
HEALTH CANADA - FNIHB

NETWORK FOR FIRST NATIONS ENVIRONMENTAL HEALTH RESEARCH AND COMMUNICATION WORKSHOP

SUMMARY REPORT of Key Discussion Points

Ottawa, Ontario

March 23, 2007

Prepared by:



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1. INTRODUCTION AND START-UP

This report summarizes the results of a meeting held on March 23, 2007 at the Delta Hotel in Ottawa. The objectives of the meeting were to:

1. relaunch the project of implementing a National First Nations Environmental Health Network;
2. agree on the key functions of the proposed Network;
3. determine the level of support for the network among stakeholders; and
4. strategize and plan next steps.

The day included presentations and small group and plenary discussions. A list of participants is provided in Appendix A.

WELCOME AND OPENING REMARKS – ROY KWIATKOWSKI

Roy welcomed participants, and noted that this is a very timely meeting because it coincides with the Health Canada planning process for 2007-2008. He indicated that the information from the meeting will be used to plan activities that will help this initiative move forward.

INTRODUCTIONS AND EXPECTATIONS

The facilitator, Lise Hebabi, briefly reviewed the agenda and process for the day, then invited participants to introduce themselves to the group and share any expectations they had for the day. The following expectations were shared:

- Hope it goes well
- Something concrete that will allow us to go forward
- Listen and learn
- Learn about what happened in the past years, is the idea still relevant, and if so how do you facilitate its growth
- Understand how this would be useful for First Nations in addressing environmental concerns
- How this can facilitate the collaborative work the Schulich school of medicine and dentistry is doing with First Nations
- What the roles could be to help move this along
- Exploring potential partnerships
- Find a way for the Canadian Water Network to help and support this network's growth
- How can the Public Health Agency of Canada (PHAC) take a larger role and help out
- Collaborate in this new initiative
- Bridge the gaps that may exist – get precise clarity on the purpose of the network

2. EVOLUTION OF THE FIRST NATIONS ENVIRONMENTAL HEALTH NETWORK

Presenter: Dr. Laurie Chan

Laurie reminded participants of the close link between the land and the concept of wellbeing for aboriginals, then reviewed earlier attempts to develop and formalize a network to share information and expertise on environmental health for aboriginals. He talked about the work that he did to develop a "clearinghouse" for about 5 years to refer people to the right expertise, conduct pilot studies with communities, and help communities with proposals. Since the funding for his original work ended, he has tried to continue



providing this kind of support, but he is limited by the lack of resources. Two years ago, FNIHB provided funding for a workshop that brought together a group similar to this one, but larger, with participants from the communities. As a result of that workshop, a working group was formed and a lot of effort went into a proposal to the Networks of Excellence for the creation of a more formal network. Unfortunately, the proposal was not accepted, and the group lost momentum as a result. Today there continues to be interest in the idea from many directions, and renewed support from FNIHB to take it to the next level.

Following Laurie's presentation, one participant asked Laurie what he thought the reasons were for the network not picking up and moving ahead by itself. Laurie responded that it is basically a question of resources and availability – everyone is busy in their own right, and it is hard to support such an effort without a dedicated resource. He also said that the level of interest may not have been high enough two years ago, and that circumstances have changed today. More and more committees are engaging in this type of research, and the need to help each other is stronger – we just need to find time and manpower to do what is required.

Donna Mergler saw a link with a communities of practice network that she has been involved in, and offered to provide information about the model for the group's consideration. It was agreed that this would be done just before the discussion on models, after the presentation on the Canadian Water Network.

3. PERSPECTIVES FROM KEY STAKEHOLDERS

In this part of the agenda, presenters from the following organizations provided their perspective on the proposed Network: the Assembly of First Nations (AFN), Health Canada, the National Collaborating Centre for Aboriginal Health, the National Collaborating Centre for Environmental Health, and the Public Health Agency of Canada.

ASSEMBLY OF FIRST NATIONS, ENVIRONMENTAL STEWARDSHIP PROGRAM (STUART WUTTKE)

Stuart provided some background information on the Assembly, its mandate and structure. He explained that the AFN's main activity is to advocate on behalf of First Nations, and they have developed the capacity to work on a number of issues on behalf of FN and to provide expertise. He indicated that Environmental Health is one of the programs in which they have been involved for some time, and that it is often overlooked by government because it is not considered a priority.

With respect to research, Stuart stated that there is a lot going on across Canada and the world, but the results are not widely known. They are often locked up in universities and research centres, and the AFN would like to ensure that First Nations communities are given this information to use it to their advantage. There are a number of challenges in achieving this, particularly with regards to ownership and control, access by First Nations communities, and intellectual property rights. On the other hand, First Nations are concerned that there has been a lot of research done on their communities, but that they do not have access to their own information. This causes a lot of distrust with regards to researchers, although processes are improving.

Stuart also talked about issues related to traditional knowledge and how it is valued. He said that traditional knowledge, for many communities, is one of the only things they have left of their traditional way of life, and it is very important to them. The AFN is interested in participating in a network that would help share and disseminate information and knowledge among the First Nations communities. He cautioned that the



network must respect the First Nations traditional government systems, and that it has to be accountable back to the communities.

Stuart closed his comments by saying he looks forward to developing strong relationships with other organizations to help out First Nations communities.

HEALTH CANADA, FIRST NATIONS AND INUIT HEALTH BRANCH, ENVIRONMENTAL RESEARCH DIVISION (CONSTANTINE TIKHONOV)

Constantine also raised the question of the gap between the large amount of research apparently happening, and the actual knowledge that is accessible. He suggested that the issue is that the research is often buried and difficult to dig out. The other challenge is to translate this research into knowledge that is useful for communities.

He also expressed a concern about the “silent” communities, the majority of small, less wealthy communities who do not know how to access research funds and often don't even think of research as a possible tool that they could use. He suggested that this is an area that requires a stronger focus, and one on which FNIHB is trying to work more.

He explained that the mandate of his section is to assist First Nations in building and supporting their capacity, and they look at knowledge as a commodity that, when shared, is not lost, but on the contrary increases in value. For the research that is funded by his section, Constantine said that the focus has to be on research initiated by First Nations - the research questions would be developed by the chief in council or the community themselves.

He expressed the hope that today the group will articulate very clear, tangible goals, and that these goals will be related to giving access to First Nations communities to research on environmental hazards, and to researchers who are capable and respectful and follow the rules. He also suggested that respect needs to be a two-way street, and that this network could facilitate that. He closed by saying that the network must help with research gap analysis and assist and facilitate the transfer of knowledge.

NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH (GINETTE THOMAS)

Ginette covered three major areas: the NCCAH and its purpose, the network and what it could do, and the NCCAH's interests related to the network. She explained that the NCCAH is one of the networks put in place by the Public Health Agency of Canada (PHAC) in response to the SARS epidemic and a number of other issues. Their mandate is to help ensure that knowledge is shared and disseminated, to help address research gaps, and to support networks of people working in different areas, to build links. The NCCAH is still in its start-up phase, and have recently completed a strategic planning exercise to define their priorities. They have constraints that could limit their involvement, such as the focus on public health – although an advantage is that they deal with public health in the broadest sense, including the wellness of communities – and they cannot fund research. The NCCAH has been looking at the interface between traditional knowledge and the scientific paradigm, and organized a circle to discuss this – there was very good discussion, and participants agreed that both traditional knowledge and the scientific paradigm are valid and necessary – the challenge will be to link them

Regarding the network itself, Ginette identified three areas of activity based on the background provided: the research itself, the network, and tools and materials to communicate the research outcomes. The NCCAH could not help with the first, but could play an active role in getting people together and supporting collaboration. She also talked about the importance of documenting the evidence from the research, to



ensure continued funding in the field. She suggested that one of the services the network could provide would be to help connect researchers and communities with funders.

On the question of the NCCAH interests, Ginette indicated that they want to support the network and get actively involved. It takes time and effort to get a network up and running, and these activities are aligned with the NCCAH mandate and something they could help with. She also said that the NCCAH could help with the synthesis of existing research – find out what does exist out there and is it applicable – and support the creation of tools.

NATIONAL COLLABORATING CENTRE FOR ENVIRONMENTAL HEALTH (CHRISTINA CHOCIOLO)

Christina explained that the NCCEH has a similar mandate to that of the NCCAH, but focused on environmental health. They support an evidence based practice, and help to identify gaps in research knowledge. In their first year, they did an environmental scan which helped with their work plan, including in depth interviews with policy-makers which helped inform their priorities. Their major activities include producing documents, monitoring and exchanging information across Canada, developing courses, and evaluating their own work.

Their first major project has been on on small drinking water systems, and they are also doing a number of other smaller projects, including mercury spills and tobacco smoke. Their process is to put out calls for researchers, and to include client groups in the work, including sharing documents for review. The NCCEH has an advisory board composed of people from across Canada, and they use them as champions to help them reach out to communities. They are interested in partnerships, and although they don't fund primary research, they are building in-house capacity to help with projects.

PUBLIC HEALTH AGENCY OF CANADA (VICTORIA EDGE)

Victoria gave a brief presentation that reviewed the mandates of PHAC as well as her division, the Foodborne, Waterborne & Zoonotic Infections Division (FWZID). She shared some excerpts from the PHAC Report on Plans and Priorities, which highlighted research findings indicating that inequity is closely linked to health, and that key health disparities in Canada are related to socio-economic status, Aboriginal heritage, gender and geographic location. The excerpts also indicated that the country's performance is slipping in some areas that are critical to future health outcomes, including indicators such as the health and standard of living of Aboriginal people, and that addressing the situation is a priority for the Agency.

She suggested that a network will help leverage existing resources to move forward on this issue, and that it will be important to draw on a lot of people to see what we can do as a team. It will be important to learn how to work with all the various groups. She questioned how effective the PHAC has been in its work with aboriginal people, even though they acknowledge the issue.

Victoria explained that FWZID is focused on outbreak response and management to foodborne and waterborne issues, and that they also do surveillance and link with academic institutions to do targeted research. The division is not brought in when there are outbreaks in First Nations communities, and she suggested that there is a real opportunity to draw on existing skills in this area.

She ended her presentation with a few provocative questions. First, regarding the comment that communities should be driving the research – how will they find the research or even know that they can or should do it – even for the initial steps? And finally, what happens with what comes out of the research is also an issue – how do we overcome the fear of publishing bad things, or controversial findings?



4. MANDATE: WHAT ARE THE KEY FUNCTIONS OF THIS NETWORK?

The group was asked whether there is anything that is missing or anything that no longer fits in the mandate as agreed two years ago. This was discussed at some length, and in the end the group agreed that the goal of the network, as described on page 4 of the June 2005 report, remains valid:

The ultimate goal of the "Network" is to assist in improving Aboriginal health, while helping to build capacity within Aboriginal communities to participate in environmental health research and to make informed decisions regarding environmental health issues and concerns.

The following is a summary of key points made during the discussion:

- There are three major dimensions to the Network's role: access point (where communities can obtain information and support), synthesis of knowledge, and mobilization
- We have to focus on knowledge translation, and tailoring information to suit communities, funders and practitioners at the community level. The Network should find existing tools, and bring into the network people with the skills to develop the tools and help them obtain funding for the work.
- We should look at successful models, for example ArcticNet, to learn what works rather than trying to reinvent something. A key ingredient in ArcticNet's success is strong researchers who dedicated a lot of time and energy to make it happen.
- Vision and purpose are essential, this will drive the process and everything we do. Research is not the vision, it is the tool to accomplish our goal.
- For the Network, the focus will be on human health impacts of environmental conditions, not general ecosystem or plant or animal health impacts.
- Community-based research is a process of exchange between researchers and communities: researchers bring information from the literature, and communities bring information from their own experience, and the exchange and interaction will bring forth the appropriate research questions.
- In some cases, we are missing the capacity to use knowledge in the community – we have to make sure that the Network is action-oriented, that it focuses on the use of information and knowledge by communities.
- One of the outcomes of the network should be to leave a legacy, a platform that gives First Nations people the capacity to run their own business related to environmental health issues.
- We have to make sure that research does not bear harm to the First Nations communities – under the Species at Risk Act, for example, which only applies to federal lands, more and more pressure is being exerted to limit activities on First Nations reserves.
- It will take time to build trust and interest more researchers, it won't happen overnight. We have to get started now, not wait until ideal circumstances are in place.
- It will be important to develop a code of ethics and standards that those who are part of the network would have to adhere to, including researchers.
- An important role the network could play is to support new researchers – to facilitate their career development, help them understand the importance of community buy-in, and also to try to influence the current system so that publication in primary journals is not the only way to advance their careers.



- One of the questions is “what do you do about publishing?” There is a lot of unpublished data out there; one suggestion would be to make this data available to young researchers and allow them to publish it.
- We need to demonstrate a research agenda that we develop as a group based on expertise.
- Regarding the researchers, it is important to have collaboration between researchers and communities; perhaps we should start accepting the qualifications of traditional knowledge holders as opposed to waiting for someone with a science background to come and accept or validate the research.

PRIORITIES

Participants divided into three small groups to discuss and identify the top two priorities on which the Network should focus in 2007-2008. The following priorities were identified through these discussions and subsequent plenary sharing:

- Set up the Network’s structure – set up the governance structure, identify a champion or champion(s), find funding, hire a coordinator, communicate with key stakeholder groups and get community approval and engagement
- Conduct a needs assessment – identify research priorities, as well as best practice priorities
- Compile relevant research from all possible sources (not just First Nations) – not just the results, but even a list of all research undertaken; sources would include First Nations communities, researchers, government departments and agencies
 - Also, as a pilot project, select a specific topic based on the needs assessment, and take the work through to analysis and knowledge translation for communities and policy-makers
- Plan and prepare a national conference for year 2, to showcase the results of the work done in year 1

The group discussed options for getting community approval and engagement. One suggestion was to use focus groups or information sessions with a number of communities to start to build trust, understanding and ownership from the beginning; we could start with the more active communities first, then involve the more “silent” ones. Maybe we could create some sort of buddy or mentoring system between communities, where a more active community takes on the responsibility to inform and support a less active community. We could also present at an AFN special chiefs assembly to find out what their concerns are.

5. OTHER NETWORK MODELS

EXPERIENCE FROM THE CANADIAN WATER NETWORK

Presenter: Mark Servos

Mark explained that the Canadian Water Network (CWN) is one of the national Networks of Centres of Excellence, whose purpose is to bring the knowledge of universities to end users. They assemble people from across Canada, and act as a catalyst to create innovation. 37 different universities are currently involved in the CWN. Scientific excellence is the basis of everything they do; their emphasis was initially on research, and now it is shifting to networking and partnerships, and knowledge translation. The CWN's



approach to knowledge translation is to involve partners at the very beginning, not to wait until after the research is completed.

He described the structure of the CWN, without necessarily recommending a similar structure for the Environmental Health Research and Communications Network: they are a not-for-profit organization hosted by the University of Waterloo, with a Scientific Director, an Executive Director responsible for managing staff, and a Program Management Committee. The organization also has a Board of Directors, and they have played a critical role in developing the CWN; Mark recommended that this new Network consider using a Board of Directors, although he recognized that they require a lot of effort initially to set up.

The last part of Mark's presentation focused on lessons learned. He stressed the importance of a clear, achievable and shared vision, and a value-added proposition for all partners. He said it is important to form partnerships, not just to collaborate – to give stakeholders a strong leadership role and empower them to deliver on it. He stated that networking is not easy, that people are its core resource and will participate only if they feel they are contributing, and a passionate champion is necessary to mobilize the network. He encouraged participants to recognize barriers but not to accept the status quo, to be patient and flexible, and not be paralyzed by uncertainty.

COMMUNITY OF PRACTICE STRUCTURE ON ECOSYSTEMS

Presenter – Donna Mergler

Donna Mergler gave a presentation on the model adopted by the Community of Practice on Ecosystem Health Approaches to Reduce Toxics in Latin America and the Caribbean and Improve Collective Health (CoPEH-TLAC). She showed how the network is established as a grouping of communities of practice, with regional nodes depicted in a flower structure, with a core group in each region that taps into a broader network within the region. Each of the regions also leads on a specific transversal theme of interest to everyone.

She explained that decisions are made collectively by the core group, and that they organize regional and thematic workshops to bring together people working in all areas who want to reduce toxic exposures. Each region has developed very differently, based on their local conditions and what they can build upon in their region.

NORTH AMERICAN PERSPECTIVE ON A CANADIAN NETWORK

Presenter: Merrell-Ann Phare

Merrell-Ann explained some of the things on which the Commission for Environmental Cooperation (CEC) is working that could be of interest to this initiative. The CEC does not fund research, their focus is cooperation, and they only work on issues on which they all agree, and which are not being looked at by anyone else. They have a series of programs that change every few years, and focus on environment and trade, not the impact on humans. They also produce an annual report called *Taking Stock*, which presents a picture of industrial pollution in North America, using data collected in their three member countries – Canada, the United States and Mexico.

She said that the CEC is looking for ways to build partnerships and get more involved with aboriginal issues, and there might be opportunities to work together. There might also be some interesting analyses from past CEC work that would provide a North American perspective on issues of interest to the Network.



Following Merrell-Ann's presentation, it was suggested that there might also be an opportunity to collaborate with the Canadian Aboriginal Science and Technology Society, who organize meetings on a regular basis, and usually have sessions focused on Environmental Health.

6. DEFINING THE NETWORK

PART 1: SELECTING A MODEL

This question was discussed in small groups, who then reported their conclusions in plenary. There was consensus among the groups that time would be required to develop a final structure. Two of the groups felt that a non-profit corporation would be the best structure in the long-term; there were reservations expressed by people in the third group, because of concerns about Board membership: common practice is for funders not to sit on the Board of the organization they fund, because of perceived conflict of interest or concern about the greater influence of funders. It was also pointed out that a Board is not limited to a non-profit corporation, so the same concern could exist with other structures. The role of the federal government members of the network, and other potential funders, should be considered during the formal set-up of the network.

It was proposed that Laurie Chan should continue as champion for the network; he suggested that it would be better to find a First Nations champion instead, although he said he was willing to continue to play this role until a new champion is identified.

In the short term, one group proposed an informal network with a supporting secretariat, while another suggested that the network could be hosted in an existing organization, i.e. the NCCAH. A participant asked what the latter would mean, and Ginette said that the NCCAH would provide a secretariat for the Network, help bring members together, provide an office location and phone number. It was suggested that NAHO might want to play this role instead of the NCCAH, since they had suggested this at the meeting in May 2005. NAHO will be consulted about this.

PART 2: FUNDING SOURCES

Participants were asked whether their organization was in a position to commit funding to the Network for 2007-2008. Constantine indicated that FNIHB is prepared to provide \$100,000.

Other groups were not in a position to make a firm commitment on funding, but Ginette indicated that the NCCAH would likely be able to provide support in kind as described above, and Mark informed the group that a proposal to the CWN for \$25 to \$50K would probably be well received. Victoria suggested that PHAC would also be open to funding Network activities that are aligned with its priorities.

Merrell-Ann raised the possibility that the Network could use the Centre for Indigenous Environmental Resources (CIER) virtual library as a database.

All participants confirmed that they were willing to support the Network through active participation.

The group agreed that it would be useful to develop a 'partnership proposal' that would describe the proposed roles and contributions of all the participants in the network – such a proposal would have a greater chance of success than individual proposals to each of the separate organizations. They also agreed to continue exploring different ways in which their organizations could actively support the Network.



7. WRAP-UP

NEXT STEPS

The group agreed to the following next steps in the short term:

- Coordinate until a new champion (or co-champion) is appointed – Laurie - Ongoing
- Co-ordinate the proposal-writing and submission, and revamp the concept paper –Asit and Laurie – by mid-April
- Establish a temporary planning group – Laurie to lead, other members to include Stuart, Ginette, Merrell-Ann (or a designate), Victoria, Asit, Olivier, possibly NAHO – ongoing
- Talk to NAHO about the Network and communicate the results of the conversation to Laurie – Merrell-Ann – next week
- Explore partnership with CIHR – Jack
- Report from today's session – Lise and Erika – by the middle of next week

EVALUATION

Participants were invited to complete evaluations of the session. The results of the evaluation are provided in Appendix B.



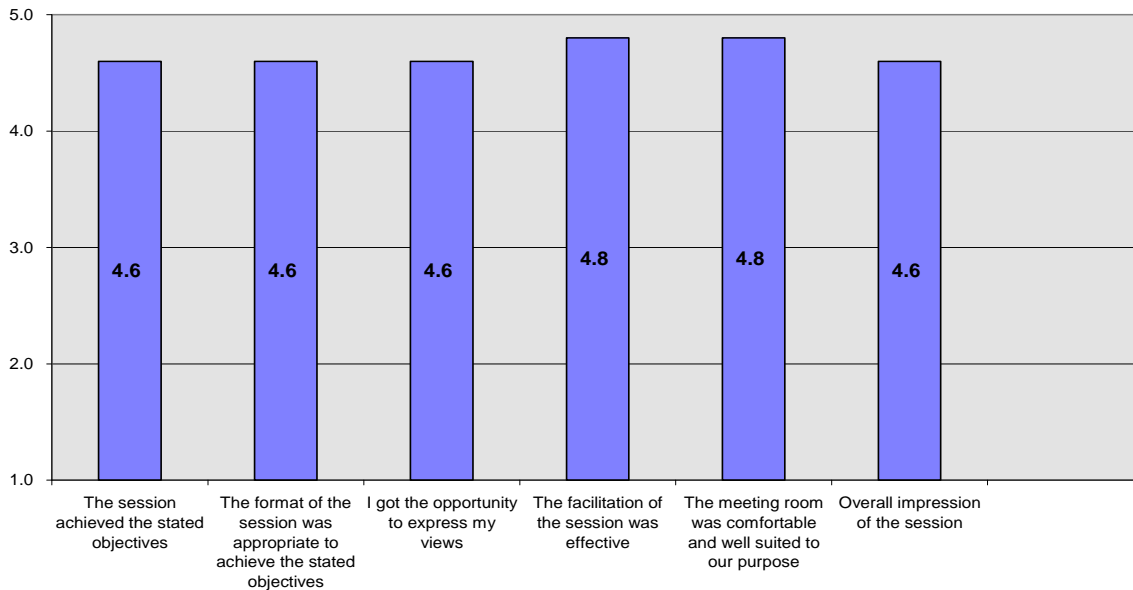
APPENDIX A – LIST OF PARTICIPANTS

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APPENDIX B – EVALUATION RESULTS

Evaluation - HEALTH CANADA
March 23, 2007



WHAT KEY MESSAGES WILL YOU TAKE BACK WITH YOU?

- This is working!
- Stakeholders are interested with this network
- This will move forward – we will be successful

WHAT DO YOU NEED TO DO FROM HERE TO MAINTAIN MOMENTUM?

- Act now
- Get proposals in
- Talk to other partners
- Keep up the good work
- Achieve our 'next steps'

THE THREE THINGS THAT WERE OF GREATEST VALUE TO ME WERE:

- Quality of people invited
- Proactive people
- The way to communicate
- The consensus building process
- The caractères involved
- Meeting and discussing in person
- Learning from everyone else

OTHER COMMENTS AND SUGGESTIONS:

- Merci beaucoup!
- Remember why we are doing this!