosocial aspects of the survey were difficult to see in the wording used under the heading that describes the information gathered through questionnaires (use of the term "lifestyle") and in the introductory text of the information sheet for people aged 18 or over, the CESP recommends that the following terms be added (in bold characters) to the introductory paragraph presenting the survey: "It will also be used to help plan programs and services to prevent heart disease, cancer, anemia, diabetes, and other health or **social problems (such as suicide, violence)**, and to improve living habits and nutrition."

### Regarding the Balance Between the Potential Benefits and Negative Effects for the Individuals Participating in the Survey as well as for the Inuit Community

First of all, the CESP hails the work of the survey directors and work teams and their concern to best serve the interests of the population targeted by the survey. The decision to establish a Consultative Committee in which community representatives would participate and to refer to the region's advisory committee, the NNHC, reflects their concern with taking into consideration and involving the population. The requirement that all researchers intending to publish based on the information collected in this survey must first submit their publications to the Inuit population or its representatives (Design, p. 23) also attests to this respect for

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<sup>32</sup> And of the circumpolar cohort study, since the CESP hypothesizes that the latter will provide for a consent that conforms to the requirements of a free, informed and explicit consent.

the population. The CESP encourages the researchers to take ethical dimensions into account when analyzing the data and, even more, when disseminating the survey results. Moreover, to demonstrate this, the CESP suggests that this consideration of ethical concerns, which guided the researchers, be explicitly and systematically stated when the results are published.

In examining the potential negative effects, the CESP focused particularly on the confidential questionnaires (addressed, respectively, to individuals aged 15 to 17 and those aged 18 or over). Its recommendation to use a different questionnaire for each of these two survey sub-groups was integrated into the survey's development. Thus, the questions on sexual abuse and violence that participants aged 15 to 17 were not asked to answer are not included in the questionnaire intended for them. Means other than the survey are being used to monitor and report on the evolution of these issues since the inclusion of such questions in the survey could have contravened the *Youth Protection Act* or breached the commitment to confidentiality if such situations were reported by minors.

The section of the confidential questionnaire intended for adults, which deals with conjugal violence, also raised concerns. In a household in which a dynamic of conjugal violence already exists, the CESP feared that the fact of knowing that the victim of assault has answered such questions could increase the individual's risk of being assaulted. The working groups studied this question and, based on the decision made in the *1992 Santé Québec Health Survey*, proposed that separate questionnaires be created for men and women, the latter being the only ones asked to answer these questions. However, the Consultative Committee rejected this option since it would make it impossible to learn more about violence against men, a situation that exists within the community and, in their opinion, should also be examined. The Consultative Committee members do not consider the fear that the questionnaire will increase the risks of assault within households to be justified. Moreover, they shared the CESP's view that the level of information initially asked by the questions was unnecessarily detailed; the rewording of this section made it possible to address these comments.

With regard to the concerns raised by the questions on violence or any question of this nature that could provoke suffering with which individuals are trying to deal, the CESP points out the moral duty to be sensitive to the suffering experienced and to offer support. In the context of a survey, this support, at a minimum, consists in informing individuals about the resources available and encouraging them to use these resources. The survey directors informed the CESP that they would make such information available, favoring information on a vast set of resources so that individuals would not be identified as having a particular problem when taking this document home with them. The CESP recommends that the confidential questionnaire, at a minimum, include a message encouraging the respondents who are experiencing problems related to one of the issues addressed, to consult one of the resources suggested in the document available on board the ship. The CESP also asks that the relevance of repeating this message throughout the questionnaire be considered (for example, when questions are asked about sexual abuse or suicide attempts). The CESP believes that it would be preferable to tell respondents that there is an awareness that the questions asked refer to private situations that may be painful. The expression of this sensitivity on the part of the survey directors could be included in the introduction to the questionnaire.

In addition to the effects on individuals, the question of the effects on the Inuit community should be considered. The search for accurate knowledge of health problems, their associated determinants and their evolution may come with negative consequences for the community. The first sign of such consequences may be seen in the inability of the community to recognize itself in a portrait established on the basis of a conception of health that does not correspond to its own conception. The complexity of a definition of health is magnified in a context where a unique cultural tradition is combined with the adoption of an "imported" practice. The fact that the objects of surveillance covered in the survey focus more on problems may also, potentially, reinforce a stereotyped and negative image of the community, which may lead to stigmatization.

Moreover, the community's representatives on the survey Consultative Committee pointed out that the survey included very few questions on positive elements.

### **Regarding Respect for Confidentiality and Privacy**

The CESP underlines that it does not find any ethical problems with regard to the security and confidentiality of the information gathered and finds that the measures provided for to ensure security and confidentiality to be reasonable; in so doing, the CESP is careful not to substitute for the Commission d'accès à l'information du Québec when the latter is asked to give an opinion regarding access to certain information.

### **Regarding the Idea of Health Among the Inuit**

The CESP encourages the survey directors and primary users of the results to pursue their processes of consultation and participation of the community in the analysis and interpretation of the survey results and their possible applications while remaining vigilant as regards the expressions of a relationship to health that may differ (relation to body, to factors that allow individuals to feel in harmony with their body, spirit, social and physical environment, etc.).