



Final Report

**Improving HPV Prevention
among Aboriginal Peoples
Workshop**

December 9, 2008

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Executive Summary

The workshop was arranged to discuss HPV issues affecting Canadian Aboriginal populations. A workshop planning team was assembled to provide advice and guidance for the day. The planning team consisted of:

- Dr. Marcia Anderson – Manitoba Health & Healthy Living
- Ms. Gina Dumaresq – First Nation and Inuit Health, Health Canada
- Dr. Brenda Elias – University of Manitoba
- Dr. Erich Kliewer – CancerCare Manitoba
- Ms. Colleen Patterson – National Aboriginal Health Organization
- Dr. Allan Ronald, Ms. Wendy Schettler & Mr. George Wurtak – International Centre for Infectious Diseases
- Dr. Thomas Wong & Ms. Katherine Dinner – Public Health Agency of Canada

The workshop was intended to discuss the ways in which HPV disease within Aboriginal populations could be reduced and controlled. Objectives for the workshop were to:

- Share current information on HPV and related Aboriginal health issues
- Identify HPV research gaps and priorities
- Identify HPV vaccine implementation challenges and strategies for vaccination program improvement

Outcomes from this workshop will assist in the improvement of Aboriginal women's health in terms of HPV disease prevention.

Approximately 50 key stakeholders from across Canada representing 24 different organizations attended the workshop. These participants represented Aboriginal-focused organizations and agencies that serve Aboriginal populations.

Following an opening blessing and smudge conducted by Elder Margaret Lavalley, Mr. Terry Duguid (President and CEO of ICID) provided opening remarks. Remarks were also provided by Dr. Marcia Anderson (Medical Officer of Health at Manitoba Health), Dr. Thomas Wong (Director of the Community Acquired Infections Division of PHAC) and Dr. Lloyd Axworthy (President of the University of Winnipeg and Board member of the MacArthur Foundation). Presentations were provided during the morning, covering a range of Aboriginal health and cultural issues, with most presentations organized into three broad themes:

- Understanding HPV
- Developing a Population Level Understanding of HPV, and
- Developing Community Understanding and Program Implementation.

Attendees participated in four break out group discussions within the aforementioned themes. The groups first discussed the issues, needs and gaps in these areas, and then discussed ways in which these issues could be addressed.

During the plenary session, rapporteurs provided an overview of the results of the discussions from their groups. These issues were then further discussed by the whole group, resulting in the identification and prioritization of issues, gaps and needs.

Eleven categories were developed to accommodate an extensive and complex list of key issues and priority needs.

Summary of Key Issues and Priority Needs:

1. Understanding of HPV must be improved within Aboriginal communities
 - a. Need to improve messaging to increase the awareness of HPV and its consequences
 - b. Need for increased sexual health awareness
 - c. Need community and family education

2. Building relationships with members of Aboriginal communities and develop mechanisms for enhanced communication, programming and partnerships
 - a. Need to address trust issues
 - b. Improve cultural competency and cultural safety (trust, respect, empowerment)
 - c. Include representation of youth, women and elders
 - d. Incorporate traditional knowledge

3. Develop capacity in Aboriginal communities and for health workers serving Aboriginal people
 - a. Training for health professionals is necessary
 - b. Community capacity building and mobilization

4. Integrate HPV with other issues affecting Aboriginal people
 - a. Holistic approach - HPV doesn't stand alone – include as a component of health issues
 - b. Acknowledge and address the historical and cultural influences
 - c. Improve access to services

5. Public Health program service improvements
 - a. Improve service delivery to rural and remote Aboriginal communities
 - b. Consider access issues, including transportation and child care needs
 - c. Consider home visits and urban Aboriginal social challenges

6. Increase research on HPV within Aboriginal populations

7. Technological infrastructure improvements
 - a. Quality assurance issues with existing technology in communities (e.g. Pap testing)
 - b. Liquid based cytology for Pap testing
 - c. Role of HPV testing in the future

8. Database improvements
 - a. Separate out Aboriginal data (break down into First Nations, Métis and Inuit groupings)
 - b. Improve access to data

9. Establish clear protocols for conducting research in Aboriginal communities and standardize methods for screening and prevention

10. Appropriate funding levels and other necessary resources

11. Shared responsibility model for making it happen

It was recommended that ICID document the discussions and recommendations from the workshop and share a draft report with the planning team. The final version of the report will be widely distributed to all participants, other health committees, federal, provincial and territorial governments, other NGO health agencies and supporting organizations. This report will also be distributed by ICID to PHAC and the John D. and Catherine T. MacArthur Foundation, as co-funders of the workshop, and possible supporters of future meetings.

As phase 2 of this initiative, it was proposed that a working group be established to develop an action plan and a timeline. A follow-up workshop in 12 – 18 months was recommended to review what has been planned, undertaken, and accomplished. It was suggested that youth, grandmothers and aunts be involved at the next meeting.

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Overview & Background

Cervical cancer is estimated to be the second most common malignant disease affecting women globally¹, and the third most common cancer among Canadian women aged 20 – 49². The Human Papillomavirus (HPV) is the leading cause of cervical cancer and anogenital warts and is linked to many other cancers and cytological abnormalities. HPV is a significant health threat in Aboriginal communities where women are at a greater risk of developing and dying from cervical cancer than the general population. Recent research indicates that the incidence rates of cervical cancer are two to six times higher among First Nations women than the overall population. Consequently, a discussion was deemed to be valuable in order to share results from current HPV research in Aboriginal populations, to identify HPV research and program gaps and priorities, and to consider the best options that could significantly improve HPV disease prevention among Aboriginal peoples.

On December 9, 2008 the International Centre for Infectious Disease (ICID) in conjunction with the Public Health Agency of Canada (PHAC), and supported by The John D. and Catherine T. MacArthur Foundation, hosted a workshop devoted to further understanding the issues with respect to health care to improve HPV disease prevention in Aboriginal communities. The workshop was held in Winnipeg, Manitoba, Canada.

A ten-member planning team was assembled representing governmental and not-for-profit health agencies, Aboriginal organizations, and research institutions. This group met by teleconference from September to December, 2008.

The workshop was held on December 9, 2008 in Winnipeg, Manitoba.

¹PHAC 2007a. National Advisory Committee on Immunization: Statement on Human Papillomavirus Vaccine. *CCDR* 33(ACS-2): 1-32. <http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/07pdf/acs33-02.pdf>

²Health Canada (2006). Screening for Cervical Cancer. http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/cervical-uterus_e.html

Workshop Objectives

The objectives for the workshop were:

1. To share current information on:
 - a. Cervical abnormalities, anogenital warts, cancer, and cytology
 - b. HPV and cervical cancer epidemiology
 - c. Vaccine developments, accessibility and uptake issues
 - d. Unique challenges with respect to Aboriginal populations
2. To identify research gaps, research priorities and strategies to move ahead with improved HPV prevention and control among Aboriginal peoples
3. To identify implementation challenges and strategies for program improvement among Aboriginal communities

Workshop Planning and Design

Members of the workshop planning team included:

- Dr. Marcia Anderson – Medical Officer of Health, Nor-Man Region, Office of the Chief Medical Officer of Health, Manitoba Health & Healthy Living
- Ms. Katherine Dinner, Health and Social Services Advisor, Public Health Agency of Canada
- Ms. Gina Dumaresq – National Program Coordinator, Vaccine Preventable Diseases & Immunization, Communicable Disease Control Division, First Nation and Inuit Health, Health Canada
- Dr. Brenda Elias – Co-Director, Centre for Aboriginal Health Research, Faculty of Medicine, University of Manitoba
- Dr. Erich Kliewer – Epidemiologist, Epidemiology & Cancer Registry, CancerCare Manitoba
- Ms. Colleen Patterson – Communications Officer, Communications and Research Unit, National Aboriginal Health Organization
- Dr. Allan Ronald – Senior Scientific Advisor, International Centre for Infectious Diseases
- Ms. Wendy Schettler – Director of Public Health Programs, International Centre for Infectious Diseases
- Dr. Thomas Wong – Director, Community Acquired Infections Division, Public Health Agency of Canada
- Mr. George Wurtak – HPV Program Manager, International Centre for Infectious Diseases

The planning team held 8 full group meetings between September and December of 2008, and numerous smaller group meetings. Through several discussions of the desired types and categories of presentations, a short list of identified speakers was developed. Specific individuals reflecting the HPV disease prevention community, researchers and key leaders in Aboriginal health programs were then approached to provide presentations.

The planning team also considered potential workshop participants who might be invited. There was a necessary limit on the number of attendees for the workshop, and the planning team strategically developed a list of participants that reflected a balance between policy makers, funders, researchers, physicians and other front line health workers, and a cross section of Aboriginal program workers from across Canada. The team attempted to balance national, regional and Aboriginal organization partners.

The planning team agreed that it was important to invite a local Aboriginal Elder to provide a smudge and prayer to set the tone of the day, as well as to provide a closing prayer at the conclusion of the workshop. The design of the workshop called for opening remarks from key stakeholders, a presentation of baseline information about Aboriginal peoples and the state of HPV research, and a series of panel presentations. This series of presentations would address issues in three broad themes:

- Theme 1: Understanding HPV
- Theme 2: Developing a Population Level Understanding of HPV, and
- Theme 3: Developing Community Understanding and Program Implementation

Eleven speakers were invited to address these topics as panelists.

Following the morning presentations and lunch break, attendees participated in break out group discussions within the aforementioned themes. The groups first discussed the issues, needs and gaps in these areas, and then discussed ways in which these issues could be addressed. Finally, the group would reassemble for a plenary session to share the outcomes from the break out group discussions, and begin an initial prioritization of activities to address the key issues.



Opening Remarks

Elder Margaret Lavallee provided a smudge and prayer in the opening ceremonies as well as a closing prayer at the conclusion of the workshop.

The workshop design called for several opening remarks that would set the tone for the day, clarify the expectations, and provide general background information. To this end, Mr. Terry Duguid, President and CEO of ICID described ICID’s interest in Aboriginal health and wellness and outlined early discussions which led to this consultative workshop. Dr. Thomas Wong, Director of PHAC’s Community Acquired Infections Division, outlined the expected outcomes and hopes for the day. The participants were then invited to introduce themselves and explain their interest in HPV prevention among Aboriginal peoples.

The complete list of participants and their affiliation is located in **Appendix I**.

Dr. Marcia Anderson (Manitoba Health Medical Officer) provided comments that provided a structure for the workshop.



Dr. Paulette C. Tremblay, CEO of the National Aboriginal Health Organization, shared a PowerPoint presentation entitled “First Nations, Inuit & Métis People in Canada” in order to provide insights into the types, demographics, health status, and socio-economic issues of Canada’s Aboriginal peoples.

Dr. Brenda Elias, Co-Director, Centre for Aboriginal Health Research, University of Manitoba, provided an outline and model of the intersecting areas of HPV research that set the stage for the upcoming group discussions.



Dr. Lloyd Axworthy, President of the University of Winnipeg, and member of the board of The John D. and Catherine T. MacArthur Foundation, provided mid-morning remarks to the participants. A media conference was arranged by ICID during the morning health break, with Mr. Terry Duguid, Dr. Marcia Anderson, and Dr. Lloyd Axworthy addressing the media.

Presentations

Dr. Axworthy shared his insights on the importance of health, especially improving the health of Canada's Aboriginal peoples. Twelve presentations were provided in the morning in order to share information, provide questions to consider, and set the stage for the afternoon's discussions.

The presentations, in consecutive order, consisted of:



- Dr. Paul Brassard, Departments of Medicine, Epidemiology & Biostatistics, McGill University; Division of Clinical Epidemiology, McGill University Health Centre. Presentation title: "Understanding HPV: Improving HPV Prevention Among Aboriginal Peoples". In this presentation, Dr. Brassard provided

background information on HPV as well as its burden in Canadian Aboriginal peoples, specifically with the peoples of Nunavik, Northern Quebec.

- Dr. Isaac Sobol, Chief Medical Officer of Health, Nunavut.
- Dr. Thomas Wong, Director, Community Acquired Infections Division, Public Health Agency of Canada.



Presentation title: "HPV Surveillance in Nunavut" co-presented by Dr. Sobol and Dr. Wong. A background to Nunavut, cancer incidence and HPV prevalence was provided, along with a description of the 1999 study and its outcomes. The Nunavut-PHAC HPV surveillance program and preliminary results were described.



- Dr. Brenda Elias, Co-Director, Centre for Aboriginal Health Research, University of Manitoba. Presentation title: “Honouring Provincial/University Innovation in Data Repositories for Community Planning”. The process and status of linking numerous Manitoban and Federal Government databases was described.

- Dr. Erich Kliewer, Consulting Epidemiologist with CancerCare Manitoba. Presentation title: “Manitoba’s Population-based HPV Surveillance System”. The HPV Vaccine Surveillance System in Manitoba was described.



- Ms. Gina Dumaresq, National Vaccine Program Coordinator, First Nations and Inuit Health Branch, Health Canada. Presentation title: “HPV Immunization Program in First Nations Communities”. The national program for HPV vaccinations in First Nations communities was described as were other immunization programs.

- Ms. Shelley Stopera, HPV Project Manager with Manitoba Health and Healthy Living. Presentation title: “Implementation of the Manitoba HPV Immunization Program: Four Main Program Elements”. The HPV immunization program framework for Manitoba was described, including the partners, funding, evaluation plan and descriptions of the four elements.



- Ms. Lyna Hart, Acting Tribal Nursing Officer, Home and Community Care, HIV/AIDS, ADI, South East Resource Development Council Corporation. Presentation Title: “Holistic Approaches to Health”. A description was provided of the roles that men, women, elders and adolescents as well as other components of the world play in providing for health of the people.

- Dr. Kim Barker, Assembly of First Nations. Presentation Title: “Knowledge, Attitudes, Behaviours and Beliefs of HPV in First Nations Communities”. A briefing was provided on cervical cancer and cancer risk factors, followed by a description of the KABB HPV Project, including the methodology, results and anticipated outcomes.



- Dr. Vyta Senikas, Associate Executive Vice-President, Society of Obstetricians and Gynaecologists of Canada. Presentation title: “Gaps and Issues in HPV Program Implementation: Lessons Learned”. A background covering HPV, Pap smear rates and vaccine timeline was provided, followed by a description of “Where the Message Went Wrong”, and suggestions of how to move forward in collaboration with Aboriginal communities.

- Dr. Allan Ronald, Senior Scientific Advisor, International Centre for Infectious Diseases. Presentation title: “HPV Programs at ICID”. A description was provided of some of the new HPV initiatives underway in Canada, the national roles that organizations could play in HPV prevention, ensuring the involvement of all key sectors and groups, and proposing national goals for HPV disease prevention and control.



- Dr. Greg Hammond, Chair of the Manitoba HPV Disease Prevention Secretariat, International Centre for Infectious Diseases. Presentation title: “Manitoba HPV Disease Prevention Secretariat”. The beginnings of this HPV Secretariat, its role, members/ partners, current HPV-related issues and opportunities were described.

Copies of most of the PowerPoint presentation slides may be found in **Appendix III**.



Break Out Group Tasks

Participants gathered into one of three break out discussion themes:

Theme 1: Understanding HPV

Theme 2: Developing a Population Level Understanding of HPV, and

Theme 3: Developing Community Understanding and Program Implementation

Theme 3 was of interest to a large number of participants; consequently participants were divided into two small groups (3a and 3b). Volunteer facilitators and flipchart note-takers assisted with the small group process at each break out group.

For the first hour of the discussion period, the groups were asked to discuss the issues, needs and gaps surrounding the theme by answering the following questions:

Q1. Gap identification:

- What are the gaps in research and program implementation with respect to Aboriginal People?
- What information is missing in order to improve HPV prevention?
- What research, or policy & practice improvements, are needed in this area?

During the second hour, the participants then focused on suggesting possible ways to address the issues and gaps that had been identified. Each group suggested ways to address the gaps by using the following questions as a guide:

Q2. Addressing the Gaps:

- What are the prioritized needs?
- How can these needs be addressed?
- What are the steps involved in doing this?
- What funding possibilities exist?
- Who should or could be involved?
- What is the timeline required?

Break Out Group Reports: Discussions of Issues, Gaps and How to Address Them

Each break out group discussed a specific theme as described above, and attempted to identify the issues, gaps and needs. The groups then discussed these issues and were asked to propose approaches that could address the needs, and prioritize the suggested activities. This was a significant challenge due to the interconnectedness of many issues and the different perspectives of the group members.

Specific issues were grouped into broad themes and are described below. The following comments (including the notes contained in appendices) were provided by individual workshop participants; these comments do not necessarily reflect the views of organizing committee members nor the positions of organizations and agencies represented at the workshop.

Group 1: Understanding HPV:

[Basic Research, Medical Issues, Health Services]

Group 1: Question 1 – Gap identification

Gaps discussion:

1. Capacity building:

- Clinical expertise: For HPV, it is a requisite
- Link between STI, HPV, Pap tests, etc.

2. Education/Awareness

- Some people literally do not know what a Pap test is
- Pap test is most often seen by the public as a screening test for STIs
- Misunderstanding by some clinicians of the purpose of a Pap test
- Other discussion points: Is HPV really a big issue in all communities? Regardless, an opportunity to 'do it right' exists

3. Building Relationships/ Other issues affecting Aboriginal communities

- Fear & mistrust: female aboriginal sexuality is culturally derived
 - o Unless there are concurrent changes by a community, any initiative will not get any further
 - o Need to involve communities, grandmothers, etc.

- Impact of culture, loss of language is far greater than what is reported
- Need for healing: e.g., extremely high rates of sexual abuse – do we really understand its effects?

Gap Identification

1. Community healing
 - a. Are all communities ready for this?
 - b. Part of the answer is relationship building: a longer term commitment
 - c. Engaging a community in introspection is only the beginning, as 'bad stuff' usual bubbles to the surface and lingers
2. Service Access: The issue of Pap tests is an important one:
 - a. E.g., in Yukon, Pap tests are not given in community health clinics – individuals from smaller towns have to travel to Whitehorse
 - b. Takes a long time to then get results back
 - c. Variation in knowledge re: Pap tests and HPV in GPs
3. Education/Awareness:
 - a. Lots of mixed messages- parents themselves are confused
 - b. Need some type of culturally-appropriate marketing/education
4. Technological Infrastructure Improvements:
 - a. Liquid Based Cytology: Lack of technical capabilities
 - b. How best to introduce new technologies was raised: often difficult without strong leadership, etc.
 - c. Need an integrated system:
 - i. Education/awareness
 - ii. Technical capability
 - iii. Single entry program
 - d. Group members raised the issue of HPV testing replacing Pap tests, as the 'scenario' will be changing in a few years
 - i. European example raised: organized screening is certainly doable
 - ii. There is indigenous knowledge that should be noted
5. Advocacy /Support:
 - a. Group members wondered whether there was political support for HPV screening/awareness in communities
 - b. Typically, investments are short-tem – however, this issue requires a longer-term view
 - c. Need to have a demonstration project – better results, less money spent, etc.

6. Group members discussed the history of Pap tests in Aboriginal vs. Non-Aboriginal women – is there credible evidence that there truly is a gap?
 - a. Aboriginal women aren't being targeted for education, and there is very little good information on HPV in Aboriginal females
 - b. However: understanding HPV is one thing, but understanding it in the context of lived experience is another – interplay of human sexuality is not discussed (e.g. two-spirited people)
 - c. To get better information, need better research - need sophisticated research designs which include both Aboriginal and non-Aboriginal women. Need to look at HPV vaccine associated adverse effects in the long term, length of protective immunity. Need large-scale, population-based studies
 - d. Need, as well, to look at oncogenic vs. non-oncogenic HPV types, and whether variation exists in different populations. Type replacement?
 - e. What are the co-factors to infectivity and pathogenicity? Are circulating types different for Aboriginal women?
 - f. Finally, need to document gaps between biomedical knowledge, and level of community knowledge

Group 1 Question 2: Solutions

1. Capacity development to increase understanding
 - a. Especially in Aboriginal communities, both community and practitioners
 - b. This is a longer-term goal
 - c. Increase sexual health awareness
2. Develop national screening policy and database
 - a. We don't need to be doing everything differently
 - b. Develop a strategic plan to reach this goal
3. Addressing stigma – perhaps a marketing campaign
 - a. Need to address it in the context of women's health, especially in Aboriginal communities
4. Answers are complex – need to explore this complexity
5. Epidemiological Studies
 - a. Need large numbers to capture ethnic differences in length of immunity, circulating types, etc.
 - b. Perhaps in the end, the above questions will not be relevant, but the implementation will be.

- c. Need to disentangle ethnicity through
 - Proper messaging
 - Capturing First Nations, Métis and Inuit data
 - Linking systems and improvement of service delivery

- d. Other potential questions/opportunities to address:
 - Ethnic differences/cultural appropriateness
 - Male vaccines
 - Demonstration projects
 - Changing screening technologies

Who needs to be involved?

1. Canadian Institutes for Health Research, Aboriginal organizations, academic communities
2. Need to have targeted cultural awareness, and all need to support a process getting children into science
3. Needs to feed into a larger system; development of a national screening policy and database; implementation of new technologies or any technology (e.g., specific application of colposcopy equipment in the North)
4. Hospitals, physicians, funding agencies, multidisciplinary research and health enterprises
5. Provincial/territorial and national governments

Group 2: Developing a Population Level Understanding of HPV

[Epidemiology, Surveillance, Monitoring]

Group 2: Question 1 – Gap identification

Gap #1: Lack of Data

- There are huge gaps in the data – no numbers (to help improve prevention), especially for Métis and First Nations in urban centres
- Key program & policy information
Epidemiological (including type) data for HPV – for vaccine effectiveness & monitoring
E.g. Scandinavian study following HPV types – would probably be taken as valid for Canada, given lack of data for comparison. But it would be far preferable to have Canadian data for regulators

Gap #2: Limited HPV Awareness/Education

- Sex education not happening in many schools – we are not reaching all young people re: sex, HPV etc.
- Information is missing on the different types of HPV
- Communication to the public = weakest link to all communities
- Much of the information conveyance is left to private companies
- There has been much negative media re: safety (e.g. Macleans & CMAJ articles); these perspectives raise questions and are a source of misinformation e.g. value of vaccination after potential exposure to HPV (i.e. have had sex)

Gap #3: Issues resulting from historical and cultural influences

- Second hand experience of residential schools, foster care, “adoptive” systems
- Many Aboriginal people have no knowledge of self, history etc.
- There are unidentified populations of First Nations / Métis etc. raised outside of communities (e.g. adoptions, raised in urban areas, etc.)
- We must build beyond “truth & reconciliation”
- Research on risk factors is needed re: residential school survivor / offspring; influence on cancer risk, mental health outcomes
- Addressing history – “opening a can of worms” with no anonymity in communities, can cause community & family tension / conflicts.
- Healing circles etc. – takes specialized people, long and time-consuming process

- Communities are sick because of historical issues – look at roots of silence
- Getting vaccinated won't solve the problem – it is very deep-rooted
- Determinants of health are key to inter-generational issues
- Gaps in accessing information (including interpretation & language)
- A challenge to Incorporate HPV messaging in the context of sexual abuse / sexual wellness / residential school history – topics often “swept under the carpet”

Gap #4: Database Challenges

- Database linkage – challenges of coordination of data collection & computer system compatibility
- Data lacking for First Nations & Inuit > gap due to lack of identifier in many databases
- Indian Registry only includes status First Nations
- But soon, inclusion of Métis by provision of membership list
- Still missing non-status First Nations
- Bill C-31 will connect children via status links. Note: Bill C-31 changed the registration system so that entitlement was no longer based on sexually discriminatory rules. It treats children equally whether they are born in or out of wedlock and whether they are natural or adopted. It also allows first-time registration of children (and in some cases descendants of subsequent generations) of those whose status is restored; and allows for the registration of children born out of wedlock if either parent was a registered Indian, regardless of their date of birth.
- Legal challenges to Bill C-31 will be coming
- Who has what heritage? There is not always a straightforward answer
- ½ status children (FN + Caucasian) have First Nations status; but ¼ FN children (½ FN + Caucasian) do not have status
- How does the data move/shape the stories? How is the story captured in the data?
- Some registries exist in the communities – but would need data sharing agreement(s) to coordinate with provincial health department
- The border (US/Canada) creates status divisions
- Some reserves are not given status by INAC – these are the “unidentified”/non-affiliated/non-registered First Nations mentioned previously e.g. Lubicon Cree (Alberta) – who have refused culturally inappropriate agreements, therefore have no money, no services, are living from the land

Gap #5: Immunization Challenges

- Delivery of vaccination programs differs between provinces (e.g. immunization at different ages)
- Prohibitive cost of vaccination if not given in school (\$450 / 3 injections)
- In Manitoba, those with low socio-economic status are not being vaccinated outside of school
- Nominal role data from INAC for on-reserve schools, plus provincial education data is providing a sense of vaccination

Gap #6: Unique Influences

- Frontline health care providers have to deal with different questions, e.g. older adults newly at risk, men etc. (Note that in men cancer related to HPV is very rare, but genital warts still possible)
- There are community capacity challenges, especially in urban centres; programs are needed to address this
- Preparedness of community health workers (on & off reserve); these people are the primary contacts
- It is necessary to design new approaches for urban/reserve/remote communities – these may need to be established “from scratch”, depending on the situation

Group 2: Question 2 – Addressing the gaps

Key themes for issues to be addressed:

- 1. Capturing First Nations/Métis/Inuit-specific data**
- 2. Improving Messaging / Communication with key stakeholders (media, community members)**
 - SOGC website has had youth consultation to develop games & information
- 3. Linking Systems**
 - Dealing with different systems – federal and provincial/territorial systems
 - Data stored in linked public health registries and unlinked community registries (e.g. in local nursing stations)

- Need to integrate electronic health records
- Must have better provincial/territorial-federal health communication
- Pap test results are centralized in Manitoba (in the cancer registry), but results don't travel if patients move out of province, thus we have many fractured databases
- Coordination of databases is very difficult (e.g. NAHO-FNIHB joint database "Honouring Life Network": a youth suicide prevention interactive site)
- Linkages required:
 - Data / analyses / surveillance
 - Jurisdictions
 - Organizations
 - Knowledge
 - Provider & community
 - Messages

4. Improving service delivery (Pap / STI), "wellness focused"

- Practice improvements: other ways to provide pap test ("woman centered")
- Experience of the woman to be tested: possible experience of abuse / unwanted touch etc.
- How do we make it possible for the woman to be comfortable with the test procedures (regardless of the sex of the practitioner)
- Presence of third party – posters available that promote bringing a person you trust
- Training tools for quick/painless experience
- Patient preparation @ time of exam
- e.g. Nurse practitioner training on-reserve to make procedure more comfortable – long time for process (1hr vs. 20mins), using specific tools (e.g. "panty pocket")
- Tools are provided for testing of adolescents but not well translated to other situations or age groups – a key barrier to surveillance!
- Possibility for self-administered tests? B.C. and Quebec trying self-sampling for HPV

Pap tests

- Make women the focal point of the community for marker of STIs
- All crisis treatment, no resources for annual "wellness" check-up / holistic approach which would include a pap test.
- Older women have many wellness issues – including immunization with discussion of menopause, bone density etc.

- Routine health care is experienced / learned as a child
- Women are called to “come for a pap”, so this appears to be the focus of the visit, even if other annual activities are included.
- Getting women “in the door” for a “well-woman clinic”
- Giving better incentive/attraction & better service to the community

Group 2: Key Needs/Challenges

1. Build better relationships for improved programming
 - Dialogue & creating / strengthening relationships & service delivery
 - Mother-child-family
 - Families, schools,
 - Health organizations
 - Inuit/Métis/First Nations health practitioners
 - First Nations
 - Regions
 - National
 - All interested partnerships
2. Improve access to data
 - Working with data “custodians” to improve / create database sharing
3. Capacity Building leading to increased awareness
 - Building capacity at the community level to engage in understanding / awareness & information – across all sectors and levels.
4. Improve messaging
 - Developing culturally-appropriate messaging with flexibility & adaptability to meet diverse community needs - e.g. Some First Nations hold traditional beliefs, others are devout Christians
 - Demystifying / clarifying medical language & terminology = recontextualizing
 - E.g. some languages where terms for the descriptions don’t even exist (e.g. ‘virus’ may not be a traditional term), using symbolic phrases. As an example, in one community the term for the RCMP translated as “people that take people”
 - High / low language levels

What is needed?

Funding - From federal and provincial/territorial governments

Who should do it? A Collaborative

- Medical authorities, e.g. Provincial/Territorial health departments, regional health authorities
- Federal government departments, e.g. INAC, IPAC, PHAC, FNIHB/HC
- Communities, mothers & grandmothers
- Aboriginal health organizations, e.g. NAHO
- Other professional organizations e.g. SOGC, CFPC (family physicians), CRP (rural physicians)
- National political Aboriginal organizations: AFN, NWAC (women), MNC etc.
- Community health workers, ANA (Aboriginal Nurses Association)
- Laboratories
- Friendship centres

Timeframe: 6 months.

Group 3: Developing Community Understanding and Program Implementation

(Vaccination, Educational Resources, Public Awareness)

Group 3a: Question 1 – Gap identification

Barriers and issues:

1. Public awareness of HPV and vaccination
2. Transportation in rural areas is a problem; also in urban areas where people cannot afford bus tickets
3. Child care issues (difficult when one has to take small children)
4. Continuity of care – people do not have a family doctor; and doctors change often; need a person with whom to build trust
5. Cultural safety (trust, respect, empowerment)
6. Fewer family doctors, so hospital staff need relevant training to provide for needs

Group 3a: Addressing the issues

Transportation:

1. Go out to the communities; meet the client where they are at
2. Be adaptable: a structure that works for one community may not work for another
3. Nurses who do home visits could potentially administer a Pap test at the same time to relieve both child care and transportation issues

Home Visits:

1. It takes time to build trust and invite a health care person into their home. Privacy is often an issue in the home to do Pap tests!
2. Must look at the community level; each community has its own unique needs and challenges – again must adapt to the different community situations
4. The degree of safety and trust must be considered
5. Fear of having the doctor see what is in the home
6. Doctors are expensive – should not spend time doing home visits
7. Home visits are done only for the elderly and for those with increased trust
8. Therefore you must meet communities and individuals where they are at

Urban issues:

1. Need home care providers who understand the culture
2. Health records of people who frequently move are difficult to maintain with accuracy
3. Removal of children from family:
 - i. What information have families received?
 - ii. Fear is instilled – there is no trust in having health care people visit
4. Tracking of people who change addresses frequently is a challenge
5. Costs? Reimbursement? Non-insured health benefits (provincial health card) are different across provinces
6. Various Aboriginal agencies are already working in this area – how do we utilize/support them?

Broad Issues:

1. HPV and STI's are side effects of broader issues
2. Therefore there is an increased need for traditional knowledge-base e.g. midwives
3. Need a National Aboriginal Council on HPV that is comprised of First Nations, Inuit and Métis with a diverse geographical representation who are nominated by the community
4. Communication between service agencies could be improved. Poor communication contributes to service provider burnout

Lack of Awareness of HPV

1. There is a poor understanding of what HPV is; information is not getting out
2. Some youth are not well-informed of HPV
3. Any session needs to first ensure basic information is provided

Lack of Resources

1. There is a lack of resources dedicated to prevention education at all levels
2. Many funding arrangements are project – based, so funding must be allocated and this requires a research focus; anecdotal information may be all that is currently available
3. Need multi-year funding rather than single-year or short term project funding
4. Need integrated projects (HPV, HIV, birth control, etc.)
5. Need access data for regional and provincial-level, e.g. at Band level (e.g. MIMS – Manitoba Immunization Monitoring System)

6. Have to ask various governance groups – is it a good process?
7. Need to also bring it back to the communities
8. Lack of Aboriginal health human resources
9. Need to develop infrastructure & services to remote areas

Priority Areas

1. Programming
2. Education/Training/ Resources (\$\$)
3. Funding
4. Access
5. Traditional Knowledge
6. Cultural Competency & Safety
7. Research
8. Community Capacity Building & Mobilizing
9. Information Structure/Communications

Discussion of Priority Areas (Group 3a)

1. Programming, Training and Funding

- a) Identify what Aboriginal programs exist at the community/provincial/national level
- b) What is working? Have the community program successes been measured?
- c) What is the role of Community Health Representatives if nurses/doctors are scarce?
Should their role change in the absence of a doctor or nurse?
- d) What about Community HIV workers? Need dedicated (Full-time) staff for HPV –
should be “sexual health educators” – programs could be “Well Woman programs”
but open to both sexes; clinical aspect is for women only.
- e) Can staff translate clinical information to the community?
- f) Identify resources (community demonstrations)
- g) Need community partnerships with Schools, Community Centres, Youth Groups,
Community-at-large; need dedicated resources for it
- h) Must be youth-driven
- i) For youth not in school, focus on Community Drop-in Centres, online (e.g. YouTube)
- j) Focus groups currently working with HIV projects
- k) Also needs to be parent-friendly

- l) Train the trainer approach
- m) For adults: 80,000 Residential School Survivors can be contacted
- n) Bring people together in a non-threatening way; be indirect; include food; provide oral information rather than printed material
- o) Youth Centres – bring Elders, do drumming & dancing to get youth to attend, then include the info
- p) Do not make it a formal program, but more of a broad community approach

2. Access

- a) Celebrate community successes through public events, and raise awareness of HPV at the same time
- b) Cultural safety is critically important, must be acknowledged and addressed (a complex concept, but includes trust, respect and empowerment of the patient)
- c) There are residual fears and reluctance due to historical events
- d) Must have informed consent
- e) Messaging is “blaming” (subtly), e.g. Gardasil ads are misleading
- f) Timelines are an issue – get nothing factual for 20+ years re: cervical cancer & HPV caused dysplasia; genital warts can be an earlier indicator

3. Traditional Knowledge & Policy

- a) There is a relationship between a healthy population and effective governance
- b) Need to consider “mega-policy” vs. “specific items”
- c) People have rights in social and economic development
- d) There is confusion between terms and terminology e.g. HPV and HIV; when referring to HPV it is important to include the word “Cancer” to differentiate it from HIV – people at the community level will need this distinction to be clear
- e) Reflect on the best way to get the message for the right people
- f) There is a limitation to looking at “groups”
- g) Take a realistic look at policy and its change; look at the weaknesses/gaps
- h) To design a policy, build on the strength of Aboriginal people
- i) Identify factors that require program change before you can address it
- j) Deal with the interests of the community – the people’s rights to development, health, etc.

Group 3a: Top Three Priorities

1. Community Capacity Building and Mobilization
2. Programming
3. Research

Group 3b: Question 1 – Gap Identification

Human Resource Issues: Health Care Providers

1. Not everyone / community has a “trusted provider”
2. We have 1 or 2 nurses who are doing everything -> this is “tyranny of the acute”: lack of resources to proactively manage illness, resulting in a reactive mode of health delivery
3. More job satisfaction in acute care
4. Limited ability to evaluate programs (reach, uptake, cervical cancer rates)
5. Lack of access to services (due to lack of human resources)
6. Allocations to nurses – measuring workload (more immunization)
7. Not all about the money
8. Systems approach – how can you find ways to deliver services? Human resources to change and deliver.
9. Underestimate community capacity.
10. Determine the appropriate role of CHRs

Facilities and Programs - limitations

1. Not specific to Aboriginal population, varies between regions
2. There is no cervical screening in some Aboriginal communities (access is an issue)
3. Community members don’t know about the HPV vaccine.
4. Pap tests done locally in remote communities – other barriers.

Funding Issues

1. Lack of ongoing sustainability funding, only 3 years.
2. Who gets public funding, how?
3. Let’s harmonize (nationally)

Lack of Awareness and Appropriate Materials

1. There is a general lack of awareness of HPV and of the HPV vaccine, resulting in a need for increased awareness of HPV generally, and awareness for specific purposes (e.g. truly informed consent for vaccinations)
2. Strengthening the political will to address the awareness gaps of Aboriginal populations is an important step.
3. Appropriate educational materials/resources targeted specifically at Aboriginal populations must be developed; however communities are diverse and somewhat different approaches may be required. Resources that are produced must be culturally appropriate, and provided in local languages where recommended. As paper pamphlets and posters are not always effective, a variety of educational resources should be developed, including voice recordings, video, DVD's, and the use of community radio and television. Alternate approaches to raising awareness may also prove effective: having elders travel to communities and speak about HPV on community radio broadcasts; serving similar roles as the "condom granny".
4. Information about safe sex should be disseminated in schools. In some jurisdictions sexual health education is not part of the curriculum; in other areas local control of the school curriculum results in wide variation in the amount of sexual health education being taught.

Overall, there is a need for credible information provided in appropriate and relevant methods.

Vaccination Program Improvements

1. Is it the right vaccine for the community and appropriate or acceptable
2. Perceived disability burden compared to life.
3. Not just ethnicity – trust, continuity, the "right" people (welcoming)
4. Wide variety of program (e.g. QC grade 4 vs. grade 8) = access equity
5. What is the right age?
6. Practical considerations – grade 6 all together
7. Parents' perception – maybe easier to convince parent of 13/14 yr old – more developed
8. Same approach for everyone, not stigmatized special population.
9. Coverage of programs targeting grade 4 vs. grade 8's.
10. Universal program – aimed at general population, not always relevant or acceptable

11. Process – how do you build in the flexibility to adapt to indigenous populations, self-determination
12. Change of political systems – funding available for other approaches.
13. The way vaccine was announced, public health was not adequately consulted. Politics.
14. System need to be ready for implementation.
15. National program to buy vaccines cheaper.

Group 3b: Question 2 – Addressing the gaps

Awareness & Educational Materials

1. Education > could develop, but need to involve community for dissemination & materials, networks, methods, resources
2. Need resources
3. Evaluation of programs, research
4. Need more research on Knowledge, Attitudes, Behaviours, Beliefs
5. KAB in National Immunization Coverage
6. Role of community (community-involved, grass roots).
7. Not connecting with what is important to community.
8. Competing needs – hunger trumps vaccine & cervical cancer. Bigger picture.
9. How do you engage them?
10. Provide people with opportunity to speak up & participate.
11. Match agendas and schedules.
12. Community politics – messages need to come from right person.
13. Everybody has different role. Need champion.

Steps to address this:

- First step: What do you want to implement / will work best.
- Who can help?

Vaccination Program

1. Implementation research – some questions
2. Stigmatization of women
3. Personal physicians immunize boys.
4. Three different sets; core knowledge but different languages in dissemination.
5. Need a local voice.

6. People have done this before, just need to get them together.
7. Honest vs. effective
8. Have to fly out for colposcopy
9. Also educate health care workers, inform yourself; not so easy to explain , not just linked to cervical cancer
10. Overall burden of disease underestimate – sold connect to cancer
11. Overlapping priorities

Steps to address this:

- Federal funding: PHAC funding; FNIH no HPV money,
- small grants : CIHR-AH/III, NCCID/APH; MacArthur Foundation
- National Indigenous professional groups, political groups, NAHO
- Aboriginal Peoples Television Network – Dr. Evan Adams

Plenary Session:

Each break out group selected a person to serve as a rapporteur and reflect the conversation of the break out group to all participants at the plenary session. The following section outlines the key issues raised by the break out groups during the plenary discussion.

Summary of Key Issues and Priority Needs:

1. Understanding of HPV must be improved
 - a. Need to improve messaging to increase the awareness of HPV and its consequences
 - b. Need for increased sexual health awareness
 - c. Need community and family education
2. Building relationships with members of Aboriginal communities and develop mechanisms for enhanced communication, programming and partnerships
 - a. Need to address trust issues
 - b. Cultural competency and safety
 - c. Include representation of youth, women and elders
 - d. Incorporate traditional knowledge
3. Develop capacity in Aboriginal communities and for health workers serving Aboriginal people
 - a. Training for health professionals is necessary
 - b. Community capacity building and mobilization
4. Integrate HPV with other issues affecting Aboriginal people
 - a. Holistic approach - HPV doesn't stand alone – include as a component of health issues
 - b. Acknowledge and address the historical and cultural influences
 - c. Improve access to services
5. Public health program service improvements
 - a. Improve service delivery
 - b. Consider access issues, including transportation and child care needs
 - c. Consider home visits and urban Aboriginal social challenges

6. Increase research on HPV within Aboriginal populations
7. Technological infrastructure improvements
 - a. Quality assurance issues with existing technology in communities (e.g. Pap testing)
 - b. Liquid based cytology for Pap testing
 - c. Role of HPV testing in the future
8. Database improvements
 - a. Separate out Aboriginal data (break down into First Nations, Métis and Inuit groupings)
 - b. Improve access to data
9. Establish clear protocols for conducting research in Aboriginal communities and standardize methods for screening and prevention
10. Appropriate funding levels and other necessary resources
11. Shared responsibility model for making it happen

Next Steps

It was recommended that ICID document the discussions and recommendations from the workshop in a draft report and share a draft report with the workshop planning team. The final version of the report will be widely distributed to all workshop participants, other health committees, federal, provincial and territorial governments and other NGO health agencies. This report also will be distributed by ICID to PHAC and the John D. and Catherine T. MacArthur Foundation, as contributors to the workshop, and possible supporters of future meetings. Establishment of a “discussion board” could allow participants to reply to the document.

As phase 2 of this initiative, it was proposed that a working group be established to develop an action plan and a timeline. One or more issues will be prioritized and a plan defined to address those issues. A follow-up workshop in 12 – 18 months was recommended to review what has been planned, undertaken and accomplished. It was suggested that youth, grandmothers and aunts be involved at the next meeting.

