

SPECIAL INSERT

# A FRAMEWORK...

## for Creating an Aboriginal Women's Health Research Centre

An Idea Connector Network  
Building Futures 2016- 2017  
framework project Produced  
in collaboration with the  
Native Women's Association  
of Canada (NWAC)  
Partners for Engagement  
and Knowledge Exchange  
(Pathways PEKE)



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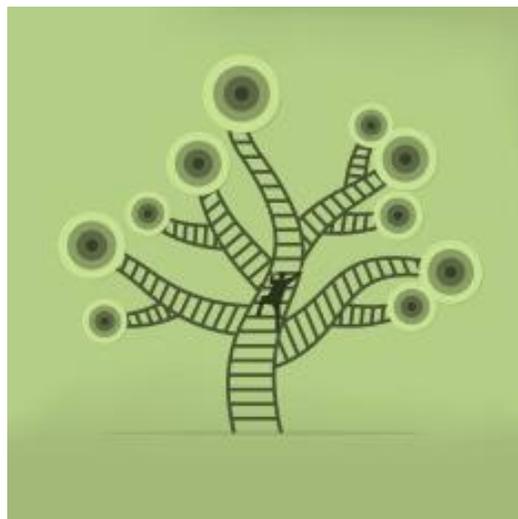


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## What is Foresight?

*'Foresight is looking ahead at the big issues, the world of change that we're facing - looking ahead at what might happen that is good and what might happen that is not. Foresight is not about finding the right answers, but about making sure that people who are involved and interested come together in an open dialogue and express in their own ways, with their own biases, assumptions, and interests the issues of importance to them.'*

David Harries, Ph.D., P.Eng.  
Foresight Director  
Idea Connector Network (ICN)



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January 2017



## Message from NWAC Pathways PEKE

The Native Women's Association of Canada (NWAC) is currently funded under the Canadian Institutes of Health Research (CIHR) Signature Initiative, *Pathways to Health Equity for Aboriginal Peoples*, as a Partner for Engagement and Knowledge Exchange (PEKE) to engage in health research in four priority areas: suicide prevention, tuberculosis, diabetes/obesity, and oral health.

In March 2016, NWAC was approved as an eligible institution to administer CIHR health research grants and funds. With this new designation, Aboriginal communities can collaborate with NWAC to engage in Aboriginal women's health research that is of interest and a priority to them. The NWAC Pathways PEKE is dedicated to promoting community-driven research that encourages self-determination and participation of Aboriginal women in health research. We also collaborate with community and academic researchers to incorporate Indigenous ways of knowing and gendered perspectives into research projects.

Using a case study approach, NWAC collaborated with the Idea Connector Network (ICN) to explore the concept of creating an Aboriginal Women's Health Research Centre. NWAC's primary objective for the case study was to produce a framework on which to build the implementation plan, process, and resource schedule needed for the creation of the Aboriginal Women's Health Research Centre. A series of secondary objectives were also identified.

For this case study, as discussed in more detail in this report, ICN has made use of the Foresight methodology to organize how to approach and deal with uncertainties. This Framework Report includes the cumulative output of the project's four steps. The Framework will help guide the development of the implementation plan, processes and resource schedule required for the creation of NWAC's Aboriginal Women's Health Research Centre.

I would like express our appreciation for the contribution of all experts that have participated as interviewees and panelists in the case study, as well as the one-hundred plus contributors that have participated online and shared their views with the panelists. Without their contributions, the development of this Framework Report would not have been possible.

In closing, I would like to recognize the important contribution the Idea Connector Network and its team, Denise-Anne Boissoneau, David Harries, Guy Dancause, James Leveque and Shane Webster.

Sincerely,

Amy Nahwegahbow  
Senior Project Manager, Pathways PEKE  
Native Women's Association of Canada

# The Importance of Context

## What others have to say on the subject

In analyses of health disparities, it is as important to navigate the interstices between the person and the wider social and historical contexts as it is to pay attention to the individual effects of inequity. Research and policy must address the contemporary realities of Aboriginal health and well-being, including the individual and community based effects of health disparities and the direct and indirect sources of those disparities. (Health Disparities in Aboriginal Canada - Naomi Adelson, PhD 2005).

Stories about Indigenous health in Canada are frequently presented without the context needed to make sense of the information provided. For example, epidemiological data is often gathered, analyzed and shared without the inclusion of adequate context related to the historical and present-day impacts of colonial policies on the social determinants of health for Indigenous peoples. In addition, this data can be shared in the absence of the voices and perspectives of Indigenous people themselves (Smylie, 2014). At the same time, it cannot be assumed that Canadian readers will automatically fill in this context — in large part, school systems, mainstream media and government-mediated communications do not expose Canadians to a range of Indigenous voices or to comprehensive, accurate information about the effects of colonization or about Indigenous peoples, cultures, histories or present day realities.

While stories about Indigenous health are frequently marked by an absence of context, they can also be characterized by the presence of racist stereotypes and inaccuracies pervasive in mainstream Canadian narratives. These include the idea that genetic predeterminations — as opposed to factors like access to the social determinants of health — are responsible for the health inequities experienced by Indigenous peoples and other racialized groups.

The importance of taking care to contextualize Indigenous peoples' health cannot be overstated since, as noted by Greenwood and de Leeuw (2012), a failure to do so may result in a presumption that the extremely poor health status and socioeconomic challenges faced by many Indigenous peoples is a matter only of physiological or biomedical failure (n.p.).

Consequently we encourage readers to further familiarize themselves with the subject of context by reading reference material such as:

:

- (i) <http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf>
- (ii) <http://pubs.cpha.ca/pdf/p24/22247.pdf>
- (iii) [http://www.naho.ca/jah/english/jah08\\_01/08\\_01\\_intimate-stories.pdf](http://www.naho.ca/jah/english/jah08_01/08_01_intimate-stories.pdf)

# Project Context

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The context for the report is the almost unanimous agreement of participants that the establishment of an Aboriginal Women's Health Research Centre would respond to clear and present needs.

In turn, that context determined which issues were most discussed during the two panels and in the public survey; the details on which govern the character of the report. Those issues were:

- That the required capable people are available
- Funding sources and amounts
- Qualification criteria and policies
- The role of and options for Partnerships
- Cultural and professional ethics
- Priorities for establishing and operating an AWHRC

# 4 STEPS to Framework Production

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*Late in 2014, it was decided that the Foresight project would have four steps, followed by the writing of this report. The steps are as follows...*

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1	<p>In early fall 2016, ICN individually interviewed three accomplished Aboriginal women and asked them to answer eight questions, all framed in terms of <b><i>their experience and observations on how research gaps affect Aboriginal women 's health.</i></b></p>
2	<p>On November 22, 2016, from ICN's Ottawa studios, a moderated live online cross-Canada Panel discussion took place. The distinguished panelists and the online participants focused their <b><i>attention mainly on questions related to the feasibility of an Aboriginal women's health research center.</i></b> (See step two for details)</p>
3	<p><b>A survey.</b> After the first panel, a survey was sent to all registered participants and panelists, some 111 people were asked to <b><i>share their thoughts on ten questions.</i></b> Contact was made using e-mail and Survey Monkey. Survey results are found in Step 3</p>
4	<p>On December 6, 2016 our distinguished panelists assembled once again and focused their minds on seven general themes: <b><i>Operations, Administration, Logistics, Relationships, Infrastructures, Ethics and Funding.</i></b></p>

*To see the results of each step, view pages following ...*

# STEP 1 the “What if” questions

*To view answers in full provided by each person, select the Interviewee of your choice*

What role do Aboriginal women play in family & community health?
Are there research gaps (lack of data/evidence) with respect to Aboriginal women’s health? If yes, what is the impact?
Would Aboriginal women’s increased involvement in health research impact health care programs, services and policies?
Would having better data improve the health & wellbeing of Aboriginal women and families? If so, how?
TRC – What does reconciliation look like for Aboriginal women’s health?
How can health equity be achieved to close the disparities (gap) in Aboriginal health outcomes?
What would the impact be if research on Aboriginal women’s health was community- driven?
What could we do to create more meaningful research and knowledge on Aboriginal women’s health?

## Interviewees



**Erica Samms-Hurley, MN BN RN**  
Nurse Educator  
Western Regional School of Nursing  
Grenfell Campus-Memorial University of Newfoundland  
**To View** <http://ideaconnector.net/interviews-awhrc/>



**Dr. Shannon McDonald**  
Deputy Chief Medical Officer  
First Nations Health Authority of BC  
**To View** <http://ideaconnector.net/interviews-awhrc/>



**Cora-Lee McGuire-Cyrette,**  
Executive Director,  
Ontario Native Women’s Association  
**To View** <http://ideaconnector.net/interviews-awhrc/>

# STEP 2 the Panelists

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**Jennifer Bouchard** is of both Scottish and Mohawk (from Six Nations of the Grand River) ancestry. Now living in Ottawa. She has a BA in Law, with concentration in law, policy and government and is an ADR practitioner. Jennifer is a Community Engagement Officer for the National Aboriginal Initiative at the Canadian Human Rights Commission. In the past Jennifer has worked as a Mediator and Human Rights Officer at the Commission.



**Cora-Lee McGuire-Cyrette** - Originally from Bingwi Neyaashi Anishinaabek, located in Robinson Superior Treaty Area, Cora-Lee McGuire-Cyrette has completed a Bachelor of Arts degree, with a double concentration in Indigenous Learning and Sociology from Lakehead University. Cora-Lee is the Executive Director of the Ontario Native Women's Association (ONWA).



**Marilee Nowgesic** -- Originally from the Fort William First Nation. Her formal post-secondary education was obtained from Lakehead University and Carleton University. Ms. Nowgesic has worked with several clients in the federal, provincial, territorial and numerous non-government agencies to develop strategic development plans, social marketing campaigns, communication strategies, education programs and policy development guidelines which were targeted for Aboriginal communities across Canada.



**Jacques Pilon, B.Sc (Hons.)** -- President, R&J Pilon Investments. His focus is on technology and commodity portfolio management employing long, short and derivative strategies; private placement, seed money for startups. Entrepreneur in Residence at Launchlab. Jacques is of Métis heritage (Georgian Bay).



**Cynthia Stirbys, Ph.D.** -- is Saulteaux-Cree from Cowessess First Nation in Saskatchewan and her research is aimed at addressing intergenerational trauma of Indigenous women by examining the Indian residential school phenomenon. Dr. Stirbys' main interest is to work in areas that affect and improve Indigenous Peoples' well-being. Dr. Stirbys is also an adjunct professor at Simon Fraser University.



**Caroline Tait, Ph.D.** Dr. Tait is a Métis researcher and professor at the U of S. She is working on a national youth research project with FN in SK and is co-chair of First People First Person, the Indigenous Hub of the Canadian Depression Research and Intervention Network.



**Denise-Anne Boissoneau, LL.B., Moderator**, Legal Aboriginal Policy Consultant has extensive experiences in the public to not-for-profit sectors; consulting senior management and recommends both law and culturally-based solutions. Primary areas of interest are the criminal justice system, conducting community engagement and social justice initiatives. Facilitating Aboriginal knowledge fosters safety and economic well-being for the betterment of Aboriginal peoples. Denise-Anne is from the Objibwe First Nation.



**David Harries, P.Eng., Ph.D., Foresight Advisor** - David is a Fellow of the World Academy of Arts & Science, Chair of Canadian Pugwash Group and a Foresight Specialist. He specializes in the use of Foresight methods to promote improvement in human security, which includes health, food, education and wellbeing.

# The First Panel

On Tuesday November 2016 from 1:00 pm to 3:00 pm EST, the first panel took place. Some of the panelists, the host, and the foresight advisor, were in the studio. The other panelists were connected live online from different locations across Canada.

The panelists and online participants were asked to explore the overarching question:

***“What if.... ... NWAC created an Aboriginal Women’s Health Research Centre and enabled research on Aboriginal women’s health to be community driven.”***

Since nothing happens in isolation we did explore “the big question” through a series of sub-questions, explored through four lenses: **(1) Women (2) Community (3) Academia (4) Policy**. These sub questions weren’t meant to be limiting but rather to start and provoke discussion. Panelists and viewers were encouraged to express their views on the implication of their answers to questions.

## Summary

In short, it can be said that the distinguished panelists focused their discussion on two subjects i.e.:

- i. Is it reasonable to think that creating an Aboriginal women's health research centre could play a major role in improving Aboriginal women's health?***
- ii. What conditions must first be satisfied if an Aboriginal women's health research centre is to contribute positively, effectively, and sustainably to an Aboriginal woman's health?***

***On the first question***, the sense of the meeting was that it was indeed reasonable to think that such a project could play a major role in improving Aboriginal women's health.

It was agreed that past efforts seemed to have left people in communities overwhelmed with being researched and seeing few lasting effects. There was however a common conviction that ‘...Aboriginal women can speak for themselves...’ as well as for others in their communities, to help identify shared problems. A key concern was to obtain culturally competent community-based research and solutions.

As to existing funding opportunities, experience was concisely summarized as ‘...we got it off the ground, the government changed and the funding was gone.’ The vulnerability of such projects to sudden changes has proved devastating to their sustainability. The unreliability of government funding indicates that new initiatives should seek multiple sources of funding.

Women’s ability to design the centre ‘...in any way we like...’, including the opportunity for Aboriginal women to be part of the research process, was viewed as a key factor in the success of any new initiative.

The panel addressed the ‘...need to reinstate indigenous women as leaders in our communities to make change.’ The thrust was to ensure that research doesn’t drive communities, but rather that communities be in the lead. Research must be inclusive of their individual experiences, their emotions, their spirituality, their geography, their history and much more.

**On this second topic**, it was generally agreed that the approach had to be inclusive of ‘...all Aboriginal women, First Nations, between status and non-status, Métis, as well as Aboriginal women on and off reserve, urban, rural and those women with disabilities, both physical and mental.’

An overriding concern was with funding, i.e. ‘...adequate financial resources being made available to all of the stakeholders...’. The point was made that large amounts of money are spent on curing illnesses, but very little funding is available for promotion of health and prevention of illness.

There was concern about the need to ensure that participants receive equitable honoraria to participate in the research.

An overarching view concerning such a research centre was ‘...we have the talent, we have the wisdom, we have the knowledge to do things differently based on our own cultural teachings and that is what's going to make this research centre different and that is what's going to bring us together to work differently and actually support our communities in a way that we're actually moving towards prosperity and reaching our highest potential.’



## 1<sup>st</sup> Panel Discussion Synopsis

To the left is a video collage of the first panel discussion.

**To view**

<http://ideaconnector.net/panel-one-awhrc/>



## 1<sup>st</sup> Panel Discussion Full

To the left is a video of the full first panel discussion.

**To view**

<http://ideaconnector.net/panel-one-awhrc/>

# STEP 3 the Survey

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Answers	Summary of Comments
<p><b>Q.1.</b> Agree that the panel of experts has strongly supported the establishment of an Aboriginal Women's Health Research Centre (AWHRC)?</p> <p><b>87.5% Agree</b></p>	<p>Research by and for Aboriginal women is important. It will make research more relevant, build capacity among Aboriginal women, and improve knowledge about our realities</p> <p>Need to know how this is different than NAHO</p> <p>What happened to the storage of NAHO's research? Where is it and is it still accessible after 2017?</p> <p>Yes for the most part but I was unsure of how some of the academics felt about grassroots community members conducting research and how much weight it had in the world of stats</p> <p>This is a fantastic idea. Aboriginal women must be part of the process, in order to find and help implement real solutions. This includes preventative measures, using traditional healing wisdom and modern medicine.</p>
<p><b>Q.2.</b> Help us define the AWHRC's priorities. What should be the first step:</p>	<p>By order of priority:</p> <ul style="list-style-type: none"> <li>• Assemble partners (42.9%)</li> <li>• Conduct a foresight exercise to anticipate the plausible social, economic and political context in which it could find itself (37.5%)</li> <li>• Secure funding for the Centre's administration and logistics (25.0%)</li> <li>• Appoint the leadership (25.0%)</li> <li>• Establish an education curriculum on Aboriginal health knowledge and practice (12.5%)</li> </ul>
<p><b>Q.3.</b> What of the AWHRC's operational priority:</p>	<p>Note: Each question had a value of 100%</p> <ul style="list-style-type: none"> <li>• Should it address a wide-range of priorities (37.5%) or</li> <li>• Focus on a small number of contemporary and pressing ones (66.7%)</li> </ul>

<p><b>Q.4.</b> How should the range of priorities be determined?</p>	<p>Top five responses:</p> <ul style="list-style-type: none"> <li>• Partner organizations consensus</li> <li>• By what the communities ask for</li> <li>• Current Women's Health Issues</li> <li>• National survey</li> <li>• Expert and non-expert discussion</li> </ul>
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<p><b>Q.5.</b> How should a focus on priorities be determined?</p>	<p>Four responses:</p> <ul style="list-style-type: none"> <li>• Consensus decision making by a council of partner groups</li> <li>• What do the communities want to focus on?</li> <li>• Create Collaborative Partnerships with existing organizations and build from there</li> <li>• Greatest need, greatest gap</li> </ul>
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<p><b>Q. 6.</b> A great deal of material exists on Aboriginal health: past and current research, studies, reports and policy analyses. ... <i>Is a "handbook" of that material needed to support informed design and planning of an AWHRC?</i></p> <p style="text-align: right;"><b>If Yes 55.6%</b></p> <p style="text-align: right;"><b>If No 44.4%</b></p>	<p>Who should produce it?</p> <ul style="list-style-type: none"> <li>• Professional team/individual</li> <li>• AWHRC</li> <li>• It's important to review research while keeping in mind the changes that may have occurred in previous consultations</li> <li>• Important to be able to refer to them when looking to resolve AWHRC's priority health issues and to refer to past studies. However, no need for a "handbook" only need an index to the studies.</li> </ul> <hr/> <p>Why not?</p> <ul style="list-style-type: none"> <li>• Priority should be developing partnerships and terms of reference rather than creating handbook</li> <li>• A depository would be better</li> <li>• Time consuming; Create a database and access for Indigenous Health Care Providers</li> <li>• Don't need another 'book', get working</li> </ul>
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<p><b>c.</b> Could international partners be an option?</p>	<ul style="list-style-type: none"> <li>• Not recommended at this point</li> <li>• Yes, would make it stronger, transparent and accountable</li> <li>• Yes, there is quite a bit of research conducted on Indigenous issues in several European countries</li> <li>• Australia and New Zealand have a lot to offer</li> <li>• If funding from International partners is available - if not, then to be considered before entering partnerships</li> </ul>
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<p><b>Q. 9.</b> How should the Centre's operations be funded? What restrictions, if any would you like to see:</p> <p><b>a.</b> If the funds were only from government sources?</p>	<ul style="list-style-type: none"> <li>• Not ideal. Change in Government means a likely change in funding</li> <li>• Governments change...need solid funding agreement with other investors</li> <li>• Full disclosure, and government does not control the money</li> <li>• Stringent guidelines with regard to how the research is conducted and by whom</li> <li>• Financial accountability needs to appear and be above what is happening now. Real research in the communities, need to build bridges. Finances need to be transparent it's critical to getting participants in research</li> <li>• Clear restrictions on use of money, that is directed to this endeavor</li> <li>• Annual audit, normal government accounting rules, i.e. Treasury Board rules govern travel, acceptance of gifts, etc</li> </ul>
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<p><b>b. If the private sector was invited to contribute?</b></p>	<p><b>c.</b> Yes good idea. There should be many funders.</p> <p><b>d.</b> Depends on who from the private sector; Why not Public Sector through Login and Article Subscriptions?</p> <p><b>e.</b> Full disclosure and we decide how funds are distributed, they don't get to cherry pick or target their funds. Our individual parts are not for sale.</p> <p><b>f.</b> Private sector funding is important but again should not benefit the companies as much as the individual communities.</p> <p><b>g.</b> Concerns about gambling or liquor money used unless that is the focus of their use.</p> <p><b>h.</b> If this is in addition to the government funding, then there needs to be rules about how the money is used, and "arms-length" agreements if the private sector partners are in the health care field. For example, be careful to keep at least 51% of the Board of Directors Aboriginal women who are NOT working for the Private sector donors or Pharmaceutical companies.</p>
<p><b>c. If Pharmaceutical companies were willing to contribute?</b></p>	<p><b>i.</b> They may want the research slanted in their favor. Also, from what I understand communities do not want to be funded in this way.</p> <p><b>j.</b> They should not be allowed to contribute. Or at least be restricted</p> <p><b>k.</b> Pharmaceutical companies often have a profit basis. Something needs to be in place to reassure participants that they are not being used by those who say they want to help. Profit often drives research so something has to be in-place to ensure that the offers are genuine.</p> <ul style="list-style-type: none"> <li>• Very scary -- Be very careful, Aboriginal people were sometimes used as test subjects for new drug treatments. – Arms-length agreement needed -- NO ONE FROM A PHARMACEUTICAL COMPANY on the Board of Directors or seconded to the staff of AWHRC. Non-disclosure agreement needed if AWHRC employs former pharma employees.</li> </ul>

**Q. 10.** What ways and means should an AWHRC deploy to promote the highest standards of stewardship and privacy in the collection, use and storage of samples and medical documentation?

- This is too much of a leap. NWAC does not have the capacity at this time. More dialogue required
- Form and Interdisciplinary Health Team to Review
- Ask someone in the privacy field
- Every effort should provide the maximum safety for participants. Participants should know that these materials are gathered with respect and a bond is developed between the Research and the outcomes
- This needs high level monitoring, there are repositories available, one in Alberta that could provide the service
- All electronic information should be stored on Canadian servers to ensure that Canadian privacy laws are followed. Other information should be stored using Federal government healthcare (personal) information. That includes using proper filing cabinets, restricting use of computers and other electronic devices

# STEP 4

## Panel 2: Discussions



**Caroline Tait, Ph.D.** Dr. Tait is a Métis researcher and professor at the U of S. She is working on a national youth research project with FN in SK and is co-chair of First People First Person, the Indigenous Hub of the Canadian Depression Research and Intervention Network.



**Cynthia Stirbys, Ph.D.** -- is Saulteaux-Cree from Cowessess First Nation in Saskatchewan and her research is aimed at addressing intergenerational trauma of Indigenous women by examining the Indian residential school phenomenon. Dr. Stirbys' main interest is to work in areas that affect and improve Indigenous Peoples' well-being. Dr. Stirbys is also an adjunct professor at Simon Fraser University.



**Jacques Pilon, B.Sc. (Hons.)** -- President, R&J Pilon Investments. His focus is on technology and commodity portfolio management employing long, short and derivative strategies. private placement, seed money for startups. Entrepreneur in Residence at Launchlab. Jacques is of Métis heritage (Georgian Bay).



**Alyssa Matheson** works at the Native Women's Association of Canada, under the CIHR funded Pathways PEKE program. A graduate of the University of Ottawa's Interdisciplinary Health Sciences program. Alyssa is currently completing a Bachelor of Economics.



**Amy Nahwegahbow** is the Senior Project Manager for the Native Women's Association of Canada's CIHR Pathways PEKE (Partner for Engagement and Knowledge Exchange) under the Health Directorate. She is a member of the Whitefish River First Nation and a graduate of Trent University in Native Studies.



**Denise-Anne Boissoneau, LL.B., Moderator**, Legal Aboriginal Policy Consultant has extensive experiences in the public to not-for-profit sectors; consulting senior management and recommends both law and culturally-based solutions. Primary areas of interest are the criminal justice system, conducting community engagement and social justice initiatives. Facilitating Aboriginal knowledge fosters safety and economic well-being for the betterment of Aboriginal peoples. Denise-Anne is from the Objibwe First Nation.



**David Harries, P.Eng., Ph.D., Foresight Advisor** - David is a Fellow of the World Academy of Arts & Science, Chair of Canadian Pugwash Group and a Foresight Specialist. He specializes in the use of Foresight methods to promote improvement in human security, which includes health, food, education and wellbeing.

# The Second Panel

During the previous Panel Discussion, attention was focused mainly on questions related to the feasibility of an Aboriginal women's health research center. On December 6, our distinguished panelists assembled once again, but focused their minds on seven general themes:

## Operations, Administration, Logistics, Relationships, Infrastructures, Ethics and Funding

Very early in the discussion, it was agreed to add 'Culture' to this list. As envisaged by the Foresight methodology, the list wasn't meant to restrict discussion in any way. Indeed, and to their credit, panelists were as vocal as they were in the first panel.

One early intervention concerned the importance of Culture as a theme in all discussions. The underlying question was how do we indigenize community-based research so that we aren't setting up just another research centre on women's health? Panelists agreed that, although culture needed to be woven throughout all the discussions, it should also be the focus of a separate reflection.

A discussion then ensued on the role that NWAC might play in accessing funding and how NWAC would fund the operations of centres. It was pointed out that funders rightly demand accountability which implies grant administrators capable of responding adequately. Among the options described were:

- a) do it all yourself;
- b) look at partnerships to share the burden.

Established funding regimes mostly require that applicants be 'eligible institutions'. That did not seem to be easily applicable to Aboriginal communities which are neither universities nor medical centers.

The group was reminded that the Aboriginal women's health research centre was meant to facilitate Aboriginal research in the community and from the community level. It was envisioned as just a centre of excellence.

On a different level, panelists were reminded that simply 'having the money' is not sufficient. Hiring a

community researcher is often impossible since '...everyone who is employable in the community is employed and in fact they're over-employed...'

**A caveat:** The planning process should not assume that the capacity to operate an autonomous research centre exists at the community level.

Seeking Federal funding was perceived as a last resort because experience shows that with a change in government comes a change in funding and the project is '...at ground zero again.'

With respect to collaborating to access funding, organizations should be careful they that they are not swayed by what the western way has always been.

Building an Indigenous way of knowing might lead to conflict between Indigenous methodology and western based university models.

On the complex and complicated issue of funding, it was noted that funding agencies '...typically want a project that has a clearly defined beginning and a clearly defined end...'

It remained unclear if, in the case of some funding agencies at least, some allowances could be made for cultural aspects.

The topic of ethics kept popping up in the conversation, and the question was 'what that would mean in the implementation of the research centre?' It was pointed out that applicants are required to have an ethics policy that abides by the tri-council policy statement.

It appears that not all stakeholders use the same definition of the term ethics, nor is there much

consistency on how the definitions are applied.

In response to a query on what 'community' meant, it included First Nations, Aboriginal urban communities.

A clarification was offered on NWAC's role in role in funding health research. NWAC will not be a funder. Rather, it is an 'eligible institution' that can apply for funding. Much as with a university, researchers apply to them as an eligible institution. And the funding is administered through the university or NWAC in this case.

Among the areas that needed further study was the matter of hiring PhDs (associated with universities or not); hiring 'consultants' who are typically very expensive; ensuring researchers get academic credits for the work they do for the centre, etc...

The Chair highlighted the importance of Indigenous methodology, i.e. the ways of being and knowing of Indigenous and Aboriginal peoples, Inuit, First Nations, and Métis.

The discussion turned briefly to 'innovation', i.e. providing something that's completely new, or innovation in doing the same thing in better ways. It was recognized that the term had become something of a buzzword. Pointing out the

innovative aspects of a project in any grant application was said to be very important as funding agencies all seemed to have a concern for advancing such projects.

The Internet and its wonders must not be set aside or ignored. One goal should be to have a database available online so communities can search for information on areas in which they would like to do research in their community. The database could also provide leads to qualified researchers already interested in the field.

There was a short discussion on private sector funding, especially that offered by companies in the pharmaceutical industry.

One of the main concerns expressed related to the impact of different partnerships on the ability to ensure that the centre remains community-based and respects Indigenous methodologies.

There were concerns about both perception and the expectations of corporations. Many communities are uncomfortable agreeing to such partnerships if they're at odds with the community's values. The aim should be for this project to be very much in-line with Indigenous values and community values and we want the community to feel comfortable. Another related concern was with the corporation's involvement in the research itself.



## 2nd Panel Discussion Synopsis

To the left is a video collage of the second panel discussion.

**To view**

<http://ideaconnector.net/panel-two-awhrc/>



## 2nd Panel Discussion Full

To the left is a video of the full second panel discussion.

**To view**

<http://ideaconnector.net/panel-two-awhrc/>

# Food for Thought

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Acknowledging that the establishment of a durable and effective AWHRC will be a major undertaking, project participants expressed their views on what will need to be addressed.

- What is already known about Aboriginal women's health must be available, including history, past and current research and TRC recommendations, and possibly material from international sources.
- The AWHRC must be for must be for Aboriginal Women by Aboriginal Women. It must not duplicate or be driven by non-Aboriginal/western academic and professional models, but identify ways and means to learn from and work with them. The design and establishment of its ways and means must be done by and for Aboriginal women.
- The difficulty of establishing community capacity – the physical and the service infrastructure – that will allow good research and care close to home.
- Indigenous ways of knowing and learning must be reflected in Accreditation and Certification criteria, policy and processes.
- The willingness to 'see' and minimize conflicts among the different ethics and ethics criteria within and among federal and provincial and municipal governments, Aboriginal peoples and specific Aboriginal communities.
- Challenges to existing policy must be done wisely, after full preparation.
- Foresight - looking ahead to anticipate Aboriginal women's health issues and needs – will always be important to the establishment and operations of a strong and effective AWHRC.
- For an AWHRC to be able to undertake both ongoing programmes and specific, stand-alone projects, it will need to not only have committed continuing funding, ideally from a combination of sources, but also the logistics and administrative capacities to meet their separate demands coherently.
- It is best to start small, and grow at a speed that is sustainable and supportable. This may call for collaboration or even partnering with existing health services and systems directed by Aboriginal professionals.

- Care must be taken to do everything possible to avoid having small communities miss 'big science' news and opportunities.
- Care will have to be exercised to minimize the frequency with which community-based professionals who are not Aboriginals take the lead on and set the tone of activities by Aboriginal professionals.
- It may be necessary to harmonize different priorities of the AWHRC and that of the communities.
- Public Relations and Public Information programmes and processes should be established so that the AWHRC is widely known about in detail.
- The AWHRC should engage community youth and Elders to strengthen its sustainability.
- Challenges will arise balancing effective stewardship of personal health information and the privacy of it.

# Recommendations

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Prioritization of the recommendations below should be a next step in the work to establish an AWHRC

- Assemble and catalogue existing, relevant histories, research, TRC output and public and private health organizations. Publicize the catalogues, acknowledge the contents, and learn from them.
- Commit to promising only what can be delivered. Start small. Do not be rushed.
- Create a directory of all Aboriginal health researchers and health professionals and of Aboriginal and non-Aboriginal individuals who have and/or want to earn the credentials required to become health researchers and care-givers in Aboriginal communities. This directory should include individuals who are competent in health infrastructure and administration.
- Determine what infrastructure and administrative resources a strong AWHRC needs.
- Establish a ‘wisdom council of Aboriginal women’ to develop ethics policies and processes and manage the interface with federal and provincial research and health care policies and processes.
- Engage Elders in discussion about the creation of the AWHRC.
- Establish two Committees, reporting to the ‘wisdom council’. One to deal with ways and means needed and appropriate to establish the AWHRC. The other to deal with the ways and means needed and appropriate to operate and sustain the Centre once up and running. Both will need competence in Public Information and Public Relations to ensure national awareness and effective promotion of the Centre to both Aboriginals and non-Aboriginals
- Explore options for mandatory and voluntary programmes for teaching Aboriginal and non-Aboriginal students about Aboriginal health issues, needs, and culture.
- Explore (a few) international connections that can advise/assist/fund start-up, and be potential operational partners thereafter.

- Commit to the goal of having health research and community health services operate as collaborative partners focused on the community as a whole.
- Ensure the ethics, accreditation and certification of Aboriginal health researchers reflects to the maximum extent possible and appropriate Aboriginal culture and ways of knowing, and not be dictated to by non-Aboriginal/western academic/professional policies and processes.
- Consider NWAC as a start-up catalyst, which may involve it as a mentor to the AWHRC in its development and deployment of policies for operations, logistics and administration.

# Conclusion

## Recommendations driving the conclusion

It is concluded that an AWHRC with a 20-30 year mandate can and should be established in Canada.

The focus of its projects should be Aboriginal women. Community health research should be culturally ethical, designed, planned and directed primarily by Aboriginal women. It should be compatible with non-Aboriginal Canadian academic framework and means to the greatest degree possible so that mutually beneficial partnerships can be established and sustained. Funding should come from a combination of sources: government, private and communities where possible.

The next step towards the establishment of an AWHRC should be a series of meetings and Webinars to:

- Address the issues raised in this report.
- Prioritize the recommendations and produce a suggested timeline for addressing them.

## Factors Driving the Conclusion

**Context factor:** There is strong support for the concept of an AWHRC and the required, capable people are available to establish and operate it.

**Recommendation factor:** Set up a “wisdom Council” of Aboriginal women to help guide the establishing of the AWHRC. The ‘wisdom council of Aboriginal women’ can express ethics, develop policies, design processes and manage the interface with federal and provincial research and health care officials and organizations.

# Facing the Future with Foresight

**The Idea Connector Network (ICN)** in collaboration with its not-for-profit partner, **the Proteus Canada Institute** brings people together to anticipate the future by developing plausible visions of what it might bring, so that preparations to deal with possible threats and to exploit possible opportunities can begin immediately.

Whether you are a strategic leader in a private sector organization looking to develop joint ventures with an Aboriginal community, or an Aboriginal community leader looking to expand the economic boundaries of your community to generate economic progress, the ICN can help you develop frameworks specific to your needs, whether they be:

- ✓ Improving knowledge and understanding of important trends and drivers,
- ✓ Identifying attractive business options for potential development,
- ✓ Creating and engaging in collaborative research programs.

***We work with organizations, large and small, which strive for excellence and innovation. ICN has the practical tools, the research strengths, and the programs which will help you highlight the critical insights that deserve attention to promote success.***

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