Aboriginal Women's Health and Healing Research Group (AWHHRG)

Report on the Regional Consultation held in

Kahnawake, Quebec – April 3, 2006

Opening prayer

The consultation meeting of the Aboriginal Women's Health and Healing Research Group (AWHHRG) opened with a prayer given by Doris A. Bobbish.

Introductions by the meeting chair

Ms. Michèle Rouleau was the bi-lingual facilitator for the meeting which provided simultaneous French/English translation. She introduced the three following representatives of the AWHHRG: Linda Day (Executive Director), Judy Hughes (Chair) and Marlyn Bennett (Consultant).

Opening remarks by Linda Day and Judy Hughes
Ms. Day and Ms. Hughes introduced themselves and gave a brief history of the AWHHRG. They said that the Kahnawake session was one of three cross-Canada meetings planned to present the Group's research and to obtain input and suggestions concerning regional priorities. The first consultation was held in Alberta in September 2005, followed by the Kahnawake session of April 3, 2006, being held for Quebec region and by a third consultation, intended for the Atlantic provinces and scheduled for April 21-22. The report on the first consultation is available at the Group's website (www.awhhrg.ca).

Presentation of the types of research by Marlyn Bennett
Consultant Marlyn Bennett presented the types of research. She began by saying that she compiled the bibliography on the basis of existing research found in various sources (Internet, government publications, Master's and Ph.D. theses, etc.). She noted that the bibliography also contained a small amount of material from the United States, which was selected only because it contained some Canadian content.

The bibliography is broken down into 13 thematic sectors. Ms. Bennett used the *Reference Manager Database* to produce the list of key words. The bibliography can be consulted numerically and alphabetically. It is available on hard copy and from the Group's website www.awhhrg.ca. Ms. Bennett said that the step following completion of the bibliography was to identify gaps in the existing research. She then listed these gaps as follows:

> Alzheimer's, Arthritis, Pain, Dental & Vision Care, Child Welfare, Prescription Use, Young Women on the Street, and Support Groups for cancer and other illnesses.

While minimal coverage may mean minimal importance, these gaps may point to new directions for research or to limitations in historical or existing health research frameworks. Ideally, such a foundation will guide health researchers and policy makers to find appropriate answers to the health and healing needs and aspirations of Aboriginal women in Canada.

Discussion on Aboriginal women's health

- **Comments on the bibliography**

It was mentioned that very little specific information on the Aboriginal peoples is available and that researchers may find the bibliography to be a highly useful document.

The comment was made that sexuality is included under the theme of violence and that it could instead be categorized instead as a distinct theme under sexual health.

- **Comments on the methodology**

It was further noted that there are no publications on Aboriginal research methodology. Aboriginal researchers follow an Aboriginal methodology, but the universities are not necessarily concerned about doing so. How does a researcher affect the research? They supposedly come to their research without any bias, but their personalities always have an impact on their research. There is no single right way to do research, but we must deal with the issue of methodology; otherwise, concerns that the research is biased will arise.

A great deal of health research is conducted by researchers who have institutional medical backgrounds. Their research may pose a problem because they only use their methodology.

Aboriginal communities need their own specific methodology to conduct research or even to participate in research. The Assembly of First Nations of Quebec and Labrador has adopted the research protocol developed by the First Nations of Quebec and Labrador Sustainable Development Institute (FNQLSDI) and the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC). This protocol covers in particular the relations to be established between First Nations and outside researchers as a means of ensuring that the latter take account of First Nations realities in their work.

The communities need tools such as this research protocol because they are asked to take part in numerous research projects. Their specific situation and needs must be taken into account when they decide to take part in a research project or to initiate their own project. Unfortunately, university researchers first want to use a university-based methodology. They must be made aware of the principles set out in the First Nations' research protocol, in particular the OCAP principles used in Canada as developed by the National Aboriginal Health Organization (NAHO).

It was noted that the AWHHRG respects the Ownership, Control, Access and Possession (OCAP) research principles; however, AWHHRG employs a gender-based approach because it is specifically concerned about women's health and healing.

It was also noted that methodology must incorporate more aspects in addition to following a protocol. How is knowledge created? How is it interpreted? Respect of Aboriginal knowledge

must be incorporated into research. For example, the plants used for healing under the Innu pharmacy project were labelled by their Innu names because their meaning in Innu is fundamental to ensuring healing. Further to healing physical conditions, the Innu pharmacy has helped in the effort to prevent the loss of the Innu language and culture. This work was done in collaboration with elders, i.e., the language experts and teachers who knew the language of the forest, even though this language was beginning to disappear.

The language of the community is not as rich, linguistically speaking, as the language of the forest. Furthermore, the Innu pharmacy does all its work in the Innu language only, so as not to lose information, or knowledge that the pharmaceutical companies want to obtain and profit from. The universities want to work with this Innu knowledge, but they remain cautious about its use. The Innu pharmacy is very open to other communities and to the sharing of its territory. Its experience has shown that methodology must come from the communities themselves; otherwise, the knowledge they posses can be lost.

An example was brought forward with regard to dietetics in which, for example, the emphasis is very much on nutriments. Researchers do not take the time to listen to the reasons Aboriginal people give for eating certain types of food, or to find out about the impact that eating these foods has on their lives. Dietetics is governed by certain dominant factors which are reflected in the methodology.

Language is a key factor in the development of knowledge. It is important, especially regarding qualitative research, to write things down in Aboriginal languages for purposes of interpreting the data and for ensuring that the data can be validated by the communities. The use of Aboriginal languages permits better appropriation of the results, while at the same time helping to keep these languages alive and providing means for their transmission to younger people. This by itself is an education process serving to preserve Aboriginal languages.

When research is done in the communities by outside researchers—and there is a great deal of this kind of research—the interpretation of results by these researchers take precedence, and then nothing is done to resolve the problems at stake. For example, studies on suicide have not brought forth any solutions. We must pay attention to the type of research involved and the subsequent reports that are written up, reports which too often treat Aboriginal people as problems to be resolved, which reduce them to mere objects for policy debates.

Research must be useful and have practical applications in the communities. Researchers must include among the steps in their planning one which will ensure the transfer to the community of knowledge acquired through their research. How can the results of research be used not just to resolve problems but also to further the work being done to support various causes?

There are people in the communities with knowledge about the topics covered by research, and no time must be wasted in the effort to persevere this knowledge. Elders possess knowledge that will be lost if it is not transmitted to others before they die. Cultures must be preserved even though they evolve and are not frozen in time.

Quebec's Institut national de recherche scientifique (INRS) has a working group, known as DIALOG, which works on issues in Aboriginal research methodology. One of the dangers mentioned in this regard was that the communities may not always be able to validate the interpretations that outside researchers give to their research data.

It was mentioned that the approach used by the FNQLHSSC for the First Nations Regional Longitudinal Health Survey involved centralizing all information, at the same time preserving the communities' ownership of that information. The FNQLHSSC was the organization that conducted the analyses and had the analyses validated by various partners. It also made sure that the findings presented in the final reports on the survey took the perspective of the communities into account. In so doing, it was able to provide the information in the form desired by the communities.

Aboriginal researchers also make the conscious decision to assume their responsibilities for their research and to find means for making it adequate from the communities' perspectives. Overall, university researchers, Aboriginal or non-Aboriginal, want to understand and learn more about Aboriginal realities, and they may be open to modifying their practices.

We need to free ourselves of a non-Aboriginal worldview, one in which Aboriginal researchers use a methodology that is respectful of Aboriginal people while other researchers do not. In this context, Aboriginal researchers can play a broker (go-between) role here, i.e., by explaining how things work in the universities to the people in the communities and vice-versa. Points of divergence must be found between the two worlds. This is one of the major challenges facing Aboriginal research methodology.

University researchers must also learn about Aboriginal realities by going to the communities. It may be easy for them to sanitize the statistics when they don't know the realities. The communities must be able to validate the results and to ensure that the results take their perspectives into account. Research done by the universities must be simplified so that it is more accessible to the communities.

Ideally, it would be preferable to see research done by Aboriginal people or to allow the communities to select the research teams they want to work with. Funding is a major problem in community research seeing that the communities are still highly dependent on governments. Because of this dependence, their needs are often dictated to them, while the needs they identify themselves are not necessarily taken into account.

- **Comments on qualitative research and quantitative research**

Comments were also made about these two types of research. It was noted that they should not be considered separately. They are often presented as contrasting options and the researchers are asked to choose one or the other. Using both two types of research can be difficult.

Qualitative research is particularly important given the need for an approach that is respectful of Aboriginal people, their cultures and their realities. However, given the nature of qualitative research, there are no certainties that it will lead to an adequate interpretation and analysis of data. Research must be conducted differently, with controls from start to finish, among other things, in order to support and strengthen Aboriginal cultures and values.

- **Topics identified as presenting possible gaps in existing research**

  - ✓ Lupus.
  - ✓ Immunity illnesses, especially in rural regions.
  - ✓ Sexual health from the perspective of a healthy lifestyle (includes love, intimacy, the couple relationship, marital and pre-marital relations, and sex education).
  - ✓ The high frequency of diabetes problems.

- ✓ A positive approach to health: When it comes to health, problems take centre stage although it would clearly be beneficial to stress the positive impacts of actions on the health of the communities' populations. Rather than focusing on problems, it would be a good idea to focus on strengths. This positive approach should be expanded to include education and the re-appropriation of everything having to do with health.
- ✓ The need to go further than acknowledging the presence of illnesses, for example, diabetes: It is important to look beyond the illness by doing research on its causes and studying its impacts on peoples' lives.
- ✓ The impacts of decolonization on peoples' lives: The loss of values, language and culture make up a major health determinant. Decolonization can resolve many health problems. But how far can it go? What does decolonization mean in reality?
- ✓ The impacts due to the death of elders and the loss of their oral knowledge.
- ✓ The high number of deaths of young mothers' babies: Young mothers need support in the mother-child relationship, particularly those who do not live with their mothers or grandmothers. In the past, the mothers and grandmothers played the role of educators in this regard.
- ✓ The overall lack of efforts to prepare young people for life: Young people are often left to themselves, which leads to excesses in their lifestyles. Action plans, along with strategies for building awareness, must be developed, with the focus not on problems but rather on educating youths, young mothers in particular.
- ✓ The body image of young girls, how they see themselves now and in their future roles.
- ✓ The roles of women in the communities: These roles are highly diverse (mother, wife, natural helper, paid worker - but often at a low salary, single parent living below the poverty threshold). Women have few resources that they can turn to for support. The existing programs are not necessarily adequate. These difficulties have impacts not only on the women, but also on their families and communities.
- ✓ The impacts of environmental damage on northern communities (food, water, etc.), and on children's health in particular.
- ✓ The impacts of pollution on women in southern communities and in urban centres.
- ✓ Mercury poisoning following the construction of hydroelectric dams.
- ✓ The study of women in their daily lives and the impacts that their day-to-day activities, e.g., their role in food and nutrition, have on their health and the health of their families.
- ✓ The need for concrete tools in the communities to keep members there and in good health.
- ✓ Cree encephalitis (*awashaksun* in the Cree language): This illness affects Cree newborns (boys and girls) only. The children born with this disease seldom live beyond the age of four. Its cause is not yet known and it continues to perplex researchers. The parents suffer a great deal in knowing that their children will not live much longer past the age of four. Support groups have been created to help them and research was recently begun, but there is a strong need for much more research on this illness.
- ✓ Sending Aboriginal woman living in remote northern regions south to give birth: Currently, this practice is being required of all women in these regions. The traditional birthing method is no longer considered. Family members no longer take part in the birthing process, except the mother of the woman giving birth or the father of the child. There are financial burdens to be considered as well, since, often, the costs of just one person are paid. In addition to huge costs, a family member who wants to participate in the birth must travel long distances and may arrive too late. There is also a language barrier. Sometimes, if a family member is not able to attend the birth, the family member(s) view the newborn as a stranger among them. The traditional preparation for welcoming a newborn is also being lost because the baby is not born in the community. The number of Aboriginal women who breastfeed is lower than in the Quebec population

overall. The Cree make all objects (clothes, bedding, and toys, etc.) for their children by hand. These gifts do not have the same value or significance if they are store-bought, because people make them out of care and love. People who are not present at the birth feel they have been left out; this applies especially to female elders. They feel they are useless because they are not there. The biological connection between the newborn and the family/community is not a given if the child is born outside the community. Sometimes, the elders teach by telephone, a method which is very different from teaching in person.

- ✓ The birth of more girls than boys in the Aboriginal communities.

- **Suggestions for various strategies and methods**

- ❖ Create a discussion forum on such topics as methodology and research.
- ❖ Develop communication strategies to avoid having to repeat the same problems and needs and to avoid the feeling that we are always starting over again.
- ❖ Consolidate the network of women's health professionals which already exists at Quebec Native Women's Association (QNW).
- ❖ Use research as a basis for obtaining improvements in policies.
- ❖ Add the variable of women's ages for the next steps of the research headed by the AWHHRG because the issues vary according to age.
- ❖ Take account of the variable of residence (on-community vs. off-community) in addition to distinct regional approaches.
- ❖ Reflect on the limitations involved in identifying issues at a consultation session such as this one, which the AWHHRG organized. The participants here have limited experience and Aboriginal women want to be involved in the work to identify these issues. It was noted that even though not all First Nations or communities were represented, the issues that were identified are the same for all.
- ❖ Make the medical community, e.g., the nurses and others in the communities, aware of the benefits of using traditional knowledge.
- ❖ Build similar awareness among representatives of Health Canada, which does not fund research that does not use a scientific methodology.
- ❖ Encourage women to get involved at the political level because intervening in health issues requires, among other things, working to protect our territories. There are links between self-government and the health needs of people.
- ❖ Maintain control of research, including its methods, objectives and uses.
- ❖ Action plans for efforts to change behaviours should include long-term objectives. For example, self-esteem is not achieved following a two-day training session. Medium-term and long-term programs are necessary. Women should be consulted at the grassroots level so that they can contribute to these action plans.
- ❖ Create an on-line or paper journal on Aboriginal women's health.
- ❖ Take account of the linguistic specificities of Quebec region. Aboriginal people in Quebec speak French, not English, so documentation should be translated into French and into the Aboriginal languages if possible. This latter translation could be done by the communities.
- ❖ Make sure that the research on any specific problem covers the persons the most affected by that problem. They are the ones who are living through the problem in question. They may not have access to resources or the Internet, and they may not be able to read. Some First Nations depend more on oral traditions. Also, in some First

Nations, the people do not all speak the same language. For example, Innu is not used by all the Innu communities.

- ❖ Keep consultation participants up to date on the future work of the AWHHRG.

Closing of the meeting

Thanks were expressed to the participants, the AWHHRG representatives, Michèle Rouleau and Andrée Savard (recorder) for their involvement. The meeting concluded with a prayer given by Doris A. Bobbish.

Consultation participants

Doris A. Bobbish, Director - Eeyou (Cree) Nation – Quebec Native Women
Linda Cree, National Aboriginal Health Organization
Treena Delormier
Ellen Gabriel, President – Quebec Native Women Inc.
Wanda Gabriel, Social Worker, teacher, trainer - Independent
Linda Girard, Health Coordinator – Quebec Native Women Inc.
Suzy Goodleaf, Psychologist – Goodleaf Consulting
Nancy Gros-Louis, Technician - CSSSPNQL
Prudence Hannis
Tina Houle, Director – Algonquin Nation – Quebec Native Women
Rita Mestokosho, Pharmacie (traditional) Innu – Conseil de bande Ekuanitshit (Mingan)
Janine Metallic, Bachelor of Science (Psychology) McGill
Joyce Rice
Chantelle A. M. Richmond
Julie Rousseau, Secretary/Treasurer – Quebec Native Women Board of Directors

Marlyn Bennett, Linda Day and Judy Hughes (AWHHRG)
Michèle Rouleau (consultation facilitator)
Andrée Savard (consultation secretary)

Note: This report was translated from French to English and edited by the Executive Director of AWHHRG. A copy of this document in French can be found at www.awhhrg.ca