

Facilitator’s Report
Privacy Policy Workshop

First Nations, Inuit & Métis Health Human Resource Inventory (FNIMHHRI) Project
Iqaluit, Nunavut
March 6, 2007

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Introduction & Background

In 2004, the Prime Minister, the Provincial and Territorial Leaders, as well as Aboriginal Leaders, jointly announced the creation of the Aboriginal Health Human Resources Initiative. At the same time, \$100 million was identified to be spent over a five-year period to support the new project. The purpose of the new initiative was to establish a foundation upon which real, long-term change could be made in the supply and demand for First Nations, Inuit and Métis professionals in the health sector. The information collected in the First Nations, Métis and Inuit Health Human Resource Inventory (FNMIHHRI) will be used to assist with planning, monitoring and improving the availability of First Nations, Métis and Inuit health human resources.

More specifically, the Initiative has three objectives:

1. To increase the number of Aboriginal people working in health careers
2. To improve the retention of health care workers in Aboriginal communities;
and
3. To adapt current health care educational curricula to improve cultural competence in Aboriginal health care.

Given its role and mandate, NAHO was given the primary responsibility, along with the Canadian Institutes for Health Information (CIHI) and the First Nations and Inuit Health Branch (FNIHB) of Health Canada, to oversee the development of a primary, minimum data set for the Inventory. NAHO is working with the National Aboriginal Organizations, paraprofessional organizations, regional and territorial governments and educational institutions to develop the project. It has established an advisory committee comprised of representatives from each of its partner organizations.

One significant requirement of this Initiative is to develop and to put into place a privacy policy that will protect the privacy rights of those whose data is included in the inventory. This is a complex task because of the nature of the data collection and storage, the privacy issues involved, as well as the large number

of jurisdictions (federal, provincial, territorial and organizational) that need to be considered.

NAHO has been leading the work on this issue, most notably in recent months through a series of workshops with key NAHO personnel and representatives from some of NAHO's partners in the FNMIHRRRI initiative, and has developed a draft policy for consideration. This report presents the discussion held at the most recent workshop, held in Iqaluit, Nunavut on March 6, 2007, and includes this draft policy for review and further discussion.

The Purpose of the Meeting

The National Aboriginal Health Organization (NAHO), as the primary Aboriginal organization responsible for the implementation of the First Nations, Métis and Inuit Health Human Resource Inventory (FNMIHHRI) initiative, is developing a privacy policy to guide the work of NAHO and, to a large extent, its partners in the protection of privacy rights in the course of collecting, managing and disseminating data.

Although work on many of the issues involved in the development of the privacy policy have been considered and studied for years, the first intensive discussions with NAHO partners regarding the approach and content of the policy was not held until the fall of last year. At a workshop in Ottawa on December 14, 2006, NAHO and representatives from some of its key partners began developing a draft policy that would effectively and adequately protect the privacy needs and concerns of all participants in the health human resource inventory. High-level policy principles, respectful of First Nations, Inuit and Métis perspectives, were identified as the start towards an eventual policy document. In some areas, more detailed language on some key issues was also developed.

Following this meeting, a second one-day workshop was scheduled, this time in Iqaluit, Nunavut, where NAHO and representatives from some of its key partners could take the outcomes from the Ottawa workshop an extra step towards completion. The hope was that, by conducting the workshop in Iqaluit, the policy would benefit from a stronger contribution from Inuit groups.¹ The Iqaluit workshop was structured to move the document from “principles” to “policies”, as is explained further below. A copy of the complete agenda for the meeting is included as Appendix “C” to this report.

This report summarizes the discussions from the Iqaluit workshop, and presents the draft policy that has been developed as a result of the direction received from the participants.

¹ To that end, a similar workshop is being considered by NAHO in a Métis community in the months ahead.

Highlights of the Discussion

The discussion generally followed the agenda for the meeting (see Appendix "C). However, the heart of the conversation could be said to have focussed on three large elements:

- **Progress Toward a Policy** - A brief overview of the work that has been done so far, and a presentation on the process that has been adopted for the completion of a privacy policy
- **Data Sources and the Data Collection Process** - A short discussion of the process through which data will come to the FNMIHHRl database.
- **Clause-by-Clause Discussion of a Draft Privacy Policy** - A clause-by-clause review of the draft privacy policy prepared after the previous meeting in Ottawa.

Each of these three main elements is summarized below.

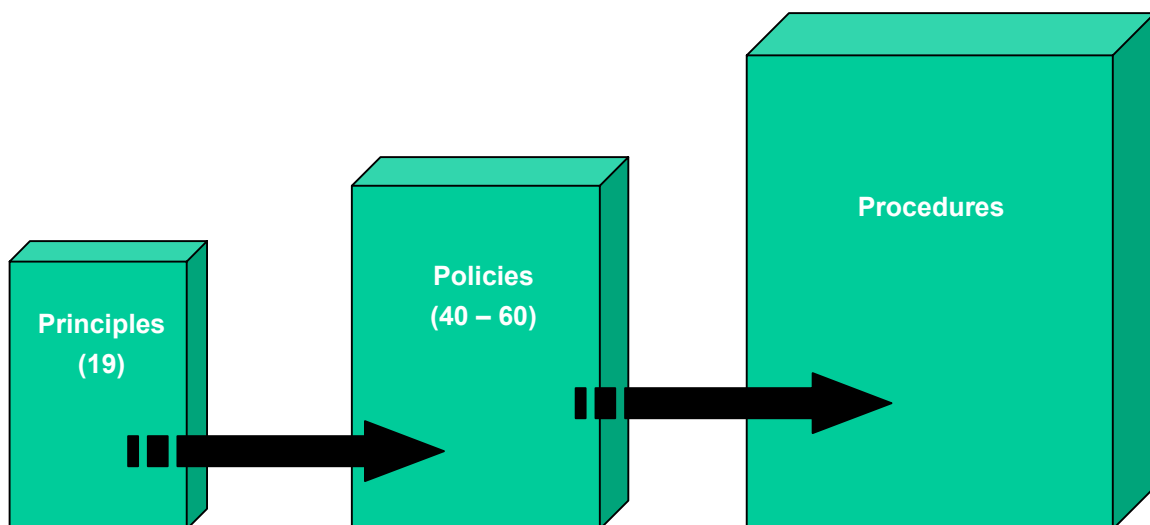
Progress Toward a Policy

Generally, the approach that is being used to develop the policy can be described as the Three "P" approach. This approach involves:

- **Principles** – an identification of some of the important principles that need to be provided for in the policy. Many of these principles have already been identified, such as in the CIHI "ten principles" document, as well as in the work of NAHO and the AFN on the "OCAP" principles of collective privacy. These were presented and discussed at the Ottawa workshop, leading to 19 high-level principles being identified by participants to apply to the FNMIHHRl privacy policy. These were then confirmed at the Iqaluit meeting as the basis for further work, and a few new principles were added and clarified.

- **Policies** – with the main principles largely identified, this three “P” approach then sees the work focus on the next level of detail: specific policies. For each principle identified, one to three specific policies are developed which help to put the principle into action as it relates to the project. It would be reasonable to assume that, for 19 principles, about 40 to 60 policy statements might be generated.
- **Procedures** – however, in many cases, a simple policy statement may not be enough to ensure that the principles identified in the first stage are fully and properly being respected. To that end, it is anticipated that an additional phase of work will be required to add detail and procedural requirements to the policy statements developed by NAHO. This phase would ideally come after the FNMIHHRI initiative has developed somewhat further and, in particular, the specific content of data sharing agreements can be considered.

This three “P” approach is illustrated in the figure below.



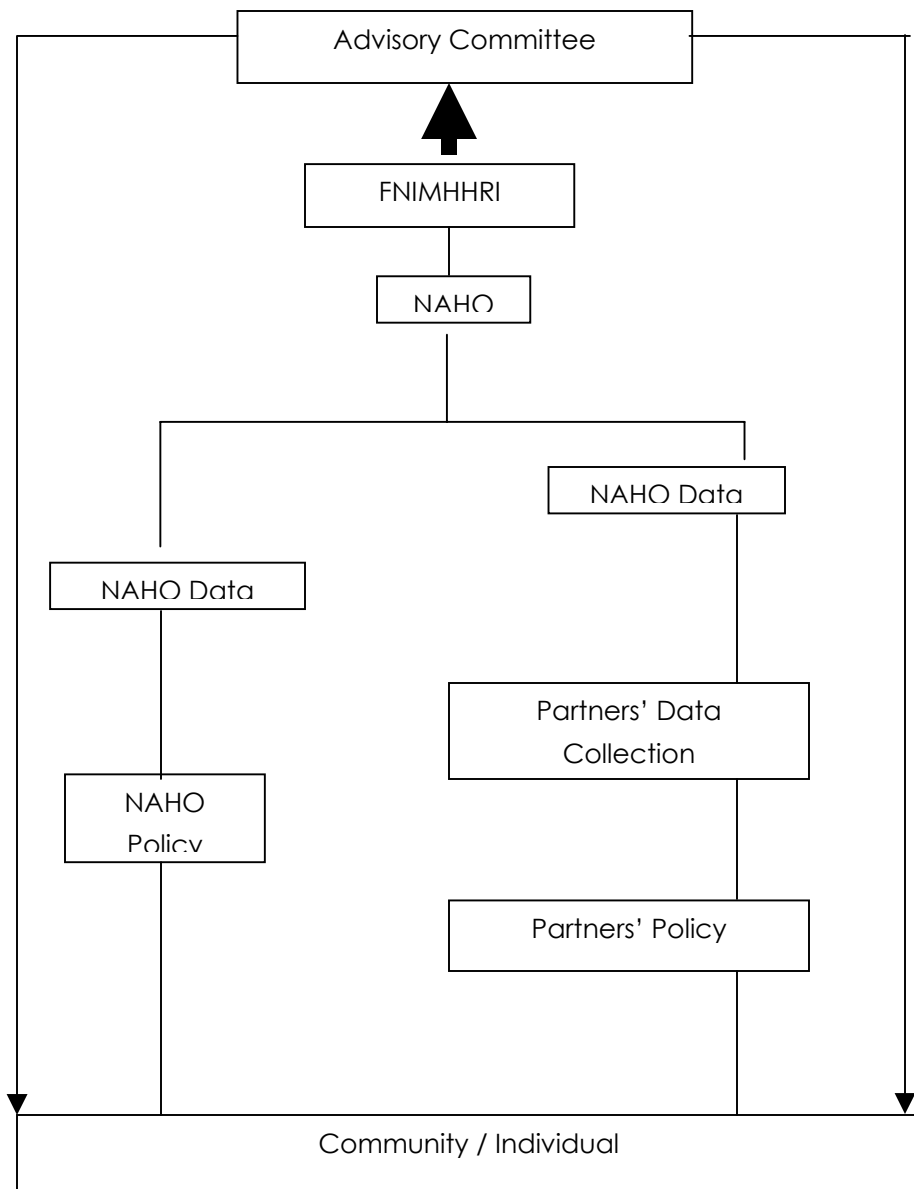
Although some draft policy statements were developed for consideration prior to the Iqaluit workshop, it was at this meeting where the policy content was more completely reviewed, discussed and, in some cases, debated. NAHO's requirement is to have a policy statement in place to apply to the FNMIHHRI

initiative in the next few weeks and, therefore, it would appear that it is well-placed to finalize this phase of the work.

Data Sources and the Data Collection Process

In the course of the discussion in Iqaluit, the participants recognized that the data will be coming into the FNMIHHRI from more than one source, including from partners over whom NAHO may have little control.

Similarly, the group decided that, to identify the appropriate content of the privacy policy, a "road map" would be helpful which helps to illustrate how data will come into the inventory. Mark Buell of NAHO prepared an illustration of the process as he understood what would be in place once data sharing agreements are in place. A representation of this illustration is included below.



The illustration shows that data will come to the inventory through two potential channels: from NAHO itself, as represented on the left side of the graphic. The NAHO privacy would then clearly apply as it relates to data collection, etc.

But data will also come to the inventory from NAHO's partner organizations. This is illustrated by the right side of the graphic. For this data, the partners' privacy policy will apply to those aspects of data collection and usage that occur at any point prior to it being received by NAHO.

There may, therefore, be a requirement to ensure that the privacy policies of NAHO and its partners are somehow harmonized, or at least provide for multiple layers of protection. The draft policy produced for this workshop included some suggested language to this effect (see article 7 in the draft policy provided in Appendix "A").

Workshop participants felt it helpful to refer to this illustration when thinking about what would need to be covered in the privacy policy, as well as what impact the existing statements would have to the future implementation and operation of the inventory.

Clause-by-Clause Discussion of a Draft Privacy Policy

The heart of the meeting, then, was a clause-by-clause review of the draft policy that had been prepared for the meeting, with a view to discuss whether the draft content properly captured the essence of the principles that had been identified.

The result of this discussion was a revised draft privacy policy that is included at Appendix "A". This draft policy builds on the content from the Ottawa workshop, and is supplemented with the feedback received in Iqaluit.

Next Steps

The path ahead, identified at the workshop, consists of the following milestones:

- A facilitator's report from the workshop will be prepared by March 31, 2007 (this document), which will eventually be circulated to project partners for their review. This document includes a draft comprehensive privacy policy which incorporates the input received from workshop participants (see Appendix "A")
- Feedback from the partner organizations on the facilitator's report and the draft privacy policy will be collected
- Another meeting is being considered at which a final, comprehensive review of the policy would be conducted, and ideally finalized. This document may then be subject to a more rigorous legal review.
- NAHO may then begin the process of developing more detailed procedures that would be used to help implement the policy, and apply it to the specific operation of the initiative.

Appendix A – Draft FNIMHHRI Privacy Policy



National Aboriginal Health Organization

First Nations, Inuit and Métis
Health Human Resource Inventory Initiative

DRAFT POLICY ON

THE PROTECTION OF INDIVIDUAL AND COLLECTIVE PRIVACY

First Nations, Inuit and Métis
Health Human Resource Inventory Initiative

Purpose

This Privacy Policy applies to the First Nations, Inuit and Métis Health Human Resource Inventory (FNIMHHRI).

1. This Policy applies to the National Aboriginal Health Organization (NAHO), its centres (the First Nations Centre, the Ajunnginiq Centre and the Métis Centre), its staff, as well as any of its partner organizations to the extent they are involved in the First Nations, Métis and Inuit Health Human Resource Inventory (FNIMHHRI) project (hereafter referred to as "the Initiative"). It applies to all aspects of data collection, analysis, management, storage, interpretation and dissemination of data included in the FNIMHHRI database.
2. This privacy policy has been adopted to protect the privacy of the individuals, communities and organizations whose information has been used for the purposes of the Initiative.

3. This Policy has been developed to take into account the diversity of the First Nations, Métis and Inuit populations while protecting their individual and collective privacy rights regardless of residency, in the context of the Initiative.
4. Any information collected under this Initiative, both primary and secondary, will only be used for the purposes of the Initiative, that being to “provide baseline information for planning policies and programs to increase the recruitment, retention and training of First Nations, Métis and Inuit people in health careers” and to (eventually) allow for the tracking of changes and gauge the effectiveness of those policies and programs.

It is intended that this Policy, and the procedures used to implement it, will harmonize with and add to the protections provided by other FNMIHRRRI partners.

5. This Policy is meant to support the privacy protections established both now and in the future of all FNMIHHRRI partners and, wherever possible, add to those protections.
6. As partner organizations develop or modify their own privacy policies, this Policy will be reviewed and amended accordingly to ensure that eventually a strong degree of harmonization between policies is reached and maintained.
7. Should there be any inconsistency between this Policy and the privacy policies of partner organizations, the more rigorous policy will be applied wherever reasonably possible.
8. It is assumed that, before partner organizations enter into data sharing agreements with NAHO as part of the Initiative, they will have developed and implemented their own privacy policy that addresses the main elements of this Policy in a similar manner.

Accountability

This privacy policy is intended to be open, public and transparent.

9. NAHO and its FNMIHHRI partners will make every reasonable effort to be open and transparent about its privacy policies and practices.
10. A copy of this privacy policy will be posted on the NAHO website, and made available at any time to all FNMIHHRI partner organizations, interested individuals and First Nations, Métis and Inuit organizations.

NAHO is the organization primarily responsible for the FNMIHHRI project.

11. Although a number of partner organizations are involved in the FNMIHHRI, the National Aboriginal Health Organization (NAHO) is the Aboriginal partner primarily responsible for the development and implementation of the HHR planning model and minimum data set.
12. To that end, the principles and policies which govern the work of NAHO also apply to the FNMIHHRI, including the following principles:
 - a) Our work recognizes and works within the Canadian Constitution, treaties and land claims agreements.
 - b) Our work is participatory and seeks the voices of First Nations, Inuit and Métis.
 - c) Our work contributes to self-determination by enhancing social change, the use of language and cultural maintenance and revitalization.
 - d) We work with our partners while ensuring cultural competency and safety; the development of skills and employment; and the use of Aboriginal language/s whenever possible.
 - e) Our work balances the protection of both individual and collective privacy rights.
 - f) We maintain transparency and accountability to First Nations, Inuit and Métis and those who fund this work.

Partnerships

NAHO and its FNMIHHRI partners commit to building partnerships with appropriate First Nations, Métis and Inuit leadership in all stages of the FNMIHHRI.

13. NAHO and its FNMIHHRI partners commit to developing partnerships with, and respecting the involvement of, the appropriate First Nations, Métis and Inuit leadership for the purpose of design, development, implementation, analysis, interpretation storage and dissemination of data.
14. These partnerships will be secured in the form of formal agreements between NAHO and these partners, and will facilitate the collection of the information necessary to build the FNMIHHRI.

The Protection of Individual and Collective Privacy

This Policy will be consistent with privacy legislation in effect in all jurisdictions in Canada.

15. The content of this policy, and the manner in which privacy rights will be protected within the context of the Initiative, shall be guided by the relevant legislation in all jurisdictions in Canada.

This policy recognizes that a First Nations, Métis or Inuit community or group possesses collective privacy rights with respect to health and other information relating to it.

16. This policy also recognizes the collective privacy rights of First Nations, Inuit and Métis communities or groups and, therefore, strives to apply the principles of self-determination and self-governance to the collection, management and dissemination of data within the context of the Initiative.
17. Whenever possible, the principle of First Nations, Inuit and Métis possession of their own data will be applied as a mechanism to assert and protect ownership, and to avoid the misuse or misinterpretation of this data.
18. More specifically, the collection, storage and management of data in the FNMIHHRI will be guided by the principle of collective ownership in all aspects of the Initiative
19. At all stages in the execution of the FNMIHHRI project, free and informed collective consent must be obtained at the community, tribal, and/or regional level, in addition

to the free and informed consent of the relevant individual, before the information is collected, used or distributed.

20. Organizations which represent First Nations, Inuit and Métis people and communities have a right to control the research and information management processes which affect them, including research projects, policies, processes, frameworks, etc.

Data will not be used in a way which will identify individuals or communities or be used in a way that may be detrimental to their interests

21. Information collected for the purpose of the FNMIHHRl will only be used for this purpose, and will not be used in a way that may be detrimental to the interests of First Nations, Inuit or Métis individuals, communities or organizations

Collection of Data

The definition of “personal information” will be broad, to include any information that could be used to identify someone

22. A definition of “Personal Information” will be used which means any information that could be used to identify someone, such as their name, address, telephone number, age, sex, marital status, education, social insurance number, race and ethnic origin, identification numbers, income, blood type, evaluations, employee files, and health or medical records.

23. This might include collective or communal information, in some instances, such as Band membership, tribal affiliation, status or non-status, Métis settlement, community, or language, to give some examples.

The purpose for the collection of information will be identified prior to collection

24. NAHO and its FNMIHHRl partners will identify the purposes for which they collect personal information prior to its collection.
25. NAHO and its FNMIHHRl partners will only collect and use that personal information which is needed to fulfill the purposes identified in the work plan, research plan or research agreement which governs the specific research being done.

NAHO and its partners will obtain ensure informed consent is obtained before personal information is collected.

26. NAHO and its partners will ensure that free and fully informed consent is obtained before personal information is collected.
27. Informed consent means that the individual, community or organization providing the information knows from the outset why their personal information is needed, what the purpose of the research is, how the information will be used, who the information will be shared with, how long it will be kept and what will be done with it when it is no longer needed.
28. In seeking informed consent, NAHO and its partners will consider both the sensitivity of the information and what a reasonable person would expect and consider appropriate in the circumstances when determining what form of consent to use.
29. Individuals, communities or organizations will not be subjected to any undue pressure or influence when approached to participate in research activities and processes.
30. There are some circumstances in which NAHO and its partners may receive information in which it is impossible to obtain consent, for example, information which has been "de-identified," or statistical or historical information. In those limited circumstances, it will not be possible to obtain consent for the collection, use or disclosure of information, as this would be impractical or even impossible.
31. In all other circumstances, NAHO and its FNMIHHR partners will require that consent is expressly given in writing, before personal information is collected, used or disclosed.
32. NAHO and its FNMIHHR partners will require that the consequences of withdrawing consent are explained at that time as well. Individuals will be given a chance to refuse to share their personal information. They will also be able to withdraw their consent to the use of their personal information at any time during the research process. If they choose to withdraw their consent, their personal information will be removed from the research database and will either be returned to them, or destroyed.
33. Consent is a continuing process and ongoing consultation with community members and/or nation citizens will be necessary at every stage of the process. If an individual belonging to a community that has consented to participate in research later

withdraws their individual consent, their personal information will be removed from the research database and either returned to them, or destroyed.

NAHO and its FNMIHHRI partners will make reasonable efforts to ensure that information is accurate and complete at the time it is collected

34. NAHO and its FNMIHHRI partners will make reasonable efforts to ensure that the personal information they collect uses or discloses is accurate and complete at the time it is collected.
35. NAHO and its FNMIHHRI partners will ensure that appropriate systems and methodologies are in place to ensure that information is accurate and complete.
36. On occasion, individuals may wish to correct errors in their personal information. Where it is reasonable to do, corrections will be made. However, it may not be possible to correct information which has been "de-identified," or has been published, or where NAHO and its FNMIHHRI partners do not have custody or control of the information. In such instances, individuals will be informed of why the information cannot be changed.

Data Storage

NAHO and its FNMIHHRI partners will keep personal information only for as long as it is needed to fulfill the identified purposes.

37. NAHO and its FNMIHHRI partners will only keep personal information for as long as it is needed to fulfill the purposes that were identified at the time written consent was provided.
38. This time period may vary, depending on the particular research involved. However, NAHO and its FNMIHHRI partners will not retain an individual's personal information for any longer period of time without their further written consent.
39. Under NAHO's IT policy, data is returned to the individuals or communities who provided it wherever possible. If personal information has to be destroyed, secure methods are used, such as erasing electronic records and shredding paper records without keeping any copies.

Security arrangements need to be in place to prevent unauthorized access, collection, use, disclosure, copying, modification or disposal of personal information.

40. If NAHO or its FNMIHHRI partners retain an individual or an organization to do research that involves personal information, they will ensure that there is a contractual or other agreement in place that commits the individual or organization providing services to comply with this privacy policy, such as through a confidentiality agreement.
41. Much of the information in NAHO's custody is electronic. Under NAHO's IT policy, NAHO's electronic information is stored off-site and is protected by firewalls. It is also backed up regularly and is accessible only to authorized persons by password. NAHO is also working on a template for its contracts with researchers that will require them to abide by the same security provisions that apply to its employees.

Access

Individuals have the right to access their own personal information at any point in the research project and process.

42. Individuals have the right to access data about themselves and their communities at any point in the research project and process. They will also have access to descriptions of the research objectives and methods at all times.

Upon request, an individual will be informed of the existence, use, and disclosure of his or her personal information and will be given access to that information

43. Where research is being conducted that is community or regionally-based, or otherwise collective in nature, guidelines and procedures for access to data will be agreed upon with the relevant authorities representing the community or collectivity participating in the research, and will be outlined in the research plan.
44. At the stages of collection and dissemination of data, consent will be obtained where possible from the appropriate level or source (to be developed)
45. Because of the sensitivity of personal information, requests by an individual for access to their own personal information must be made in writing. NAHO and its FNMIHHRI partners may require that individuals prove their identity before giving them access.
46. On receiving a written request for personal information, individuals will be informed of what personal information of theirs is held by NAHO and its FNMIHHRI partners, and

will inform them how the information is being, or has been, used and the names of the individuals and organizations to which their personal information has been disclosed. Requests for personal information will be answered as soon as reasonably practicable after the written request is received.

47. There may be situations in which it is impossible to provide access, such as where information has been “de-identified,” or where NAHO or its FNMIHHRI partners do not have custody or control of the information. If an access request is denied, the applicant will be informed of the reason why and will be informed of what further steps may be available to him or her.
48. Where a request is made for information by a government agency, NAHO and its FNMIHHRI partners may require that the request be made by an authorized official in writing, on government letterhead, for example. Third parties requesting data will be required to enter into a data sharing agreement with NAHO that respects this Privacy Policy.
49. NAHO will respect existing national, regional and local protocols (to be developed)

NAHO and its FNMIHHRI partners will not disclose personal information to outside agencies, and will never sell or rent personal information to third parties.

50. NAHO and its FNMIHHRI partners will not disclose personal information to outside agencies and will never sell or rent personal information to third parties.
51. In certain circumstances, NAHO and its FNMIHHRI partners may be required by law to disclose personal information without consent only, for example, due to a court order or a search warrant.
52. Where personal information is used for research purposes such as publication and communication activities personal information will be made anonymous (“de-identified”) and will remain confidential.
53. In all cases, NAHO and its FNMIHHRI partners will take steps to ensure that the dissemination of information meets accepted research standards of ethics and protocols.

Redress

Individuals will be entitled to challenge the compliance of NAHO and its partners with this policy

54. An individual will be able to address a challenge concerning compliance with this policy as it relates to the FNMIHHRI to (to be determined whom), who is accountable for compliance.

Appendix B – Meeting Participants

Chris Barney (National Aboriginal Health Organization)

Mark Buell (National Aboriginal Health Organization)

Ian Kenney (Consilium)

Jeff Tabvahtah (National Aboriginal Health Organization)

Nadine Grow-Louis (Assembly of First Nations)

Deborah Hyndman (First Nations and Inuit Health Branch – Health Canada)

Evelyn Korkmaz (Native Women's Council of Canada)

Carole Lafontaine (National Aboriginal Health Organization)

Susan McBroom (Oopiks Consulting)

Danielle Soucy (National Aboriginal Health Organization)

Clayton Thomas-Muller (National Aboriginal Health Organization)

Barbara Van Haute (Métis National Council)

Erin Wolski (Congress of Aboriginal Peoples)

Appendix C – Meeting Agenda

National Aboriginal Health Organization

NAHO - FNIMHHRI Privacy Policy Workshop

March 6, 2007

Iqaluit, Nunavut

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|------------|--|
| 8 a.m. | Coffee |
| 8:30 a.m. | Introductions
Opening Prayer
Opening Comments: Carol Lafontaine, CEO, National Aboriginal Health Organization |
| 9:00 a.m. | The Spirit of this Work and NAHO's Role – Clayton Thomas-Muller, National Aboriginal Health Organization |
| 9:15 a.m. | Our Path Towards a Privacy Policy – Ian Kenney, <ul style="list-style-type: none">○ Introduction○ What Needs to Be Achieved○ Approach to Brainstorming |
| 9:30 a.m. | Overview of Privacy Principles (Discussion) |
| 10:30 a.m. | Break |
| 10:45 a.m. | Policy Development Discussion |
| 12:00 a.m. | Lunch |
| 1:00 p.m. | Policy Development Discussion (cont'd) |
| 2:15 p.m. | Break |
| 2:30 p.m. | Policy Development Discussion (cont'd) |
| 4:15 p.m. | Summary Discussion |
| 4:45 p.m. | Closing Comments
Closing Prayer |