Oral Health and the Aboriginal Child: A forum for community members, researchers and policy-makers

June 7 & 8, 2007

Winnipeg, Manitoba

Forum Proceedings

Oral Health and the Aboriginal Child: A forum for community members, researchers and policy-makers

Authors: Dr. Robert J Schroth, Dr. Rosamund L Harrison, Dr. Herenia P Lawrence and Dr. Sabrina Peressini

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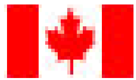

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Executive Summary

"Oral Health and the Aboriginal Child: a Forum for community members, researchers and policy-makers" was held June 7 and 8, 2007 at the Manitoba Institute of Child Health in Winnipeg, Manitoba. The focus of this event was the oral health of young Aboriginal Canadians. While the majority of Canadian children experience little or no dental decay (dental caries) during early childhood, a shocking number of children still suffer extensive tooth decay. This disparity is most apparent in Aboriginal children from both urban and remote First Nations and Inuit communities.[1-6]

This "invitation-only" workshop was attended by 42 community members, researchers and policy-makers from across Canada who gathered with the goal of developing and improving national collaborations and relationships between and among child oral health researchers and Aboriginal communities; researchers and other researchers; and researchers, Aboriginal communities, and oral health policy decision makers. The event was supported by a number of organizations, universities, and companies including three institutes of the Canadian Institutes of Health Research: the Institute of Human Development, Child and Youth Health, the Institute of Musculoskeletal Health and Arthritis and the Institute of Aboriginal Peoples' Health.

The Forum began on Day 1 with presentations by four experts in Aboriginal health. Dr. Kue Young spoke broadly on health disparities in the Northern regions. Ms. Jane Gray gave an overview of the First Nations Regional Longitudinal Health Survey 2002/2003 bringing this long-awaited survey to life for the Forum attendees. Following Ms. Gray, Dr. Marion Maar contrasted Aboriginal and academic worldviews related to research. She then focused on the Aboriginal and academic perspectives on research values and ethics and described how one community took action to make research work better for them. The final speaker, Dr. Peter Cooney of Health Canada, reviewed data on the current status of children's oral health in Canada. He then discussed the role of the office of the Chief Dental Officer in terms of access to care. Finally, he reviewed the Federal Government's involvement in oral health care.

These presentations were followed by facilitated small group discussions on pre-selected topics. Topics included the following:

- Making child oral health a priority.
- Oral health for the family and the community.
- Child oral health research - together we can do it better.
- Understanding the goals and measuring the outcomes of research.
- Honoring beliefs.

Day 2 of the Forum began with a panel discussion that allowed attendees to ask questions of the speakers from Day 1. Topics discussed included the following:

- Ethics committees in Aboriginal communities.
- Incentives for research participation.
- Cultural competence of institutional review boards.

Following the panel discussion, each of the four members of the Forum's Steering Committee presented research that they had been part of that focused on Aboriginal child oral health. Dr. Herenia Lawrence described a research-community partnership that addressed children's oral health inequalities in the Sioux lookout Zone of Northwestern Ontario. She provided an overview of the strategies for preventing oral diseases in young children currently in place on First Nations reserves located in the Sioux Lookout Zone, and highlighted the most recent strategy, "Baby Teeth – Keep them Beautiful with Fluoride Varnish," which has recently been evaluated for its effectiveness and feasibility. Dr. Rosamund Harrison presented a "case study" of a research project in the interior of British Columbia in which she had been a principal investigator. She described her role as a non-Aboriginal researcher from outside the community; the project itself; how the project "stood up" in the context of recent Canadian Institutes of Health Research guidelines related to Aboriginal research; how the project could have been organized differently given what we "know now," and her views on future directions for such research. The presentation by Dr. Robert Schroth discussed barriers to moving research evidence into policy, identified the benefits of collaboration, discussed how community-development can be used to improve child oral health, and discussed the benefits and history of a multi-agency, multi-disciplinary, and intersectoral collaborative partnership in Manitoba. Finally, Dr. Sabrina Peressini presented an example from Manitoulin Island that explained how a qualitative research methodology could aid our understanding of how to improve Aboriginal child oral health.

Following these presentations, workshop attendees either completed their deliberations on the break-out group topics from Day 1 or discussed in their small groups whether the workshop had fulfilled its original goals and objectives and proposed some "next steps."

Some key components of the recommendations that evolved from the presentations and discussions of the Forum were:

- *Disseminating the Proceedings* in a variety of formats to a variety of key organizations and individuals.
- *Establishing a "clearing house",* easily accessible to Aboriginal communities, cataloguing resources, information, protocols, data and "lessons learned" from previous research and oral health promotion projects (successful or not).
- *Nurturing the relationships* developed at this Forum by expanding the Steering Committee to enhance Aboriginal representation. The suggestion was for a follow-up meeting to be held in an Aboriginal community that would give an opportunity for Aboriginal people to share their stories about child oral health.
- *Developing an Aboriginal Oral Health Research Network* to champion an integrated and collaborative research environment for Aboriginal communities, researchers and policy-makers for trials and demonstrations projects with a goal of improving Aboriginal child oral health. Some basic considerations for the research network would be to listen to communities, integrate traditional knowledge, consider oral health in terms of overall child health, tackle the social determinants of health, involve Aboriginal groups often overlooked in research,

(urban Aboriginals, Métis), and be committed to qualitative research and participatory action research.

- *Building the capacity* of Aboriginal communities for oral health research by, for example, establishing a mentoring program for young Aboriginal scholars to promote more interest in child and community oral health research.
- *Highlight the importance of oral health to overall child* health in all research undertakings.

Objectives and Goal of the Forum

The Forum was held at the Manitoba Institute of Child Health (MICH) on the Bannatyne Campus of the University of Manitoba. MICH is the only research centre in Manitoba solely devoted to child and youth health research. Aside from its central location in Canada, a key reason for the selection of Winnipeg to host this event is the fact that Manitoba has the greatest proportion of Aboriginal residents among the 10 provinces (12%). In fact, nearly 1/6 of all of Canada's Aboriginal peoples call Manitoba home.[7] Two-thirds of Aboriginal people in Manitoba are considered North American Indian while nearly one third are Métis.[7] In addition, the city of Winnipeg too is proud to be the home to a large Aboriginal community of more than 45,750 persons.[7]

The overall *goal* of this workshop was to develop and improve national collaborations, partnerships, and relationships between and among child oral health researchers and Aboriginal communities; researchers and other researchers; and researchers, Aboriginal communities and oral health policy decision makers.

The specific objectives of the research workshop were to:

1. Explain differences in how the *ethics of research* are perceived by academic researchers and collaborating Aboriginal community partners, and how child oral health research should be conducted so that it will be considered to be ethical by both groups.

2. Explain how the *social determinants* of health influence Aboriginal children's overall health and, more specifically, their oral health and demonstrate how these "causes of the causes" could be integrated into oral health promotion programs.

3. Describe current successes in the *prevention of Early Childhood Caries* and *innovations in the promotion* of *improved oral health* in young children from at-risk communities and, specifically, Aboriginal children. In addition, explain the needs and gaps in the existing research strategies and research projects focused on child oral health.

4. Demonstrate how *early childhood oral health research* could be *integrated into the larger framework of research* focused on the health of Aboriginal children and families.

5. Explain how successful preventive and oral health promotion initiatives influence *health policy decisions* by government and what factors in addition to research evidence shape early childhood oral health policy decisions.

6. Develop a framework for *participatory early childhood oral health research* involving Aboriginal communities.

7. Develop a *collaborative network* between early childhood oral health researchers and Aboriginal communities with the goal of developing Canadian research capacity.

Oral Health and the Aboriginal Child

Dental decay during infancy and the preschool years or Early Childhood Caries (ECC) is defined as the presence of tooth decay on any primary tooth in a child under 6 years of age.[8;9] A further sub-classification, Severe Early Childhood Caries (S-ECC), is more rampant decay that frequently requires extensive treatment (fillings, crowns, and usually tooth extractions) under general anesthesia. However, this dental "surgery" merely treats the "signs" or outcomes of the disease, and has limited impact on slowing the disease process. In fact, children with a history of ECC are at increased risk for future dental decay throughout the continuum of childhood.[10;11]

The poor oral health of Aboriginal children in Canada is a major public health issue. In some Aboriginal communities, the prevalence of ECC exceeds 90% (Table 1).[1-4;6;12-14] Unfortunately, only 22% of Aboriginal children 4 years of age and younger with dental benefits have a yearly dental visit.[15] Therefore, it is imperative to develop a national research strategy that will ultimately reduce the caries burden experienced by Aboriginal preschool children on-reserve, in remote northern locales, and those living in urban centers.

Pediatric dental surgery remains the most common surgical day-care procedure at many pediatric hospitals in Canada. More than two thousand preschool aged children (includes Aboriginal and non-Aboriginal children) undergo dental surgery in Manitoba hospitals annually for the treatment of ECC[16-18] while many more receive treatment in private surgical centers. In Manitoba, nearly $9 million is spent annually to treat ECC including general anesthesia, transportation and dental fees.[19] In British Columbia, over $10 million is spent annually to provide dental treatment under general anesthesia to children under 4 years of age.[20] The cost of treatment for an Aboriginal child can be staggering as it usually involves transportation, accommodation for family members, dental treatment, and hospital care, including the general anesthetic fee.[19;21;22]

Of course the "cost" of treating extensive caries in a young Aboriginal child goes beyond the dollar figure. The technology and unfamiliar surroundings of a hospital in a distant city can make the experience a harrowing event for a small child, and it can be even more so for a child from a different cultural background. It is no less distressing for parents who themselves may have had unpleasant dental or hospital experiences as children. Finally, it must never be overlooked that a general anesthetic, while in experienced hands is a procedure with low risk of mortality and morbidity, is not without risk.

The consequences of ECC and S-ECC can be devastating for Aboriginal children, for families, and for communities. ECC may affect children before their first birthday, and can be a painful condition, influencing a child's ability to eat properly, sleep through the night, grow and develop normally, and thus achieve their full potential.[23] Caries in the

primary teeth has a significant and positive association with caries, mal-alignment and crowding of the permanent teeth.

ECC prevention and early childhood oral health promotion programs with predictable long-term results for Aboriginal communities have yet to be found, but a collaborative approach is more likely to achieve workable, community-based strategies. This Forum was organized to focus on the individual, family, and community factors that influence the oral health of Aboriginal children and to explore collaborative and effective approaches to the prevention of child oral health problems. The workshop brought together:

- Representatives from Aboriginal communities who would enable early childhood oral health researchers to better understand the Aboriginal viewpoint and experience of research involving children and families and their personal experiences with ECC.

- Researchers who are currently conducting (or plan to conduct) epidemiological studies, demonstration projects or clinical trials to determine successful interventions to improve the oral health of young Aboriginal children.

- Other researchers with experience in Aboriginal child health.

- Implementers and developers of government policy related to oral health of Aboriginal children.

Opening Remarks and Greetings

Opening Remarks by Dr. R. Schroth and Dr. R. Harrison

Dr. Robert Schroth, Assistant Professor – University of Manitoba and Canadian Institutes of Health Research (CIHR) Strategic Training Fellow, and Dr. Rosamund Harrison, Professor – University of British Columbia, welcomed attendees to the Forum. Together, they co-chaired the 2 day event. Next, all attendees introduced themselves including where they came from and which “group” they represented (Aboriginal community member, researcher, or health decision-maker). The co-chairs gave special thanks to the Aboriginal community of Manitoba, to all attendees who traveled long distances to attend the workshop, and to local grandmothers of young children who were in attendance on behalf of their grandchildren.

Next, Drs. Schroth and Harrison described the 18-month development and planning of the Forum and introduced the others on the Steering Committee: Drs. Herenia Lawrence and Sabrina Peressini, both from the University of Toronto. Finally, Drs. Schroth and Harrison introduced those individuals bringing official greetings to those attending “Oral Health and the Aboriginal Child”.

Greetings by:

Dr. M. Ogborn**, **Director of Research, Manitoba Institute of Child Health and Associate Head (Research), Department of Pediatrics & Child Health, Faculty of Medicine, University of Manitoba

Dr. Malcolm Ogborn welcomed all the delegates to the Manitoba Institute of Child Health (MICH) on the Bannatyne Campus of the University of Manitoba. He informed attendees that MICH is the hub of child health research in Manitoba, bringing together both clinicians and basic scientists into a multidisciplinary research environment. When the request was first made to host this workshop at MICH, Dr. Ogborn stated that he had no reservations about doing so and gave his and the Institute's full support to the event. In fact, hosting such research events is a perfect match to the vision and mandate of MICH. He highlighted the Institute's commitment to early childhood oral health research. This commitment is operationalized in several ways: by providing matching funds for Dr. Schroth through the Canadian Child Health Clinician Scientist Program over the past 4 years, by supporting other ECC research, and by providing the needed infrastructure for this area of pediatric research.

Dr. Ogborn also mentioned that Manitoba has a large Aboriginal population whose children face many health challenges, including poor oral health. He stated that there is a growing need for research that is community focused and he highlighted the accomplishments of the Manitoba Collaborative Project for the Prevention of Early Childhood Tooth Decay (Healthy Smile Happy Child) in working in partnership with several Manitoba communities to promote good early childhood oral health.

Dr. J.E. Scott, Associate Dean (Research), Faculty of Dentistry, University of Manitoba

Dr. Elliott Scott brought official greetings on behalf of the Faculty of Dentistry at the University of Manitoba. He said that the Faculty was proud to co-host this research Forum that has brought together researchers, community members and those in the policy realm. He mentioned the specific relationship that the Faculty has with the Manitoba Institute of Child Health, which provides research funding and infrastructure to faculty members conducting child health research. Dr. Scott reflected that Aboriginal oral health is one of the key priorities of the Faculty of Dentistry and that this workshop demonstrates this commitment. Considering that Aboriginal children and families face many challenges including increased dental disease, there is a growing need to focus attention on improving the oral health of the growing Aboriginal child population.

Mr. R. Maytwayashing, Senior Policy Analyst, Assembly of Manitoba Chiefs

Mr. Robert Maytwayashing brought greetings on behalf of the Assembly of Manitoba Chiefs (AMC), the political and territorial organization representing First Nations (FN) people of Manitoba. Mr. Maytwayashing is from Lake Manitoba First Nation in the Interlake region of Manitoba, and is a former Chief as well as a council member of ten years experience with the health portfolio.

Mr. Maytwayashing stated that many of the health issues faced by FN people are a result of their loss of autonomy and loss of control over decision making and governance. He added that the health issues faced by young Aboriginal children are closely related to the social determinants of health. He welcomed delegates to Manitoba which has 63 FN communities belonging to 7 Treaty areas and reflected on the need for partnering with Aboriginal people and leaders to improve the oral health of Aboriginal children. He concluded his greetings with a quote from Sitting Bull –

"Let us put our minds together for a better world."

Keynote Speakers' Presentations

Dr. Kue Young

Professor & Trans Canada Pipelines Chair in Aboriginal Health and Wellbeing (University of Toronto)

Expertise: Aboriginal Health Research & Epidemiology

Title: North-North and North-South Disparities in Health: A Circumpolar Perspective

Dr. Young's presentation was focused broadly on health disparities in the North, rather than limited to only oral health disparities. Given that a substantial proportion of the northern population is Aboriginal, the presentation was properly related to the scope of the symposium. The Canadian experience suggests that people in the North have worse health than those in the South and, within the North Aboriginal people are worse off than non-Aboriginal people. The North is defined by a variety of geographic markers such as the Arctic Circle and the tree-line. However, the North is not just a geophysical entity, but has a human and social dimension. For the purpose of this presentation, an operational definition of North was presented based on political and administrative units from where health data are usually collected and reported.

Dr. Young described how the populations of the North worldwide do not share universal characteristics. In making comparisons, one could compare northern regions among themselves, or compare northern regions with their respective, "national" or "southern" counterparts. Various determinants of health disparities could be investigated, including

geographic, demographic, socio-economic and health-care resource factors. In terms of health status, most indicators are derived from mortality, although some limited data are available from health surveys.

Another challenge is to know what outcome measures to compare when looking at health disparities. Comparing absolute differences between groups rather than ratios often tells different stories about whether disparities are getting worse or better. Different measures offer different possibilities for interpretation and have different policy implications. Therefore, the task of determining how much disparity exists and what it means is not simple.

In general, regions with a high proportion of Aboriginal people in their population tend to have higher fertility rates. The health gap between "north" and "south" is particularly pronounced in Canada, Greenland and Alaska, whereas in the Nordic countries, little difference can be observed.

The presentation highlighted the gaps that exist in data comparing all the northern regions and the lack of data on non-mortality health outcomes, on survey-based health determinants, and on environmental variables. Ethnic-specific data are generally unavailable with some exceptions. Dr. Young suggested additional analyses such as factor analysis that combine different variables and also expanding the collection of data on potential determinants of disparities. Such analyses help address questions such as why some northern peoples are healthier than others and provide policy guidance towards developing strategies to improve the health of northern peoples.

Ms. Jane Gray

National Coordinator: First Nations Regional Longitudinal Health Survey (RHS), Assembly of First Nations

Expertise: Aboriginal Governance; Conceptual Models; Regional Health Survey; Community Measures Survey

Title: **Implementing the RED STANDARDS for Community Based Research: Results from the First Nations Regional Longitudinal Health Survey (RHS 2002-03)**

Ms. Gray presented an overview of the First Nations Regional Longitudinal Health Survey (RHS) and successfully brought this long-awaited survey to life for the Forum! The RHS is considered the "survey of choice" for FN research in Canada because it is in keeping with the FN principles of Ownership, Control, Access and Possession (OCAP). The RHS is the only national research project thus far under complete FN control. It is rooted in self-determination, nationhood, self-governance and nation re-building. This project has enhanced FN capacity and control over research, provided key information for planning, policy and advocacy and will serve as a model for community-based research.

The RHS is based on a holistic perspective because it addresses all determinants of health. In addition, it provides scientifically and culturally validated information. The RHS is based on values of trust and respect for FN peoples, communities and nations, because FN were involved fully in the process. Therefore, the data received are more valid than any previous surveys. The key information from the RHS will and already has influenced FN planning, policy and advocacy at community, regional and national levels.

Ms. Gray described the mandate, partnerships, funding, and coordination involved in conducting the survey. She presented the timeline from 1994 (a year when on-reserve FN were excluded from 3 major Canadian longitudinal surveys) to instrument development and data collection in 2002-03. After data processing, an independent review of the project was conducted by Harvard University. The Assembly of FN is planning for the next wave of survey for 2007, development work is currently underway. There will be two more cycles of data collection in 2011 and 2015. Ms. Gray described the sampling: the longitudinal and cross-sectional component and community and individual selection. Data were collected by local FN interviewers using computer assisted person interviewing (CAPI). Final reporting will range from a national technical report to people's reports to fact sheets and 10 regional reports.

The RHS surveyed adults, youth and children (by proxy). For children, topics covered were, for example, activity, injuries and dental health. Ms. Gray then shared some highlights of the RHS survey results that relate to children and their oral health:

- 44% of FN children live in households with less than $20,000 yearly income.
- Higher proportion of FN children (25%) compared to Canadian children (17%) live below the poverty line.
- 40% of FN children live in a single parent household.
- Top 5 medical conditions (excluding dental) amongst FN children are asthma, allergies, chronic ear infection, bronchitis and learning disability.
- Traditional culture is important or somewhat important to 81% of FN families.
- 33.6% of households require major repairs.
- 1 in 3 FN children require some form of restorative dental work. In remote communities this proportion increases to more than half of the children needing restorative dental care.
- Increased access to dental care occurs when mother has obtained some post-secondary education.
- 76% of FN children affected by "baby bottle tooth decay" (a term familiar to FN families) actually received treatment.
- FN children living in isolated communities were twice as likely to report "baby bottle tooth decay" compared to those in non-isolated communities.
- 25% of FN children in Manitoba had not accessed dental care for at least 5 years prior to the RHS survey.

Ms. Gray highlighted the problem of inclusion of urban FN populations. On reserve, FN are represented by the Chief and Elders but in an urban setting, FN people usually need to

be engaged at an individual level which is a challenge. Inclusion of an off-reserve sample is part of the next steps for the new surveys.

The methods used for the RHS are a best practice model and the new gold or RED standard for FN community-based research. Unfortunately, the RHS has no committed funding for further data collection which will seriously impact the RHS credibility as a longitudinal survey. The website for the RHS is www.RHS-ERS.ca.

Discussions from the audience focused on some of the major problems of the FN communities that affect dental health:

- High cost of fresh foods that result in poor nutrition.
- Low frequency to breast feeding and brushing baby's gums.
- Loss of traditional knowledge.
- Cultural change due to modernization.
- Cost of health choices.
- Cost of dental items in on-reserve stores.

Dr. Marion Maar

Assistant Professor at the Northern Ontario School of Medicine

Expertise: Aboriginal Community Health and Research Ethics; Community-based/Participatory Action Research; Community-capacity Building for Research.

Title: Beyond the Participatory Paradigm: Negotiating worldviews, ethics and actions in research with Aboriginal communities

Dr. Maar's presentation began by contrasting Aboriginal and academic *worldviews* related to research. She then focused on the Aboriginal and academic perspectives on research values and *ethics*. Finally, she described how one community took *action* to make research work better for them.

Research involves the generation of knowledge which can be in the form of art, scientific and ecological knowledge, or oral or written history. Epistemology is the study of how knowledge is created. Differences exist between Aboriginal and Western epistemologies. According to Dr. Maar, the academic perspective of basic research is that it is a contribution to available scientific knowledge and offers an enhanced understanding of a subject. Initially, no specific application is intended for this new knowledge and, therefore, the notion exists in academics that basic research is "objective". In contrast, the indigenous perspective, in the words of Linda Tuhiwai Smith, is that research is a highly institutionalized enterprise that is an integral part of political structures. Western approaches to research generally marginalize indigenous approaches which are seen as biased or subjective.

Dr. Maar talked about how participants of the FN & Inuit Health Survey (1998) discussed the trend of the previous decade, where an increasing number of Aboriginal communities have refused to participate in any externally initiated research activity whether it is collection of census data or medical research. The major concern was the perception that despite decades of research on social problems in Aboriginal communities, these problems appeared not to have improved as a result of this research. Another concern was that the research seems to solely benefit non-Aboriginal researchers in terms of career advancement and employment. Furthermore, the research questions were often inappropriate in the context of the Aboriginal community (FN and Inuit Regional Longitudinal Health Survey 1998, A-45).

Dr. Maar then presented some concrete ways to bridge the research gap or, in the words of Willy Ermine, to create an "ethical space." She explained the concept of Participatory Action Research (PAR) which has emerged as a means to reduce monopolies of knowledge and to address the power inequities between established authorities and marginalized grassroots or oppressed groups. However, PAR will only be consistent with the aims of Aboriginal self-determination and empowerment and with Aboriginal epistemologies if the degree of collaboration goes beyond consultation.

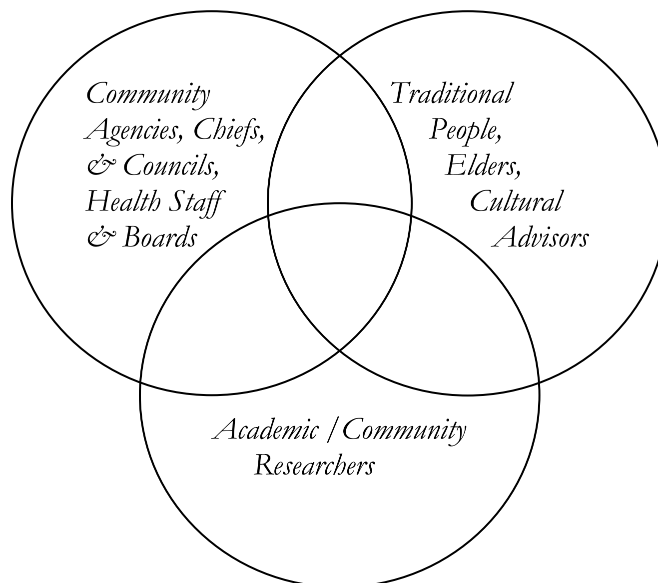
Dr. Maar then illustrated how a FN community-based research ethics committee could be developed using the model of the Manitoulin Anishnabek Research Review Committee (MARRC). About ten years ago, the community of Manitoulin recognized the need for good information to inform their program development strategies. However, they also felt that their participation in various research programs had not yielded any benefit to individuals, families or the community as a whole. In fact in 2000, the community expressed concerns about the ethics of two studies that had received clearances from hospital and university research ethics boards and simply shut them down. The specific concerns included lack of free and informed consent, linkage of collected personal data with patients' health information, potential harm to participants, and inappropriate research methods. In addition, a lack of respect for participants and community, lack of community consultation and lack of a strategy for knowledge uptake were all cited as difficulties.

A conference in the Manitoulin produced a vision for Ethical Aboriginal Research which included adherence to local Aboriginal as well as Tri-Council Policy Statement (TCPS) guidelines and privacy laws and a design that benefits the community, is respectful to the diversity of the communities and produces useful documents for the communities. The vision went on to say that ownership of the generated data should go to the communities, the research should be respectful to the traditional Aboriginal knowledge and culture, and should build local capacity for research. In addition, research topics should fit into a local strategic plan for research and be directly relevant to local communities. Conference participants wanted to be proactive in research and thus they formed a research committee. This committee formulated Aboriginal community-based ethical research guidelines. In this regard, the committee included the expertise of a traditional advisory group and Elders with health-related skills. The committee also wanted local

Anishnabek values, the "Seven Grandfather Teachings" (respect, wisdom, honesty, bravery, truth, love, humility) to be honored in the research process.

Manitoulin Island now has a fully functional community-based research ethics board (REB). Its members are trained according to national standards by National Council on Ethics in Human Research (NCEHR). They evaluate research projects according to their adherence to local Aboriginal values. The REB now builds research capacity with local communities and academic researchers, instead of acting as a gate keeper. They have constituted guidelines and a workbook which can serve as an educational tool for everyone related to any research project. Involvement of all the stakeholders leads to successful research.

The composition of a local research committee or research Steering Committee is indicated in the figure below:



The Manitoulin REB has also networked and exchanged knowledge with other Aboriginal organizations and initiatives. A key message in this regard is that collaboration in research leads to better research questions, greater insight, more valid and reliable results and better knowledge transfer. The major take-home message from this presentation was to "listen, listen, listen" to the Aboriginal community members and stakeholders before we attempt to act on their behalf.

For more information on MARRC please see
http://www.noojmowin-teg.ca/default5.aspx?l=,1,613

Dr. Peter Cooney

Chief Dental Officer of Canada

Expertise: Canadian Dental Health Policy; Dental Public Health; Aboriginal People's Oral Health

Title: Health Canada, Oral Health Policy for Canadians

Dr. Cooney reviewed data on the current status of children's oral health in Canada. He then briefly discussed the role of the office of the Chief Dental Officer in terms of access to care. Finally, he reviewed the Federal Government's involvement in oral health care.

He first of all presented the National Health and Nutrition Examination Survey (NHANES) data from the USA (1988-94) that demonstrate dental decay to be by far the most common disease which affects the children (58.6%) from 5 to 17 years of age. He also shared data from Quebec, Ontario and the 1996/97 Oral Health Surveys of FN and Inuit children that clearly show the increased dental disease and treatment needs of Aboriginal children.

Dr. Cooney then briefly described the background to his appointment as Canada's first Chief Dental Officer. He informed the gathering that for a number of years national and international groups had been campaigning for a Chief Dental Officer (CDO). Canada was the only G8 country without a CDO (or equivalent) compared to over 140 countries in the World Dental Federation who had a CDO. Finally in October 2004, a CDO position and the Office of the Chief Dental Officer (OCDO) were created. Priority areas of the OCDO include:

- Assessment of needs.
- Identification of gaps.
- Health promotion, prevention of disease and protection of health.

Dr. Cooney reminded the Forum of the recently underway Canadian Health Measures Survey (CHMS.) which will help to address the first priority area: "assessment of needs". This survey of 5000-6000 Canadians in 5 age groups and at 15 sites will collect data via self (proxy) reports and by physical examination. Oral health will be part of the assessment. Dr. Cooney said they are now working to include an Aboriginal component to the oral health section of the CHMS. which will allow a more informed comparison of oral health status between Aboriginal and non-Aboriginal Canadians.

The second priority or "identification of gaps" is being addressed by a variety of activities which include, for example, an environmental scan regarding fluoridation status and another one looking at public health resources in Canada. Dr. Cooney also reviewed

the current federal government funding of direct oral health programs which includes FN and Inuit Health Benefits.

Access to care issues was briefly discussed. It is noteworthy, but not surprising, that higher income earners (more than $49,000 per year) are more likely to have recently had a dental visit, compared to Canadians who have lower incomes.

In conclusion, Dr. Cooney summarized some of the recent gains in knowledge. We now know the types of oral health infrastructure across the country. The office of the CDO is filling other information gaps. Federal, Provincial and Territorial (FPT) Dental Directors, associations, boards, universities and other government departments are all working well in partnership with the office of the Chief Dental Officer. Because of the new knowledge and these positive working relationships, informed decisions are now possible as we work to continue to address access to care issues in Canada.

Day 2:

Drs. Schroth and Harrison acknowledged that Procter & Gamble Professional Oral Health (Crest Oral B) was the official sponsor of Day 2.

Panel Discussion with Keynote Speakers

A panel discussion began Day 2 of the Forum. The panel included all of the keynote speakers and gave attendees an opportunity to ask questions that could be discussed by all of the speakers together. The panel discussion centered on the following:

1. Research ethics

The keynote speakers were asked several questions that focused on the ethics of doing research with Aboriginal communities. Specifically, attendees wanted to better understand the differences between *ethics* committees and *research* committees in Aboriginal communities. Research committees help guide research processes and protocols while ethics committees focus on whether the proposed research is conducted in an ethical manner that fits with the community's values and way of life. Panelists indicated that many Aboriginal communities have established research committees, but are also interested in creating their own ethics review panels. The difficulty is that most communities are not ready or do not have the necessary capacity to establish such review boards. There are some exceptions as mentioned by Dr. Maar in her presentation the previous day. Another challenge that community ethics review committees face is the need to remain apolitical and not get involved in those affairs of the community that do not pertain to research ethics.

Another question was raised about whether such Aboriginal ethics boards are recognized by the Tri-Council on ethics. It has been recommended that researchers submit their proposals to both their own Institutional Review Boards (IRBs) and to the community's ethics review board for review. This practice can pose difficulties to researchers when different revisions are requested from each of the committees. Attendees were also made aware that Health Canada now has its own ethics review board.

While all research participants must give informed consent, obtaining consent has become a lengthy process. Many communities would prefer shorter, more easily understood consent forms. Dr. Young mentioned that the circumpolar health study recently created a DVD that demonstrated every step of the survey to ensure that participants are properly informed when giving their consent. This approach is currently being implemented in the study underway in Nunavut.

2. Incentives to research participants

The question of whether incentives should be offered to research participants was raised. In essence, is it appropriate to pay research participants for volunteering in a study? Any incentive should be viewed as a token of appreciation from the researcher to the participant for the time commitment made to take part in research. However, with random sampling methods, it is difficult to justify honoraria paid to selected participants to those who were not randomly selected to participate.

Some IRBs are concerned about paying participants to take part in research but may approve nominal amounts of money, as long as the amount is not an enticement. Ultimately, the decisions should be left up to the community about what is an acceptable incentive method and amount. It was mentioned that some Aboriginal communities have opted for raffles for participants with a few big prizes rather than giving each individual participant a small honorarium. This approach might improve enthusiasm and, ultimately, participation.

3. Institutional Review Boards and cultural competency

A general discussion also centered on the role and composition of IRBs who review research involving Aboriginal peoples. For the most part, IRB members need additional training in cultural sensitivity. They may not possess the necessary knowledge of the community or have experience in working with Aboriginal communities to adequately protect or support the community. Overall, IRB members need to carefully listen to what the community is saying about how they want the research conducted rather than telling them what to do.

4. Canadian Health Measures Survey

Several of the attendees were concerned that the CHMS that is currently underway does not include a representative sample of Aboriginal people. It is also unfortunate that the CHMS does not sample Canadian preschool children given the fact that the prevalence of ECC is increasing and is a predictor of dental decay later in childhood. Ms. Gray indicated that the RHS does provide self-reported national information on the oral health of young FN children and baby bottle tooth decay. Dr. Cooney stated that there are discussions underway to include a FN sample and capture a snapshot of their oral health, although there is no current plan for the federal government to include young children in the survey.

Aboriginal child oral health research presentations by Steering Committee

Each Steering Committee member presented an overview of their research on Aboriginal child oral health to allow sharing of "what worked, what didn't, and what we would do differently next time."

Addressing Children's Oral Health Inequalities in Northwestern Ontario: A Research Community Partnership

Dr. H. Lawrence

Since 2000, Dr. Lawrence has been working in partnership with the Sioux Lookout Zone Dental Program Staff and FN communities in Northwestern Ontario evaluating oral health promotion programs and developing preventive interventions to reduce oral health inequalities. She began her presentation with an introduction to health inequalities. Dr. Lawrence summarized the different explanations for health inequalities and emphasized that doing health care as "business-as-usual", in other words, delivering health care the same to all people, *i.e.*, "one-size fits all", maintains (and often exacerbates) health inequalities. For example, in isolated Aboriginal communities, emergency dental care is often provided by "fly-in" professionals who arrive, fill cavities or extract teeth, and then come back again when problems arise. This approach does not improve the overall oral health of the population and therefore maintains, rather than reduces, the inequalities in oral health. Conversely, community-run health services or programs with a focus on early intervention that ensure that all groups have access to effective treatment services are more likely to reduce health inequalities.

Dr. Lawrence gave an overview of the financing and delivery of dental care to Aboriginal communities. She noted that the delivery of dental services to isolated Aboriginal communities remains a difficult undertaking. Approximately half of Aboriginal Canadians live on non-fluoridated FN/Inuit/Métis communities with significant geographic and socio-economic barriers that hinder access to dental practitioners, dental hygienists and therapists, despite the fact that these Aboriginal groups all have dental benefits through the Non-Insured Health Benefits (NIHB) Program of Health Canada. At the same time, early preventive care and effective and culturally appropriate strategies to promote good early childhood oral health in Aboriginal communities are lacking. Variables influencing the effectiveness of preventive and treatment-focused programs in these communities include the ongoing problem of finding adequate numbers of dentists, dental hygienists and therapists to work in remote areas, the logistics of organizing travel and accommodations for these workers, the prohibitive cost of flights, as well as the difficulties in motivating parents/caregivers to subscribe to preventive oral health practices for their young children, particularly when there are far greater challenges and health concerns facing Aboriginal populations in Canada.

Dr. Lawrence also provided highlights from the 2002/03 First Nations Regional Longitudinal Health Survey (RHS), in particular the Child Survey, which indicated that 69% of FN children have received some form of dental care in the past year. However, when the results were analyzed by age group, the pattern that emerged revealed that school age children were more likely to have received dental care in the past year, followed by preschool age children, with almost no dental care for infants and toddlers.

In the second part of her presentation, Dr. Lawrence gave an overview of the strategies for preventing oral diseases in young children currently in place on FN reserves located in the Sioux Lookout Zone (SLZ), and provided highlights of the most recent strategy – "Baby Teeth – Keep them Beautiful with Fluoride Varnish," a research-community partnership initiative to address children's oral health inequalities in the SLZ.

Since the mid-1990s, a strategic preventive effort has been underway in the 28 FN communities of the Sioux Lookout Zone to reduce the number of young children receiving dental treatment for ECC under general anesthesia (GA) at hospitals. This community-based oral health promotion program operates in conjunction with the Woman and Child Community Nutrition Program and is delivered to prenatal women and new mothers by community-based nutrition educators. The program underwent an evaluation in 2001-2002 and while it was found to improve caregivers' knowledge of ECC and children's oral hygiene and body mass index, the program did not eliminate the demand for dental services under GA, but simply delayed rehabilitative dental surgery. The program evaluation recommended that a combination of preventive and health promotion strategies be implemented to assist in reducing ECC and the backlog for pediatric dental surgery.

In 2003, the Zone Dental Program in partnership with the SLZ communities and researchers at the University of Toronto introduced a Fluoride Varnish Program to be offered in tandem with the prenatal and child nutrition programs. The first step was to assess a varnish program's effectiveness (under field conditions in the North) and its feasibility. The study was designed to measure the effectiveness, safety, practicality and cost of a fluoride varnish preventive intervention in a high-caries-risk population, when used in combination with caregiver oral health counseling. All 28 SLZ communities were eligible to participate in the study, and from those, 20 were randomly selected to take part in the study. Community leaders were then consulted and all agreed to participate. The researchers sought community involvement by making presentations to the Nishnawbe Aski Nation Health Planning Group and to the SLZ Health Program Managers, physicians and public health nurses. During the partnership-building process the researchers made several visits to Sioux Lookout to learn about the community's values and beliefs in relation to the research and the appropriate protocols for accessing the information and collecting data. Posters, pamphlets and displays at health fairs were also created to describe the project and have been used along with media promotions as strategies to raise the level of awareness about ECC and the means to prevent it in these communities.

From the 20 FN communities, 1275 children were enrolled between August 2003 and February 2004. At the final, 24-month follow-up, 952 children were examined, representing an excellent retention rate of 75% (no community dropped out of the study). Analysis was carried out for 1146 children in the SLZ and 102 in Thunder Bay. The study found an 18.3% reduction (or prevented fraction) in the levels of ECC among FN children receiving the fluoride varnish and caregiver counseling. This percentage increased to 24.5% when non-Aboriginal children recruited from eight childcare centers in Thunder Bay (NW Ontario) as well as through 'request for volunteers' advertisements in the local newspapers were included in the analysis. The SLZ Hospital provided data on children's dental general anesthetic (DGA) procedures. Approximately one-quarter of the participants had a DGA during the study period, but most importantly, the proportion of children who had dental care under general anesthesia was 25% percent lower in the varnish group than in the control group.

The present community-based fluoride varnish program has the potential to reduce oral health inequalities between Aboriginal and non-Aboriginal children. But at the same time, fluoride varnish programs must be offered in conjunction with caregiver oral health education and health promotion programs targeting improved prenatal and young children's nutrition so that the root causes of ECC are also addressed. The evidence presented supports shifting some resources away from the dominant treatment and curative services towards preventive care and health promotion strategies.

Dr. Lawrence concluded by stating that consultation with the community requires time and this is essential to establishing a successful and strong partnership between all the parties involved; that is the researcher, the local health professionals, the community representatives and most importantly, the members of the community. Therefore the researcher who develops an ongoing relationship with local health professionals and the leaders of the community will likely have greater success in reducing the health inequalities that exist in these communities.

Case Study: Preventing Nursing Caries – A Culturally Sensitive Approach

Dr. R. Harrison

In order to familiarize attendees with Aboriginal child oral health research projects and to better understand relationships that develop between researcher, public dental health staff and communities, Dr. Harrison presented a "case study" of an early research project in which she had been a principal investigator. She described:

- Her role as a non-Aboriginal researcher from outside the community.
- The project itself.
- How the project "stood up" in the context of recent CIHR guidelines related to Aboriginal research.
- How the project could have been organized differently given what we "know now".
- Her views on future directions for such research.

The overall goal of the project described (funded by the B.C. Health Research Foundation) was to develop a community-based, culturally appropriate oral health promotion program that would lead to improved dental health in children in the community of interest. Because of previous negative experience with outside researchers, this community did not want to be identified. The project had three phases: information-gathering, project planning and project evaluation.

Information gathering involved interviews of mothers of young children and Elders about dental health behaviors and child-rearing practices. In addition, the dental health status of preschoolers was assessed in the "test" community and in a comparison community. Findings were a high prevalence of dental caries in preschoolers from both communities; over 40% of children drank from a bottle after 2 years of age and 60% went to sleep with bottle. Most parents took their preschool aged child to the dentist only if problems occurred. Generally, moms needed more support and resources to implement healthy behaviors. The Elders' recommendations to improve child oral health included more traditional foods, use of a swing for child comforting, and more discipline.

A committee of mothers, chaired by the project's Research Assistant who was hired from the community, developed a variety of projects aimed at improving child oral health. Projects included a service to loan moms willow cradles for comforting babies (an alternative to a bottle); development of a project logo, pamphlets and posters; construction of a smokehouse for smoking meat (a traditional comfort for fussy infants); radio announcements by an Elder in the local native language; one-to-one counseling at well-baby visits, and various community get-togethers to maintain awareness of the project (anniversary party, healthy nutrition workshops). The final evaluations of the program demonstrated positive, though not statistically significant, trends compared to the comparison community: more children were "off the bottle" by age 2, fewer children were sleeping with a bottle, fewer young children with nursing caries and a general awareness in the community of the program's existence.

The presentation then examined this demonstration project in relation to six of the 15 articles from the May 2007 CIHR guidelines for health research involving Aboriginal people.

1. *Was this research a partnership within a framework of trust and cooperation*? The project was initiated after discussions with key community members. However, consultation with the wider community should have taken place. After baseline information was collected, the project was developed by a committee from the community and resources (logo, pamphlets) were developed locally. All publications and the final report were reviewed by the Band Manager and results were presented at community meetings.
2. *Did the community have the option to do participatory research?* Although the project was initiated by outsiders, community representatives were involved in planning (e.g. mothers, Elders). Frequent community get-togethers attempted to keep the community up-to-date.

3. *Was community and individual consent respected?* All questionnaires were completed in person and with the assistance of community members (the community health representative (CHR) for the mothers' questionnaires and the project's research assistant for the Elders' questionnaires.) At the time of this project, the community did not have its own research committee thus ethics approval was obtained from University of British Columbia (UBC). Parents signed consents for dental examinations of their children.
4. *Were privacy and confidentiality respected?* Names of either the test or comparison communities were not revealed in any scientific publications. However, the "test" community was identified in poster presentations by the Research Assistant, for example, at local Wellness Conferences. Participants were never identified by name.
5. *Was there ongoing communication about project within community?* The local planning committee, the involvement of Elders, community presentations, and various community events were all undertaken in the spirit of maintaining ongoing communication and awareness of the project.
6. *Did the research have beneficial outcomes?* Trends reported at project's end suggested positive changes in dentally-healthy behaviors. The project's legacy included revitalization of traditional practices, e.g. cradle loan project and dental counseling as part of well-baby care. The Band was also successful in soliciting outside funding for various projects.

While the spirit of each of these 6 CIHR articles was fulfilled by the project, many unplanned and unexpected challenges occurred. Examples of the challenges, most likely common to other projects involving Aboriginal communities, include long distances required for the Project Coordinator and community members to travel for events and meetings. In addition, the Research Assistant and thus the project would have benefited from more training in areas like project and time management. Financial issues caused tension because the indirect costs assumed by the Band were not budgeted in the grant. To give the mother's planning committee more time to develop ideas, it should have been formed right after the project was funded rather than after the baseline information had been gathered. Furthermore, funds should have been provided for committee members' honoraria, transportation and child care. Personnel changes in the 4-year span of the project also caused upheaval and delays. The seasonal changes in the life of community were overlooked in the initial planning of the project. While the community was looking forward to a positive future, the negative legacy of previous research projects always cast a shadow. In addition, the problem of poor child oral health was eclipsed by tragic historical issues like residential schools.

Experiences from this project could certainly inform future projects. Recommendations for strategies for future projects included paying close attention to project logistics, a role for fluoride varnish applications in the interventions, consideration of a counseling intervention that was parent centered, e.g. motivational interviewing, training local women to do the counseling rather than medical professionals, and paying more attention to social determinants when planning interventions. Some of the more "global" lessons learned included the realization that communities do have good ideas and are "experts" on what will work for them. Interventions that integrate traditional wisdom and practices

should always be considered for Aboriginal communities. For young children, approaches to oral health promotion that are integrated with existing health services, rather than stand-alone dental programs, make sense. In other words, research should not compartmentalize the mouth from the rest of a child's body.

Furthermore, independent "one or two community" approaches that target parental and family continue to be helpful before embarking on multi-center, long-term projects if only to problem-solve the many logistical challenges, i.e. the feasibility of the project. It should also be remembered that whatever programs are implemented, there is unlikely to be one overall "pan-Aboriginal" approach. Finally, rather than focusing on parents alone, any approach needs to achieve a balance of targeting both parent and child level factors and also the social environments in which health behaviors are developed and sustained.

Things Are Better When We Work Together: First Hand Experiences From The Manitoba Collaborative Project for the Prevention of Early Childhood Tooth Decay

Dr. R. Schroth

The main objectives were to: 1) discuss barriers to moving evidence into policy, 2) identify the need for partnerships and the benefits of collaboration, 3) discuss how community-development can be used to address the problem of ECC, 4) discuss the benefits of a multi-agency, multi-disciplinary, and intersectoral collaborative partnership in Manitoba, and review the project's history, and 5) share methods for ongoing project evaluation and a framework to address ECC in communities.

There are numerous factors that influence the development of health policy and determine whether evidence guides decision making. Factors impacting whether research evidence influences the development of health policy include the following:

- Evidence and the Researcher: (How well is evidence shared? Is the research relevant? Is it practical? Will the researcher advocate for communities after the research is over?)
- The importance of health issues: (Are only some affected? Consequences of the health problem. Is the issue important to the community?)
- Policy-makers: (Who reviews the evidence? Is the issue a priority? Involvement of policy-makers in research planning may help change policy as they are connected to the evidence.)
- Service providers and professions: (Are they familiar with the process? Is there willingness and capacity? Lack of vision. Biases and values.)
- Relationships: (Interpersonal, between organizations and between governments. A willingness for people and groups to work together.)
- Populations at risk: (Acceptance of issue and opinions. Epidemiology of disease.)
- System capacity and economics: (Can governments afford the policy change? Does the evidence call for more money or re-allocation of resources? Can the system handle it?)

Combined efforts can be synergistic and can accomplish more. Partnerships improve the chances that communities are heard, that research is focused and increases the likelihood of policy change. In addition, researchers must explain the need for undertaking the research, how communities can benefit from it, and how it will be conducted.

Manitoba Collaborative Project for the Prevention of Early Childhood Tooth Decay
This project began in 2000 in response to the large wait list for pediatric dental surgery. A collaborative partnership developed including clinicians, researchers, academics, policy-makers and community members to find solutions using a community-development approach. The purpose of the project was to improve early childhood oral health, minimize reliance on dental surgery and identify potential preventive interventions for ECC at the community level. Traditional oral health promotion has had little impact on reducing the prevalence of ECC among those considered to be at high risk. This prompted an innovative solution to the problem. The Manitoba Collaborative Project for the Prevention of Early Childhood Tooth Decay (Healthy Smile Happy Child) is a multi-disciplinary and intersectoral group addressing ECC in Manitoba. Three pillars have guided the project: 1) community-development, 2) oral health promotion and ECC prevention, and 3) evaluation and research.

By definition, community-development is the process by which members of a community begin to identify issues they face, including diseases, and then proceed to obtain and acquire the essential skills and capacity needed to develop and undertake action to foster change. In essence, community-development enhances the bonds between individuals and groups resulting in an enhanced capacity to work towards common goals.

Four pilot communities initially participated including two FN communities. The goals were to: 1) gain community acceptance of the importance of early childhood oral health and ECC prevention, 2) build on existing programs which target young children, 3) increase parental knowledge of ECC prevention, 4) increase the knowledge of existing service providers (i.e. public health) in the community of the importance of prevention of ECC, and 5) encourage existing service providers to incorporate ECC prevention activities into their practice.

A baseline study was conducted in 2001 as there was no published information on ECC and its risk factors in Manitoba children. A cross-sectional study design was selected. Children under 6 years of age and their parents or caregivers were studied. 53.7% of the children surveyed had ECC. Surprisingly, the prevalence did not significantly differ among the participating communities, whether on-reserve or urban centers.

Significant effort was devoted to knowledge transfer of the baseline data. Profiles were compiled for each community and key risk factors were shared. A project coordinator assisted with community-based oral health promotion and helped to develop community-based health promotion tools (e.g. True or False game, anticipatory guidance bags, posters, etc). A number of these resources were featured in his presentation including a link to the project webpage hosted on the Winnipeg Regional Health Authority website -

http://www.wrha.mb.ca/healthinfo/preventill/oral_child.php. In 2005, the partnership received the Canadian Dental Association (CDA) Oral Health Promotion award.

In 2006-07, the project received a grant from Manitoba Health to expand to all communities in the province. Five community facilitators along with a project coordinator now carry out the project's mandate. Printed resources have been developed, some of which have been translated into French and Cree. These resources have been made available on-line. Telehealth is a new medium being used to support staff and pioneer 'distance' early oral health promotion activities.

A follow-up study in the four pilot communities was recently conducted to assess changes in knowledge, attitudes and behaviors relating to early childhood oral health and to determine the level of awareness about the project and its resources, in addition to caries rates and ECC prevalence. Preliminary results indicate that there has been significant improvement in caregiver knowledge and attitudes towards preschool oral health. A significant drop in the number of children with untreated decay in their baby teeth has also been found. Community specific profiles are now being created to share results with the four original communities.

In order to remain accountable to government, Regional Health Authorities (RHA), and stakeholders in the project, reports are compiled and disseminated at regular intervals. Other forms of evaluation either underway or planned include a 'pre and post' workshop evaluation of participants and focus groups with service providers, parents/caregivers, and cultural groups.

Some of the challenges in working with communities on such a large scale project include project staff turnover, changes in staff and leaders at the community level, difficulty seeking initial funds and sustaining funds, weather and accommodations, busy service providers, the fact that oral health may not be a high priority, jurisdictional differences and the knowledge that ECC is linked to determinants of health including the social determinants of health. The ideal framework to solve ECC will need to be based on principles adopted in this project - empowering communities, partnering with local stakeholders, understanding that oral health is part of overall health, encouraging sustainability by adopting an equitable intersectoral approach, and engaging in a process of ongoing evaluation.

Lessons learned throughout this process include:

1. Dental health is an essential part of overall health and well being.
2. It is both cost effective and efficient to incorporate oral health education and promotion into existing programs and services. This approach builds on existing relationships between providers and parents. Furthermore, it ensures that oral health education and promotion are provided on a sustained basis.
3. Sharing survey information on prevalence and risk factors for ECC specific to communities is a powerful tool to engage community members and leaders. Communities cannot develop their own strategies and solutions unless they are

well informed. This is the basis to successful community building and community-development.
4. Following up with community requests and suggestions is critical if community support and involvement is to be maintained.
5. To affect change, education must occur at a variety of levels: policy-makers, professional service providers and educators, program staff, parents and caregivers and the community at-large.
6. In conjunction with health promotion and community development strategies, it is critical to consider the many determinants of health related to ECC. A singular approach to a multi-factorial problem is not appropriate.
7. Intersectoral, multidisciplinary partnerships can work. They may take time to develop but are beneficial in the long run.

Using Qualitative Research Methodology to Aid in Our Understanding of Children's Oral Health: An Example from Manitoulin Island

Dr. S. Peressini

Dr. Peressini was unable to give her presentation in person. Instead, her presentation was given by Dr. Marion Maar who previously worked with Dr. Peressini in the District of Manitoulin on this research project.

The first objective of Dr. Peressini's study was to describe a qualitative methodology (Grounded Theory) that can provide useful information about childhood oral health. This qualitative approach is unique in ECC, but has an important role to play in Aboriginal research as it allows participants to share their personal experiences in an in-depth manner similar to story sharing. Therefore, it allows the researcher to gain a greater understanding of "why" certain behaviors are engaged in, which goes beyond the mere identification of risky health behaviors. The second objective was to share the results of a study with FN children aged 3 and 5 years in the District of Manitoulin in Northern Ontario.

The objective of this study was to develop a substantive theory that employed the Grounded Theory (GT) Methodology as outlined by Strauss and Corbin (1998) of some of the individual and societal barriers to adopting dentally healthy infant and child rearing practices among selected primary caregivers in several FN communities. The majority of the participants in this study resided on Manitoulin Island, in the District of Manitoulin (DM) located in Lake Huron. The 4,400 FN people living in the DM account for nearly half of the district's population.

Some key components of GT methodology are:

- *A priori* hypotheses are not made; a priori means based on hypothesis, not experiment.
- Sample size is determined <u>during</u> the study, not before the study. The respondents are recruited until theoretical saturation is achieved, that is, until your respondents are not telling you anything that you have not already heard.

- Sample selection can be random, but is typically purposeful.
- A thorough literature review is done after the study is completed.

Data for the study was collected using a small number of open-ended questions to help guide the conversation. No standardization of questions is done since new questions may be added as more participants are enrolled and interviewed. The “constant comparative” method is used whereby one interview is conducted and analyzed before the next interview begins.

The data analysis involved 3 steps that were done concurrently:

- Open coding – forming concepts and the properties of each concept; this is the process of breaking apart the respondent’s answers.
- Axial coding – arranging the data into a “coding paradigm” or “logic diagram”; this is the process of putting the pieces of the puzzle back together.
- Selective coding – writing the “story”; identifying hypotheses.

A total of 12 primary caregivers took part in the interviews. Half of the caregivers had children with ECC (defined as decay on 2 or more primary upper incisors or canines, manifesting as either untreated caries, fillings, or extractions due to decay or a total number of decayed, extracted or filled teeth >3). Epidemiological data from Dr. Peressini’s study indicated that 45/87, or 52%, of 3 and 5 year olds had ECC according to the case definition she selected.

Dr. Peressini next explained the theoretical model that she developed from the data. The theoretical model included the “causal conditions”, “context”, “intervening conditions”, the “central phenomena” and “strategies” that affected primary caregivers that lead to the “consequences” of developing or not developing ECC in their child(ren). She found that some of the barriers that a primary caregiver faced that prevented adoption of dentally-healthy habits included:

- Being an overburdened primary caregiver (i.e. caregiver busy with work or school outside the home).
- Negative dental health perceptions (i.e. thinking that baby teeth are not important or that ECC was a normal part of childhood).
- Lack of correct dental knowledge (i.e. what beverages should not be used in a baby bottle to help prevent ECC development).
- No transmission of positive infant and child rearing and feeding practices from the previous generation to the present.
- Accessing dental health information (i.e. it was more readily gained from family members rather than from health professionals), and
- A difficult family situation.

Some of the main conclusions from this work were:

- Oral health is not limited to individual choices but is linked to larger social factors as well.

- Primary caregivers of children with ECC have different social experiences than those of children without ECC.
- Oral health promotion programs may require more than education, but also an examination of the social influences of each family.
- Oral health promotion programs need to target extended family members as well as primary caregivers.

The results of this study are specific to those who participated in this study and cannot nor should not be generalized to other caregivers in the DM or to other Aboriginal people. Further research will be needed to generalize these findings.

Break-Out Groups (Day 1 and 2)

The Forum included break-out groups on both days. Group membership was pre-arranged to allow equal representation from community members, researchers and policy-makers. Groups that did not get through their assigned questions on Day 1 continued with them on Day 2. Groups that completed their assigned questions used Day 2 to discuss the overall success of the workshop in achieving its original objectives and goals.

Topics with preambles and guiding questions were developed by the Steering Committee. Group facilitators were chosen in advance from the attendees.

Group 1: Making Child Oral Health a Priority

Group Participants:
Jeanette Edwards, Herenia Lawrence, Lynn Maytwayashing, Jennifer Melville, Doug Graham, Earl Nowgesic, Peter Cooney

Preamble:
Diabetes, childhood injuries, anemia and asthma are examples of health priorities for Aboriginal children. These conditions may have a serious effect on any child. Because oral health is viewed (by some) as less of a threat to a child's quality of life, oral health problems are often forgotten in the "life of a child." Consequently, research related to child oral health does not get the support that it deserves, despite that fact that extensive dental decay in young children is a painful and distressing condition. In fact, dental caries is the <u>most common</u> chronic disease of childhood.

Guiding questions:

- How important is oral health in the life of a child?
    - Why do you believe this? What do you think most people in your community or your organization believe?
    - Do you think more attention should be paid to child oral health and to child oral health research, especially related to Aboriginal children? Why or why not?
    - Should improving Aboriginal child oral health become a "research priority" at all?
    - If the impact of dental decay on young Aboriginal children is not commonly recognized or understood by many of us, what kind of strategies might enhance people's understanding of the seriousness of the problem?
- Why does oral health go unnoticed at times (in comparison to other health issues) by Aboriginal child health care workers, community workers and other "key" community people?
    - Has this lack of attention changed (gotten worse or better) in recent years?
    - If you have seen changes (positive or negative), tell us what you have seen and why you think changes have taken place.

- If health research is indeed one of the keys to decreasing disparities in health, how can we make child oral health research a higher priority in Aboriginal communities and to agencies that support research?
    - Do you think oral health research should have a higher priority? Why/why not?
    - Do you think linking child oral health research to other child health research areas (like diabetes, heart health) would be helpful? Why/why not?
    - How could such links be promoted?
- Oral health research is currently mostly focused on the young child, but what about the oral health of youth? We know that dental disease in early childhood can often lead to crooked teeth and poor self-esteem in teens.
    - What do you think about linking Aboriginal child oral health research with Aboriginal youth oral health research to create an oral health research "continuum" for Aboriginal children and youth?

Day 1:

Increase awareness: Dental caries is more prevalent than any other chronic disease of childhood. Since conditions such as diabetes, childhood injuries, anemia and asthma are health priorities for Aboriginal children, oral health problems are often viewed by some as less of a threat to the "life of a child." People think these teeth fall out so it doesn't matter if these teeth decay. Increased awareness towards children's oral health is required to establish its importance in children's general health and overall well being.

Collaboration: There is a need for interdisciplinary participation since one person or group cannot do it alone. Collaboration with other health professionals is essential for success. Existing allied health care professionals can play a vital role to reach the general population. They should be encouraged to incorporate ECC prevention activities into their practice. Success will only be possible if other branches of the health sector respect and recognize this problem and work together with dental professionals to attain this goal. It is also crucial to bridge the gap between researchers, communities and policy-makers.

Building family knowledge: Changes in the school curriculum may be needed. Key risk factors for ECC should be shared with the communities. Community-based oral health promotion strategies and community-developed health promotion tools should be made available to educate entire families. The goal is to increase the knowledge of parents and caregivers about preschool children's oral health and its contribution to their health and general well being.

Mouth-body connection: The mouth is the gateway to other systemic organs of the body. Therefore, to maintain good health, it is imperative to pay attention to good oral health. We have to communicate that oral health is an integral part of total health and well being – a holistic approach is needed in this regard.

Better evidence that prevention works: In Manitoba, more than 2000 children need dental surgery under general anesthesia each year to treat ECC. Early intervention to prevent ECC is required. If left untreated it will cause pain which will eventually lead to poor quality of life. Cost of general anesthesia will certainly be a factor for policy-makers. NIHB would be more supportive of preventive practices if they were provided with evidence based knowledge, which can be supplied by the researchers.

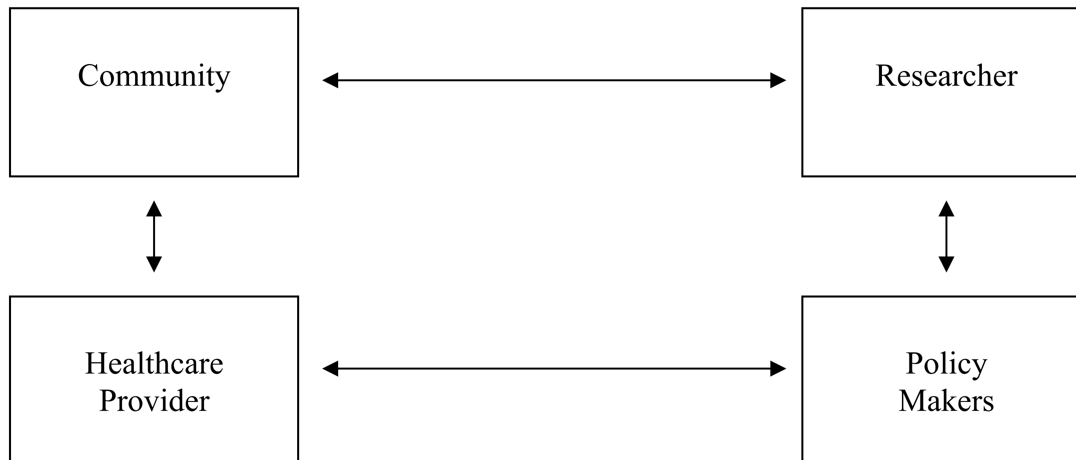
Community partners (Chiefs, Elders): The key is to convince the Chief and Council in FN communities that it is important to make policy decisions based on these findings. Cultural proficiency on the part of the researchers and administrative staff of the research unit can prove to be very useful. Recruiting the help of the Elders from a community to promote the importance of oral health is always a good strategy. The community members respect the Elders while the children love the stories the Elders tell.

Develop community capacity and community resources: The prevention program will be sustainable if a coordinated and comprehensive strategy is adopted which includes community initiated capacity building strategies. If the community can be made aware of the problem of ECC and its consequences on the life of the child, community members will ask for solutions. Through human development more Aboriginal professionals will be trained to handle the problem on site and become resources for ECC prevention in their communities. Eventually this will empower the community and remove their dependencies on external help, which will help to grow and maintain community capacity. Support from external sources must be available during this development phase but soon these support structures will no longer be necessary.

Day 2:

Group 1 felt that they had adequately discussed their break out group topics during Day 1. Instead of continuing with the questions, this group used the break-out session on Day 2 to revisit the goals and outcomes of the Forum.

Goal of the Workshop: The group emphasized the need for building relationships between the community, the researcher and the policy-maker. Any prevention program will be sustainable if a coordinated strategy is adopted which includes community initiated capacity building policy through human development. Empowerment can be achieved by training the indigenous population and providing them with support, knowledge, advice and counseling from research resources. If the community can be made aware of the problem of ECC and its consequences on the life of the child, community members will take the initiative by either asking for solutions or finding solutions themselves. Collaboration with other health professionals is essential for the success of an ECC prevention project. Existing health care professionals can play an important role by using their infrastructure and expertise.



Outcomes of the Workshop: This workshop has provided an opportunity to promote higher visibility of the dental health challenges faced by Aboriginal children. A spirit of multidisciplinary cooperation, collaboration and camaraderie is evident. A "qualitative" analysis of the Proceedings revealed interesting data and promise for future early childhood oral health research. The workshop was indeed inclusive with representation from all major stakeholder groups; the community, researchers and administrators.

Future Directions: Coalitions are formed when different groups work towards a common cause. The interdisciplinary coalition that has started at this Forum should be maintained and nurtured. The emphasis should be towards building relationships, not bridges. The general consensus was to continue the research and maintain the network which has been established through this two day workshop. The next phase should be to form a committee to develop a three year action plan for the initiative.

The group pondered where and when the next round table conference should be held, agreed that the next conference should include presentations from each of the stakeholder groups and that the conference should be chaired by community members. The next conference could be in another region of Canada, ideally in an Aboriginal community.

The research data should be taken to the next level with a focus on knowledge translation activities. Presentations of research findings should be shared at Primary Care Conferences. These Proceedings should be disseminated and delivered to FN communities, NAHO, provincial governments, funding agencies, health authorities, the CDA, family physicians, pediatricians, nutritionists, public health officials and representatives of Aboriginal urban populations.

Group 2: Oral Health for the Family and the Community

Group Participants:
Greg Jones, Shirley DeClercq, Linda Johnnie, Kue Young, Val Maladrewicz, Margaret Reade, Rebecca Van Horn, Steve Patterson

Preamble:
Most child oral health research is focused on the child, but the health of a child is closely linked to the health of siblings, parents, extended family and community. For example, we are learning more and more all the time about the close relationship between a mom's oral health and that of her baby, but there is still much more to be learned and much to be shared. Certainly, the support of family and community is helpful in promoting "healthy behaviors."

Guiding questions:
- Why does the oral health of a young child sometimes get "forgotten" by parents and family members?
  - What kind of research or interventions might change this situation?
- How do we integrate oral health into the "agenda" of Aboriginal communities who commonly are dealing with other major health, environmental and social challenges?
- Social and environmental determinants e.g. access to safe water and good housing influence Aboriginal children's oral health. How can these "causes of the causes" be better integrated into oral health research?
- How could oral health interventions and health promotion programs be developed (and tested) that incorporate Aboriginal beliefs about family and community?
  - How can Aboriginal families be included in the development of such interventions?
  - How do we collaborate with families and communities in planning oral health promotion projects and research? [Collaboration implies contributing to the research at different levels, be it the design of the project, the collection of data or its interpretation.]
  - As researchers, what do we do if a community suggests doing research that includes an intervention that a researcher would judge, from experience, not likely to be successful in the long-term?
- How can improving child oral health become a "family" issue and eventually a "community" issue?
  - How can we develop the understanding that *everyone* in the community has a role to play in promoting better oral health for Aboriginal children? For example, moving junk food away from the check out counters at the local grocery store.
  - What outcomes could we measure that would demonstrate community involvement and commitment to child oral health?
- How do we share strategies "that work" with other Aboriginal communities, with Aboriginal organizations, and with policymakers?

Day 1 and 2:

Making oral health a family issue: Awareness about a child's oral health should start during the prenatal period, so that care for baby's teeth can begin early. Incorporating oral health into other initiatives such as Head Start and Baby First provincial initiatives and immunization programs will also help propagate the message using pre-existing infrastructures. This will ensure that we reach children where they already are.

Customized age-specific information packages may prove to be useful tools for information dissemination (anticipatory guidance). Sharing resources between regions, groups and agencies will ensure that we avoid "re-inventing the wheel." Health professionals should work together as a group to support programs that are successful to communities. Modern technologies such as websites, list serves, conference calls and Telehealth should be used to improve networking and dissemination.

Oral health is a family issue. Another way to encourage good oral care is to ask family members such as siblings and grand parents to mentor young children's oral health practices. If family members highlight the benefits of good oral hygiene and the consequences of not caring for preschool children's teeth, they will encourage younger children to adopt good oral hygiene practices. Parents should ensure that they are positive role models to their child in terms of oral health.

Making oral health a community issue: First we need to identify areas where children and families gather. It is also very important to first identify, then educate and engage the formal or informal leaders in the community to become "champions" for the cause. Organizing health fairs to meet with families is another great way to raise awareness within the community. Providing incentives such as meals and gifts to come to dental check-up appointments or organizing check-ups at health fairs is another idea.

Other health professionals should be approached and an integrated, multidisciplinary effort should be implemented to fight oral health problems. Discussions should be held among health care professionals to arrange a coordinated effort. Dental health is not an isolated entity; it is part of the overall health. Therefore, the problem should be addressed by all the branches of the health profession.

Local media can be involved to spread the message. Local success stories can function as milestones and their model should be followed as a guideline. Collaboration with other existing programs is needed to avoid any conflicting messages. Consistent messages are powerful tools to gain trust from the community members. Other medical conditions, e.g. obesity and diabetes will benefit from a combined preventive effort. Future and present parents and caregivers should be encouraged and facilitated to access needed services. Sharing of information should be in narrative (story) form. Elders should be involved to share their wealth of knowledge. A network of key people can create a healthy atmosphere for the community members to work together. Telehealth is a great way to reach distant areas to deliver and educate people.

While interdisciplinary efforts will pay dividends, it is more important that dentistry speak with one voice. For example, dentists disagree about the recommendation of a first dental visit by the first birthday mostly because toddlers are difficult patients to handle. Therefore, it is very important to find advocates for prevention of dental diseases from among the dental professionals. This will enable dental professionals to advocate the "first-visit-by-age-one" policy as well as ensuring compliance.

Sharing of information and experience: Information is best received when it is conveyed in an active, participatory environment involving group activities (e.g. sewing, canning, etc). The information should be balanced and conveyed in a fun and relaxed format. Using incentives and arranging group activities such as health festivals can also help with information delivery. Lots of visual aids, story telling activities and other resources help so that the same message can be relayed through many sources. Most importantly, we have to ensure that the participants recognize where oral health fits in the "big picture" and convey the importance of oral health to overall health in a loud and clear manner.

Evaluation of programs: The Forum participants recommended that some guidelines (success indicators) for evaluation of a program be adopted to ensure that outcomes are measured. For example, a parent/caregiver survey may yield the following data:

- Number of parents/caregivers attending (a program).
- Knowledge & attitude of parents/caregivers towards child's dental health.
- Parent/caregiver behaviors and attitude about their own dental health (so that they can be good role models).

Participants reiterated their advice to not "reinvent the wheel" regarding resources for oral health promotion. A common Forum or clearinghouse to hold and house resources would be useful. Health professionals should work together to support programs that have proven to be successful in communities rather than working anew on isolated projects.

It is also important to respect traditional control structures within the communities so that communities buy into the project objectives. Chiefs and leadership could identify who we could talk to in the community. It is important to work with both the formal and informal leadership within a community. We should use local Aboriginal radio and TV stations to share information and educate the community regarding good dental hygiene practices. As always, it is a good idea to share what works with others involved in research in the Aboriginal population.

Group 3: Child Oral Health Research: Together We Can Do It Better

Group Participants:
David Benton, Robert Schroth, Jane Gray, Laurel White, Darlene Binguis, Brenda Elias, Patricia Allewell, Michael Young (On Day 2, Marion Maar and Jan Douglas joined this group)

Preamble:
Aboriginal oral health research should be "by, for and with" Aboriginal participants. Research is no longer a passive process that is "done" to Aboriginal communities. The days of "drive-by researchers" and "random acts of research" are behind us.[24]

Guiding questions:

- What are the challenges that Aboriginal communities face in being partners in research and developing their own oral health research agendas?
  - How do communities and researchers collaboratively overcome these challenges?
- How do Aboriginal communities develop their own research capacity?
  - How can the research community and the Aboriginal community work more collaboratively to develop research capacity?
- Suggest some strategies to help inform Aboriginal communities about the value of research to their children's oral health?
- How do Aboriginal populations living off reserve, especially in urban settings, engage in research and develop their research capacity?
- How do we manage the concerns that researchers encounter when approaching Aboriginal communities to participate in oral health research?
- Knowledge translation: what is the best process for researchers to share their "data" with Aboriginal communities and with Aboriginal governing bodies and organizations?
  - How does the issue and understanding of knowledge translation fit in with Aboriginal oral health research?
  - How can the sharing of oral health promotion strategies "that work" be improved amongst all the research "players" i.e. communities, researchers and policymakers?

Day 1 and 2:
Researchers face many challenges, but also bring some of their own misunderstandings to research projects involving Aboriginal communities.

Researchers' challenges:

- Earning trust.
- Learning the "rules of engagement": researchers often unclear about how to work with Aboriginal communities.
- Identifying key players: researchers often unaware that key players are different in different areas (i.e. urban vs. on-reserve) and different Aboriginal communities.

- Communication: poor understanding of native language or the way Aboriginal people and communities communicate.

Researchers' misunderstandings:

- Lack of respect for intelligence and insights of a community and individual residents.
- Research results not disseminated to Aboriginal peoples in a timely and/or accurate manner and communities are not acknowledged in publications.
- Researchers take over rather than work alongside Aboriginal communities and therefore lose the respect of the community.

Resolving the challenges:
Some of the ways these challenges could be resolved include:

- Build a relationship of trust: the researcher must meet with the community before any research is started and genuinely listen to them and to what they have to say in regards to the research being proposed. The researcher must answer the question of how will this research be beneficial to the community?
- Meet with all key players: (on and off reserve) with leadership, health & social service departments and "significant others" (e.g. Community Health Representatives) that are already respected in the community; community advisory committees; Friendship Centers.
- No single group represents Aboriginal people in urban areas. Populations in urban centers are not well defined and people may still identify with their home communities.
- Communication: use the language of the community; speak and listen to Elders; recognize the importance of silence and no eye contact.
- Collaborate at each and every stage of the research project: co-develop and co-manage the project; co-analyze the data, co-author and co-disseminate the reports.
- Involve Aboriginal youth in the research process: ask school teachers to suggest students to help with research.

Strategies to inform communities about the value of oral health research:

- Important messages to deliver.
  - Oral health is part of overall health. "The mouth is the opening to your body that you can actually see."
  - Risks to a child from dental surgery under general anesthesia.
  - Health risks when dental problems (e.g. abscesses) go untreated.
- Research will provide communities with their own survey data that will be relevant for community development and planning.
- Research that reveals a major health concern may lead to better health services.
- Researchers can become advocates for the community once the research is complete.

Group 4: Understanding the Goals and Measuring the Outcomes of Research

Group Participants:
Catherine Cook, Rosamund Harrison, Barbara Morgan, Marion Maar, Jan Douglas, Jim Carson, Michael Moffatt, Heather Nash

Preamble:
Community-based participatory research or action research is an accepted approach to developing health promotion interventions with Aboriginal communities. However, there may still be a place in Aboriginal communities for other types of research, such as randomized controlled trials (RCT) that compare a test intervention with a "control" intervention. Conducting a rigorous research project like an RCT is often impractical in isolated communities where it may be difficult to implement the intervention reliably. Given these challenges, what types of research are most feasible in Aboriginal settings and what outcomes should be measured?

Guiding questions:

- What are we trying to achieve in research projects related to Aboriginal child oral health? What should be our goals?
- Are we setting communities who engage in research "up" for failure by setting unattainable research goals? For example, we say that dental caries is "completely preventable" but is it?
- What are your suggestions for developing realistic short-term and long-term research objectives?
- What types of child oral health research would you like to see conducted in Aboriginal communities? What is feasible and do-able given the challenges of, for example, isolated communities?
- What types of early childhood oral health research are currently missing in Canada?
- What should we be measuring as indicators of successful oral health research?

Day 1:

Qualitative approach: There is a need for qualitative insights into Aboriginal belief systems about child dental health, the importance of primary teeth and dental treatment under general anesthesia. Baby teeth may still be viewed as unimportant because they eventually fall out. There is also a rite of passage for general anesthesia in many communities.

"Generational" negative attitudes: There is also a need to change "generational" negative attitudes towards dental care. This can be done by promoting positive attitudes and especially involving the youth in this process.

Aboriginal-driven research agendas: Agendas should be set and driven by Aboriginal communities. Community capacity (in both research and health promotion) needs to be increased in order to affect dental health.

Problems of remote communities: There needs to be research into "daily social realities" of isolated/remote/northern communities (i.e. the high cost of toothpaste, milk, fresh fruit and vegetables) that have an impact oral health. Perhaps having management of commercial enterprises (stores) on advisory committees would improve the oral health in these communities.

Other research topics: Cataloguing all current Aboriginal child oral health studies (their successes and shortcomings); reviewing the effectiveness of "lay health workers" in improving oral health.

Group 5: Honoring Beliefs

Group Participants:
Jacques Veronneau, Juliana Matoush, Kathi Avery-Kinew, Lavonne Harms, Lorna Lisowski, Tara Monkman, Joyce Bourne, Robert Maytwayashing

Preamble:
Any research involving Aboriginal peoples will likely involve the sharing of some cultural knowledge, practices and/or traditions which provide context for the research. It is the responsibility of the researcher to support a mechanism for protection of any cultural knowledge that is shared during the research[25].

Guiding questions:
- How do we develop and conduct oral health research that honors and integrates traditional Aboriginal beliefs about health, disease, and healing?
- How do we integrate Aboriginal knowledge, for example about child rearing, along with the researcher's evidence-based knowledge?
- The ethics of doing research are often perceived differently by academic researchers and Aboriginal community partners. How do we conduct ethical research that is respectful of Aboriginal beliefs and traditions?
- What are some strategies for incorporating the wisdom of Elders into planning and conducting oral health research?
- How can researchers learn to be
    - More respectful of Aboriginal culture, i.e. develop cultural competence and cultural respect and
    - More aware of the diversity of Aboriginal culture?

Day 1:

This group discussed how to develop and conduct oral health research that honors and integrates traditional Aboriginal beliefs about health, disease, and healing. They also looked at some strategies for incorporating the wisdom of Elders into planning and conducting oral health research.

Changing role of Elders: The relationship with Elders and their communities has changed over time. Today youth and adults are less connected to Elders and are more reluctant to ask their advice. This is in part because the Aboriginal lifestyle is different now with families more separated, living in the city, and working away from home. Many youth also do not speak their native Aboriginal language which makes it more difficult to communicate with Elders. Residential schools also added to the disconnections that may Aboriginal people feel.

Revival of traditions and ceremonies: There is a trend to revive traditions and ceremonies of the past (e.g. Cree rites of passage; Honoring the Child (Baby), Walking Out Ceremony (Child), and the Snowshoe Ceremony (Teen).

Recognize a community's uniqueness: In order for researchers to build trust with Aboriginal communities, they must respect each community as being unique and different. Getting involved in the community regarding the people and events/ceremonies is an integral part of building a trust relationship. Be a participant-observer. Interact.

Community "buy in" to the process of the research is important. Have Aboriginal people on the Ethics Review Board. Ask people what their issues are! Don't tell them.

Dissemination to community: Share the results of research in an "easy to understand" fashion. Translate the information and deliver the information to the Elders first out of respect. Aboriginal research exists but is often not recognized because it is not in the "conventional research stream" (as Dr. Marion Maar talked about earlier). If it is shared, the Elders want people to come to them in their environment to share their knowledge; they are more comfortable with this method.

Groups 4 and 5 on Day 2: Fulfilling the Goals of the Workshop

Group Participants:
Rosamund Harrison, Marion Maar, Jan Douglas, Jim Carson, Michael Moffatt, Jacques Veronneau, Juliana Matoush, Kathi Avery-Kinew, Lavonne Harms, Lorna Lisowski, Tara Monkman, Joyce Bourne, Robert Maytwayashing

Day 2:

Aboriginal involvement from "square one": It is important to make sure the people who need to be at the table are present from the start. Aboriginal people should be identifying research needs and inviting a researcher "in," which is not typically done by researchers whether they are working with FN people or otherwise.

Urban Aboriginals: The urban Aboriginal group is missing in research and it's a struggle to know how to connect with this group as they are often individual families with no formal connection to a group in an urban setting. They are not a unified group.

Training of health professionals: There is a need to train health professionals better in being interested in social change to improve the health of Aboriginal Canadians. The time is right to think about providing primary care in different ways such as Aboriginal trained midwives and dental therapists who could play an integral role in child oral health.

Changing social processes in Aboriginal communities: Aboriginal family dynamics are changing; for example, increasing number of single dad families. FN young people are tired of being portrayed as victims and want to move forward.

Concluding Session

Drs. Schroth and Harrison closed the workshop by recapping the themes that emerged and confirming the consensus of attendees that Aboriginal child oral health is a priority and is an essential part of total child health. They thanked all for attending and sharing their views. Relationships have been formed and it is now time to work together and develop these relationships to improve child oral health.

Forum Action Plan and Next Steps

1. Dissemination of Forum Proceedings

The Proceedings of this Forum will be available electronically on the following websites:

- Manitoba Institute of Child Health
- University of Manitoba, Faculty of Dentistry
- University of British Columbia, Faculty of Dentistry
- University of Toronto, Faculty of Dentistry

Every Forum participant and supporter of the workshop will receive a printed copy of the Proceedings and the Proceedings will be sent to other institutions and organizations that are likely to have an interest in the Forum's deliberations. This includes but is not limited to:

Institutions at Canadian Universities

- All 10 Faculties of Dentistry (Associate/Assistant Dean of Research and heads of Divisions of Pediatric Dentistry)
- Departments of Pediatrics and Departments of Public Health/Community Health at Faculties of Medicine
- Heads of Departments of Pediatrics at Children's Health Centres
- Identified institutes and colleges with interest in Aboriginal health: e.g. First Nations House of Learning, UBC.

Aboriginal Organizations

- National Aboriginal Health Organizations (NAHO)
- Assembly of First Nations (AFN)
- Assembly of Manitoba Chiefs (AMC)
- Indigenous Health Research Development Program (IHRDP)
- Aboriginal Capacity and Developmental Research Environment (ACADRE)

Dental Organizations

- Canadian Dental Association (CDA)
- Provincial Dental Associations
- Canadian Academy of Pediatric Dentistry (CAPD)
- Canadian Association of Public Health Dentistry (CAPHD)

Government Health Departments

- Public Health Agency of Canada, Health Canada
- First Nations and Inuit Health, Health Canada
- Provincial and Territorial Health Departments

Pediatric Groups

- Canadian Paediatric Society (CPS)
- The National Child and Youth Health Coalition (NCYHC)
- Canadian Association of Paediatric Health Centres (CAPHC)

Regional Health Authorities and Public Health Offices
Aboriginal Health Centres on-Reserves

Since internet access can be problematic in remote Aboriginal communities, a CD-rom will be available upon request to ensure universal access to the electronic version of the Proceedings.

Manuscripts describing the Forum and its outcomes will be submitted for publication.

2. Establishing a Clearing House for previous programs and research
Locating information on protocols, data, resources, and lessons learned from previous research and health promotion projects related to Aboriginal early child oral health is difficult and time consuming. This is especially true in Aboriginal communities. Attendees of this workshop suggested that all relevant previous and current oral health promotion programs, research projects and clinical trials related to Aboriginal early childhood oral health be reviewed, summarized, and made available for reference and easy access. The community's "response" to a project or program should be described. Even the results and lessons-learned from unsuccessful projects or programs should be

included. This on-line research repository or “Clearing House” could be accessed, for example, via the websites of existing Aboriginal organizations.

3. Nurture and enhance relationships

The overall aim of the Forum was to develop relationships between community members, researchers and policy-makers to further Aboriginal child oral health. The relationships formed at the Forum now need to be developed and nurtured. Expanding the Steering Committee to include a broader representation of interested parties from Aboriginal communities, local, provincial and federal governments and from the health professions were suggestions made by attendees to reflect the intent of the meeting and any resulting research network.

This expanded Steering Committee will organize a follow-up meeting within the next two-three years to build on the discussions that took place at this meeting. It was recommended that the follow-up meeting be held in an Aboriginal community or on Aboriginal land. At the follow-up meeting Aboriginal people will share their stories about early childhood oral health and oral health in general.

4. Develop an Aboriginal Oral Health Research Network

The Forum was the start of an Oral Health and the Aboriginal Child Research Network. The purpose of the network will be to develop an integrated and collaborative research environment for Aboriginal communities, researchers, and policy-makers for trials and demonstration projects with the goal of improving Aboriginal child oral health. One of the first tasks of the Network will be to identify potential funding sources to fund the “Clearing House” project (see #2).

The network will work with the FN Regional Longitudinal Health Survey (RHS) proposal for the second cycle of its longitudinal data collection. The RHS is supported through a number of Chiefs resolutions as the “survey of choice” for FN in Canada. The proposed Oral Health and the Aboriginal Child Research Network will ensure that oral health is an integral component of the RHS.

Some basic guiding principles for the research network that arose from the discussions at the Forum are:

- Involve those Aboriginal groups often overlooked in past and current research, particularly, infants and preschool children, urban Aboriginals, and the Métis[26].
- Adhere to the May 2007 CIHR Guidelines for Health Research Involving Aboriginal People.
- Include traditional knowledge in research projects and protocols.
- Develop a 3-year plan for the network that will include research grant proposals at the national level.
- Consider innovative research methodologies such as qualitative research and participatory action research (PAR) with Aboriginal communities.
- Determine how to properly share results with communities and then advocate on their behalf once the research is complete.

- Include research focusing on the determinants of health, including the social determinants of health.
- Link with other disciplines and professions so that future research, whether epidemiological or interventional, is multidisciplinary.

5. Build community capacity in oral health research

Workshop attendees stressed the importance of building capacity within the Aboriginal community to undertake research projects relating to both child and oral health and to undertake health promotion strategies at the community level. Community partnerships will require an interactive process requiring active and conscious participation of both researchers and research users throughout the whole process moving away from the simple dissemination of findings to a united effort from the beginning of project undertakings. Communities cannot develop their own solutions unless they are well informed. Additionally, there is a need to consider establishing a mentoring program for young Aboriginal scholars who are interested in child and community oral health research. Researchers should explore opportunities to expose Aboriginal youth to oral health research to raise a future generation of Aboriginal researchers. At the organizational level, linkages with the ACADRE program or other pediatric health research institutes should be explored.

Knowledge translation is important. Key elements to consider include: 1) the transfer of both Western and Indigenous knowledge; 2) the exchange of knowledge in a bidirectional fashion and; 3) undertaking research with community partnership that is meaningful and relevant, linking research with practice (http://socserv.socsci.mcmaster.ca/ihrktn/).

6. Highlight the importance of oral health to overall child health

An observation that emerged throughout the Forum was the importance of oral health and its essential role in overall child health. As one attendee stated "the mouth is the gateway to the rest of the body". Oral health is of great consequence to Aboriginal parents and communities. However, many Aboriginal families face daily challenges that prevent them from obtaining early preventive dental care for their children, purchasing basic supplies like toothbrushes and toothpaste, and providing their children with nutritious and healthy foods. Research that highlights the importance of oral health to overall child health was advocated at the Forum. Examples of such research include:

- Timely access to dental care for Aboriginal children.
- Collaboration with early childhood and prenatal nutrition programs (e.g. Aboriginal Head Start, Breakfast for Learning, Canada Prenatal Nutrition Program).
- Collaboration with the Canadian Paediatric Society, First Nations, Inuit and Métis Health Committee.
- Promotion of overall childhood health and safety.

Appendix 1: Table 1-Prevalence of caries among Aboriginal children

Recent studies reporting the prevalence and severity of dental caries among Aboriginal preschool children in Canada (modified from Schroth & Moffatt 2005)[14]

Study	Region of Canada	Population	Age	Prevalence of ECC*	Mean deft ± S.D.
Harrison et al 2006[12]	Hartley Bay (Gitga'at) First Nation	First Nation	3.7 ± 1.2	31%	9.9 ± 12.1
Schroth et al 2005[1]	Northern First Nation	First Nation	2.9 ± 1.8	58.6%	4.5 ± 4.9 (0-17)
	Thompson	Urban	2.8 ± 1.7	51.4%	4.3 ± 5.2 (0-17)
	Winnipeg	Urban	3.0 ± 1.7	43.3%	3.1 ± 4.4 (0-16)
	Roseau River First Nation	First Nation	2.9 ± 1.8	56.5%	4.4 ± 5.2 (0-16)
Schroth et al 2005[2]	Garden Hill First Nation, Manitoba	First Nation	3-5 year olds	98%	13.7 ± 3.2
Lawrence et al 2004[3]	Sioux Lookout Zone, Ontario	First Nation High Intervention Community	2 year olds	91.5%	10.2†
			3 year olds	85.2%	10.2†
			4 year olds	79.4%	10.0†
		Low Intervention Community	2 year olds	86.5%	8.0†
			3 year olds	90.5%	12.2†
			4 year olds	88.1%	10.9†
Peressini et al 2004[4]	District of Manitoulin, Ontario	First Nation	3 year olds	67%	3.5 ± 4.0
			5 year olds	78%	4.8 ± 4.1
Young et al 1995[6]	Keewatin region, Northwest Territories	Inuit	0-2 years	50% to 100% depending on community	≈ 1.8
			3-5 years		≈ 8.0
Harrison & Davis 1993[13]	British Columbia (1988 survey)	First Nation	5 year olds	87.5%	7.5 ± 4.9

*ECC is defined as ≥ 1 primary tooth affected by decay in children < 6 years of age (based upon deft ≥ 1)[8;9];
deft is the cumulative score of all decayed, extracted, and filled primary teeth.
†Excluding stainless steel crowns

Appendix 2: Planning Committee

The Steering Committee for this Forum included Dr. Robert J Schroth (University of Manitoba), Dr. Rosamund L Harrison (University of British Columbia), Dr. Sabrina Peressini (University of Toronto), and Dr. Herenia P Lawrence (University of Toronto).

Other members of the planning committee included Shannon McAteer, Research Support Officer with the Manitoba Institute of Child Health, and Eleonore Kliewer, Research Coordinator (University of Manitoba) for Dr. R. Schroth.

Thank you to Eleonore Kliewer and Mohammad Haque for their assistance with the Forum Proceedings.

The Steering Committee is also grateful to Brenda Richard, the Aboriginal artist who designed our logo. Brenda has creatively captured the essential concept that good child health evolves from good family health and from a strong family unit.

Appendix 3: Workshop Participants

A total of 42 people participated in the 2 day workshop and they are as follows:

Dr. Patricia Allewell, FNIHB/Alberta Regional Dental Officer, Edmonton, AB
Dr. Kathi Avery Kinew, Assembly of Manitoba Chiefs, Winnipeg, MB
Mr. David Benton, Brighter Smiles Project, Hartley Bay, BC
Mrs. Darlene Binguis, Preventative Dental Worker, Sioux Lookout Zone, Sioux Lookout, ON
Ms. Joyce Bourne, Government of Northwest Territories, Yellowknife, NT
Dr. Doug Brothwell, University of Manitoba (absentee)
Dr. James Carson, Canadian Paediatric Society, Winnipeg, MB
Dr. Catherine Cook, Winnipeg Regional Health Authority, Winnipeg, MB
Dr. Peter Cooney, Chief Dental Officer-Health Canada, Ottawa, ON
Mrs. Shirley Declercq, Aboriginal Community Member, Winnipeg, MB
Ms. Jan Douglas, Preventative Dental Program Coordinator, Sioux Lookout Zone, Sioux Lookout, ON
Ms. Jeannette Edwards, Regional Director, Primary Health Care, Winnipeg Regional Health Authority, Winnipeg, MB
Dr. Brenda Elias, Centre for Aboriginal Health Research, Winnipeg, MB
Mr. Douglas Graham, Executive Director of Mnaamodzawin Health Services, Little Current, ON
Ms. Jane Gray, National Coordinator, FN Regional Longitudinal Health Survey, Wendake, QC
Ms. Lavonne Harms, Healthy Smile Happy Child, University of Manitoba, Winnipeg, MB
Dr. Rosamund Harrison, Oral Health Sciences, University of British Columbia, Vancouver, BC
Ms. Linda Johnnie, Healthy Families Program, Whitehorse, YT
Dr. Gregory Jones, FNIHB/Maritime Regional Dental Officer, Halifax, NS
Dr. Herenia Lawrence, University of Toronto, Toronto, ON
Ms. Lorna Lisowski, Canadian Dental Therapists Association, Winnipeg, MB
Dr. Marion Maar, Northern Ontario School of Medicine, Sudbury, ON
Ms. Val Malazdrewicz, Health Canada-Office of the Chief Dental Officer, Ottawa, ON
Dr. Bruce Martin, University of Manitoba, Winnipeg, MB (absentee)
Ms. Julianna Matoush, Cree Board of Health & Social Services of James Bay, Ottawa, ON
Ms. Lynn Maytwayashing, Aboriginal Community Member, Lake Manitoba FN, MB
Mr. Robert Maytwayashing, Assembly of Manitoba Chiefs, Winnipeg, MB
Dr. Sheri McKinstry, Dentist, Winnipeg, MB (absentee)
Mrs. Jennifer Melville, Q'wemstin Health Society, Kamloops, BC
Dr. Michael Moffatt, Director of Research, Winnipeg Regional Health Authority, Winnipeg, MB
Ms. Tara Monkman, Métis Community Member, Winnipeg, MB
Ms. Barbara Morgan, Manitoba Métis Federation, Winnipeg, MB
Ms. Heather Nash, Canadian Child Health Clinician Scientist Program, Toronto, ON
Mr. Earl Nowgesic, CIHR-Institute of Aboriginal Peoples' Health, Victoria, BC
Dr. Steven Patterson, University of Alberta, Wetaskiwin, AB
Dr. Sabrina Peressini, University of Toronto, Toronto, ON (absentee)
Dr. Margaret Reade, Sioux Lookout Zone, Sioux Lookout, ON
Dr. Robert Schroth, University of Manitoba, Winnipeg, MB
Ms. Rebecca Van Horn, Procter & Gamble Professional Oral Health, Chicago, Illinois
Mr. Jacques Veronneau, Public Health Department, Cree Nation, Montreal, QC
Ms. Laurel White, Health Canada, Ottawa, ON
Dr. Kue Young, University of Toronto, Toronto, ON
Dr. Michael Young, Stanton Territorial Hospital, Yellowknife, NT
*Mr. Mohammad Haque, University of Manitoba, Winnipeg, MB
*Ms. Eleonore Kliewer, University of Manitoba, Winnipeg, MB
*Ms. Shannon McAteer, the Manitoba Institute of Child Health, Winnipeg, MB

*= Organizers

Appendix 4: Workshop Agenda

Thursday, June 7, 2007 DAY 1	
7:35	Shuttle departs Hotel Fort Garry-please be in the lobby. Booked under "Dental Forum"
8:00	Registration: MICH 5th Floor, 715 McDermot Avenue, Winnipeg, MB Continental Breakfast sponsored by Henry Schein Ash Arcona
8:30 – 9:00	Opening Remarks – R. Schroth/R. Harrison Greetings: ▪ Dr. M. Ogborn, Director of Research, MICH ▪ Dr. J.E. Scott, Associate Dean (Research), Faculty of Dentistry ▪ Robert Maytwayashing, Assembly of Manitoba Chiefs
9:00 – 9:05	Introduction of keynote speaker by Robert Schroth
9:05 – 9:45	"North-North and North-South Disparities in Health: A Circumpolar Perspective" Dr. Kue Young, Professor & TransCanada Pipelines Chair in Aboriginal Health & Wellbeing, Faculty of Medicine, University of Toronto
9:45-10:00	Nutritional Break sponsored by Hedy Canada Facilitators meeting JBRC 501E
10:00 – 10:05	Introduction of keynote speaker by Herenia Lawrence
10:05 – 10:50	"Implementing the RED STANDARDS for Community Based Research: Results from the FN Regional Longitudinal Health Survey (RHS 2002-03)" Jane Gray, RHS National Project Coordinator Health and Social Secretariat, Assembly of FN Supported by the Canadian Institutes of Health Research – Institute of Aboriginal Peoples' Health
10:50- 11:45	Group Discussion/Open Forum
11:45	Group photo
12:00 – 12:55	Lunch sponsored by 3M ESPE Dental Division
12:55	Introduction of keynote speaker by Herenia Lawrence
13:00 – 13:45	"Beyond the Participatory Paradigm: Negotiating worldviews, ethics and actions in research with Aboriginal communities" Dr. Marian Maar, Assistant Professor at the Northern Ontario School of Medicine. Supported by the Indigenous Peoples' Health Research Program
13:45 – 14:45	Break out groups (see attached for objectives)
	#1 Making Oral Health a Priority Room 518A | #2 Oral Health for the Family and Community Room 500 | #3 Child Oral Health Research: Together We Can Do It Better Room 501E
	#4 Understanding the Goals and Measuring the Outcomes of Research Room 403 | #5 Honoring Beliefs Room 404
14:45	Refreshment Break
15:00 – 16:00	Report back
16:00	Introduction of keynote speaker by Rosamund Harrison
16:05 – 16:50	"Health Canada, Oral Health Policy for Canadians" Dr. Peter Cooney, Chief Dental Officer, Health Canada
17:00	Shuttle departs for hotel
EVENING PROGRAM	
	Hotel Fort Garry, LaVerendrye Room
18:00	Cocktails
18:30	Entertainment by Nay-A-No
19:00	Welcome by Robert Schroth/Rosamund Harrison/Herenia Lawrence
	Honor song performed by Nay-A-No
	Dinner
20:30	Dessert Served

<table>
<tr><th colspan="7">Friday, June 8, 2007
DAY 2 (Sponsored by Procter and Gamble Professional Oral Health)</th></tr>
<tr><td>7:35</td><td colspan="6">Shuttle departs Hotel Fort Garry-please be in the lobby. Booked under “Dental Forum”</td></tr>
<tr><td>8:00</td><td colspan="6">Continental Breakfast</td></tr>
<tr><td>8:25</td><td colspan="6">Opening Remarks –R. Harrison/R. Schroth</td></tr>
<tr><td>8:30 – 9:00</td><td colspan="6">Panel Discussion with Keynote speakers</td></tr>
<tr><td>9:10 – 9:40</td><td colspan="6">Herenia Lawrence, DDS, MSc, PhD
“Addressing children’s oral health inequalities in Northwestern Ontario: a research-community partnership”</td></tr>
<tr><td>9:40-10:10</td><td colspan="6">Rosamund Harrison, DMD, MSc
“Case Study: Preventing Nursing Caries – a Culturally Sensitive Approach”</td></tr>
<tr><td>10:10 – 10:30</td><td colspan="6">Nutrition Break</td></tr>
<tr><td>10:30 – 11:00</td><td colspan="6">Robert Schroth, DMD, MSc, CIHR Strategic Training Fellow in the Canadian Child Health Clinician Scientist Program”
“Things are better when we work together: Firsthand experiences from the Manitoba Collaborative Project for the Prevention of Early Childhood Tooth Decay”</td></tr>
<tr><td>11:00- 11:30</td><td colspan="6">Presented by Dr. Marion Maar on behalf of Sabrina Peressini, PhD, CIHR Post-doctoral Fellow
“Using qualitative research methodology to aid in our understanding of children’s oral health: An example from Manitoulin Island”</td></tr>
<tr><td>11:30 – 12:30</td><td colspan="6">Lunch</td></tr>
<tr><td>12:30 – 13:40</td><td colspan="6">Break out groups. The topics for these group discussions will emerge from the Proceedings of Day 1</td></tr>
<tr><td></td><td colspan="2">#1
Room 518A</td><td colspan="2">#2
Room 500</td><td colspan="2">#3
Room 501E</td></tr>
<tr><td></td><td colspan="3">#4
Room 403</td><td colspan="3">#5
Room 404</td></tr>
<tr><td>13:45 – 15:00</td><td colspan="6">Report Back with Nutrition Break</td></tr>
<tr><td>15:00</td><td colspan="6">Wrap up/Adjournment – R. Schroth/R. Harrison</td></tr>
<tr><td>15:30</td><td colspan="6">Steering Committee Debrief Meeting</td></tr>
</table>

Appendix 5: Keynote Speakers' Biographies

Dr. Kue Young

Bio: Dr. Kue Young is Professor and TransCanada Pipelines Chair in Aboriginal Health and Wellbeing in the Department of Public Health Sciences in the Faculty of Medicine, University of Toronto. Prior to joining University of Toronto in 2002, he was Head of the Department of Community Health Sciences at the University of Manitoba. He received his B.Sc. and M.D. degrees from McGill, his MSc in community health from Toronto, and D.Phil. in biological anthropology from Oxford. Dr. Young's research focuses on the health of Aboriginal populations in Canada and the circumpolar countries.

Ms.. Jane Gray

Bio: Jane Gray is a Mi'gmaq from the community of Listuguj, Quebec. She has held positions at the national, regional and community level in a career spanning 20 years in advocating FN health. She considers herself a data warrior and upholds the FN Principles of Ownership, Control, Access and Possession (OCAP). Ms. Gray advocates for FN self-determination in the area of research and dedicates herself to improving the health status of FN. She currently holds the position as the Project Manager for the FN Regional Longitudinal Health Survey currently housed at the AFN.

Dr. Marion Maar

Bio: Dr. Marion Maar is a medical anthropologist and is Assistant Professor in the Northern Ontario School of Medicine. Previous to her current position, she worked as a Research and Evaluation Coordinator for an Aboriginal Health Access Centre on Manitoulin Island in Northern Ontario. This work focused on community-based Aboriginal health research that emerged from community identified health issues. Her research collaborations include Aboriginal research ethics, child health, oral health, FASD prevention and health services research. Dr. Maar has also worked as an Aboriginal health services consultant specializing in long-term care, program evaluation, Telehealth and culturally competent health care.

Dr. Peter Cooney

Bio: Dr. Peter Cooney was appointed as the Chief Dental Officer for Health Canada in January 2005. After several years in private dental practice, Dr. Peter Cooney completed his Specialty, Masters and Fellowship in Community Dentistry. He joined Health Canada in 1991 in the Manitoba Region. In 1997, he moved to Ottawa to further his career as the National Dental Officer of the Medical Services Branch and was later appointed Director General of the Non-Insured Health Benefits Division of FNIHB. Dr. Cooney is a former President of the Canadian Association of Public Health Dentistry and is currently the Chief Examiner for the specialty of Dental Public Health with the Royal College of Dentists of Canada.

Appendix 6: Researchers' Biographies

Dr. Herenia P Lawrence
Bio: Dr. Herenia P. Lawrence is Associate Professor in the Discipline of Community Dentistry at the Faculty of Dentistry, University of Toronto where she conducts health services research and teaches graduate dental students in the specialty of Dental Public Health. One of her main areas of research is in Aboriginal child oral health. Since 2000, Dr. Lawrence has been working in partnership with the SLZ Dental Program and FN communities in the SLZ (Northwest Ontario) on the planning and evaluating of oral health promotion programs for prenatal women and mothers of young children. She just completed a 2 year community-randomized trial of the effectiveness of fluoride varnish to prevent ECC funded by Institute of Aboriginal Peoples' Health-CIHR and the Toronto Hospital for Sick Children Foundation. In 2005, she collaborated with the NAHO on its National Reports of the FN RHS 2002/2003 writing 3 chapters of the report related to dental care, treatment needs and the use of dental services in FN adult, youth and child populations.

Dr. Rosamund Harrison
Bio: Rosamund Harrison is a pediatric dentist and is Professor and Chair of the Division of Pediatric Dentistry at UBC. She has previously collaborated with other health professionals and FN on demonstration projects and trials focusing on preventing ECC. Projects with Aboriginal communities have involved a Shuswap community in the Cariboo region of B.C., a Tsiamshian village on the Pacific coast, and a current project is a CIHR-funded randomized controlled trial with the Cree communities of northern Quebec (Eeyou Istchee).

Dr. Robert J Schroth
Bio: Robert Schroth is Assistant Professor at the University of Manitoba and a CIHR Strategic Training Fellow in the Canadian Child Health Clinician Scientist Program. He has graduate training in Community Health Sciences and practices part-time at two community clinics where he cares for many young children with ECC. His main research interests include ECC and the role of nutrition and prenatal factors. One of his major studies is investigating the relationship between vitamin D deficiencies and both enamel hypoplasia and ECC in an urban Aboriginal population. He has also been involved in other ECC epidemiological work involving Aboriginal, rural, and Hutterite preschool populations. Robert is a participant in the Healthy Smile Happy Child Project, a Manitoba Health grant funded project guided by the pillars of community-development, oral health promotion/education, and research. This project has partnered with communities to produce needed oral health promotion resources.

Dr. Sabrina Peressini
Bio: Sabrina Peressini is a CIHR postdoctoral fellow in the Department of Public Health Sciences, University of Toronto. She has an epidemiology and anthropology background. Her past research has included a combined qualitative and quantitative study of S-ECC among three and five year-old Aboriginal children in the District of Manitoulin, Ontario. Currently, she is involved in a multi-site, multi-faceted oral health promotion program addressing both the individual and social factors that contribute to the high prevalence of caries among FN children.

Appendix 7: Group Photo

Appendix 8: Acronyms

ACADRE = Aboriginal Capacity and Developmental Research Environment
AFN = Assembly of First Nations
AMC = Assembly of Manitoba Chiefs
CAPHC = Canadian Association of Paediatric Health Centres
CAPI = Computer assisted person interviewing
CDA = Canadian Dental Association
CDO = Chief Dental Officer
CHR = Community Health Representative
CIHR = Canadian Institutes of Health Research
CPS = Canadian Paediatric Society
DGA = Dental general anesthetic
DM = District of Manitoulin
ECC = Early Childhood Caries
FASD = Fetal alcohol spectrum disorder
FN = First Nations
FNIHB = First Nations and Inuit Health Branch
FPT = Federal, Provincial & Territorial
GA = General anesthetic
GT = Grounded Theory
IAPH = Institute of Aboriginal Peoples' Health
IRB = Institutional Review Board
IHRDP = Indigenous Health Research Development Program
MARRC = Manitoulin Anishnabek Research Review Committee
MICH = the Manitoba Institute of Child Health
NAHO = National Aboriginal Health Organization
NAN = Nishnawbe Aski Nation
NCEHR = National Council on Ethics in Human Research
NCYHC = The National Child and Youth Health Coalition
NHANES = National Health and Nutrition Examination Survey
NIHB = Non-Insured Health Benefits Program
OCAP = Ownership, Control, Access and Possession
PAR = Participatory Action Research
RCT = Randomized controlled trials
REB = Research Ethics Board
RHA = Regional Health Authority
RHS = Regional Longitudinal Health Survey
S-ECC = Severe Early Childhood Caries
SLZ = Sioux Lookout Zone
TCPS = Tri-Council Policy Statement
UBC = University of British Columbia

Appendix 9: References

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