

Final Report

Enhancing HPV Prevention among Indigenous Populations:

International Perspectives on Health

A Symposium of the 26th International
Papillomavirus Conference

Montreal, Canada

July 5, 2010

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Executive Summary:

Enhancing HPV Prevention among Indigenous Populations: International Perspectives on Health and Well-Being

The Symposium, held on July 5, 2010, was presented as part of the International Papillomavirus 2010 Conference in Montreal, Canada. The Symposium was planned and organized by a Planning Committee representing public sector agencies and not for profit organizations. The event was coordinated and hosted by the International Centre for Infectious Diseases (ICID). The Public Health Agency of Canada (PHAC), and the First Nations and Inuit Health Branch (FNIHB) of Health Canada financially supported the Symposium, with assistance provided by the National Aboriginal Health Organization (NAHO), ICID, and members of the Aboriginal HPV Working Group (2008 workshop Winnipeg, Canada). Approximately 100 conference delegates from 19 different countries attended the Symposium, and 80 provided contact information in order to continue communications on HPV and Indigenous peoples internationally.

Available studies indicate that Indigenous peoples are disproportionately affected by HPV infections, are at a greater risk for HPV-related genital cancers, are more likely to be diagnosed at a later stage in the disease process, and remain less likely to survive a diagnosis of cervical cancer than non-Indigenous peoples. To inform the international symposium and the work of the planning committee, as well as provide a resource for participants, a global literature review was undertaken and is appended to this report (see Appendix 1: “HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations”).

The objectives of this unique Symposium were to share current information on the burden of HPV and related diseases and to identify promising interventions and wise* practices among Indigenous populations internationally.

The design of the symposium included an overview of the health of Canadian Aboriginal peoples with a focus on HPV issues, two panels of two speakers each, and a question and answer period following the panel presentations.

Opening remarks by Dr. Paulette C. Tremblay, Chief Executive Officer, National Aboriginal Health Organization (Canada) along with presenters from the first panel, Professor Suzanne Garland, of the Royal Women’s Hospital, Royal Children’s Hospital and the University of Melbourne (Australia), and Dr. Isaac Sobol, Chief Medical Officer of Health, Department of Health and Social Services, Nunavut (Canada), described the significant burden of HPV (and other STIs) among female Aboriginal and Torres Strait Islanders in Australia and among First

** Wise practices in this context are actions, processes, principles or decisions that contribute significantly to the achievement of effective, culturally appropriate steps in preventing or controlling HPV related diseases, adapted from the UNESCO definition⁴*

Nation, Inuit, and Métis women in Canada.

Speakers highlighted that, in order to support policy and programming, continued efforts are needed to address information gaps and collect pertinent and specific information from those populations most affected.

The second panel shared promising interventions and wise practices on the primary and secondary prevention of HPV diseases, cervical and other cancers. Dr. Eileen Dunne, Medical Epidemiologist, U.S. Centres for Disease Control (USA) and Ms. Telphia Joseph, National Indigenous Immunization Co-ordinator, National Centre for Immunization and Surveillance (Australia) presented overviews of promising programs for Alaska Natives and American Indians as well as for Aboriginal and Torres Strait Islander Australian females that addressed issues surrounding access to services, specifically HPV immunization and the potential role of cervical self-sampling.

The panelists were joined by Dr. Paul Brassard, McGill University (Canada) to answer questions and discuss innovative approaches to enhancing HPV prevention. The Symposium speakers and participants indicated their interest for continued dialogue regarding HPV issues among Indigenous peoples internationally.

Key messages from the symposium included:

- HPV is a significant public health issue within Indigenous populations in the jurisdictions described; a higher prevalence (up to five times) of HPV infection and cervical cancer, and increased cervical cancer mortality is experienced in Indigenous populations in certain regions of Australia, Canada and the United States compared to other populations
- There is a lack of information regarding HPV incidence, screening and cervical cancer rates amongst Indigenous peoples in some countries/regions; new surveillance research is being conducted in some jurisdictions to identify HPV types in Indigenous populations prior to vaccinations that will enable evaluation of population-based HPV immunization programs; a number of ongoing studies and evaluations of HPV vaccine and cervical cancer are being implemented in order to improve HPV prevention activities
- HPV programs in the jurisdictions described include publicly funded school based HPV immunization programs, and some have fully funded catch-up and multi-pronged programs; school program coverage rates are up to 80%, and in some areas Indigenous female vaccination exceeds that of the general female population; e-health tracking systems that allow for recall mail outs and targeted approaches have been very useful
- There are many opportunities for cervical cancer prevention in Indigenous communities to address the many challenges, including: filling the information gap in various areas; developing culturally appropriate educational materials and services; improving service

access and addressing barriers to screening including transportation and distance issues; working with the Indigenous communities rather than taking a patriarchal intervention approach

- Innovative approaches should be considered to: recruit Aboriginal women into screening programs; work towards a disease prevention approach; improve cooperation and vaccine buy-in of all stakeholders including staff and community members; and undertake research studies on HPV and cervical cancer among Aboriginal populations.

As a follow-up to the symposium, the following activities will be undertaken by members of the planning committee:

- a. Distribute the annotated bibliography (“HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations”), the executive summary of the Winnipeg workshop (“Improving HPV Prevention among Aboriginal Peoples”), and the Indigenous HPV Symposium final report to all participants who provided contact details
- b. Request permission to include names/contact details in networking list
- c. Share list of participant contact information with all participants, once their approval is gained
- d. Request examples of educational products, descriptions of innovative practices, and research projects to share with the participant list
- e. Request additional items to add to the annotated bibliography

The symposium, as well as the internationally focused background document, pointed to some key areas for ongoing and future activities to further advance HPV prevention among Indigenous peoples, including the formation of Indigenous HPV Networks to:

- a. support a focus on HPV issues among Indigenous peoples; promote dialogue between interested parties; encourage sharing of information, materials and practices; and share innovative methods of engaging Indigenous populations in HPV prevention activities.
- b. promote research related to HPV type distributions, and knowledge, attitudes and beliefs with respect to HPV and HPV vaccines among both males and females; identify contributing/risk factors for infection and HPV related diseases; and develop knowledge on the cost-effectiveness of introducing new interventions and technologies.
- c. advocate for additional programs and research to help reduce the burden of HPV disease in Indigenous populations and facilitate the implementation of publicly funded high risk vaccination programs for Indigenous peoples with direct input and direction from Indigenous communities.

It was not possible at this symposium to develop a specific mechanism to move forward on additional programs and research into HPV disease in Indigenous populations. However, the strong interest shown by participants in ongoing dialogue and collaborative partnerships could serve as a starting point towards the development of innovative strategies to address these needs.

Overview & Background

The Human Papillomavirus (HPV) is the leading cause of cervical cancer and anogenital warts, and is linked to many other cancers and cytological abnormalities¹. Cervical cancer is estimated to be the second most common malignant disease affecting women globally². Indigenous peoples constitute approximately 5% of the world's population, are disproportionately affected by HPV infections, are at a greater risk for HPV-related genital cancers, are more likely to be diagnosed at a later stage in the disease process, and remain less likely to survive a diagnosis of cancer than non-Indigenous peoples³.

The 26th International Papillomavirus (IPV) Conference was held in Montreal, Canada from July 3 to 8, 2010. During the period leading up to the conference, a planning committee was convened to discuss the value of extending previous discussions of HPV issues amongst Canadian Aboriginal populations to an international Indigenous peoples focus. Consequently, the development of a symposium was proposed, to be held as a component of the IPV conference. The IPV conference organizers embraced this proposal and the symposium was held on July 5, 2010 and offered to IPV conference delegates. This was the first-ever IPV Conference in its 26 year history to incorporate a symposium dedicated to Indigenous HPV issues.

The Indigenous HPV Symposium Planning Committee (see below for list of members) undertook the preparation and organization of this important symposium, building on dialogue which began during a workshop held in Winnipeg, Canada on December 9, 2008, entitled "Improving HPV Prevention among Aboriginal Peoples." The participants of this workshop, representing governmental and not-for-profit agencies, discussed the need to share recent information on current research, research gaps, public awareness strategies, and promising immunization program implementation practices. Eleven key issues and priority needs were developed from the discussions, which helped to frame and move forward the planning of the international Indigenous symposium at the 2010 IPV conference (see Appendix 2: Improving HPV Prevention among Aboriginal Peoples Workshop: Final Report).

The International Indigenous HPV symposium, entitled "**Enhancing HPV Prevention among Indigenous Populations: International Perspectives in Health and Well-Being**" aimed to create a forum for sharing and discussing current information on the burden of HPV and related diseases and to identify promising interventions and wise practices among Indigenous populations internationally. Potential speakers working with Indigenous populations around the world were identified and recruited to provide presentations at this Symposium.

The International Centre for Infectious Diseases (ICID) based in Winnipeg, Canada coordinated and hosted this international symposium. The Public Health Agency of Canada (PHAC), and the First Nations and Inuit Health Branch (FNIHB) of Health Canada financially

supported the Symposium, with assistance provided by the National Aboriginal Health Organization (NAHO), ICID, and members of the Aboriginal HPV Working Group (2008 Workshop, Winnipeg, Canada).

Symposium Objectives:

The objectives of the workshop were:

- 1) To share current information on the burden of HPV and related diseases within Indigenous populations
- 2) To identify and share promising interventions and wise practices to reduce the burden of HPV among Indigenous populations

Symposium Planning and Design

The Symposium Planning Committee held planning meetings between March and July, 2010. The group considered topics that would be of interest to an international audience, potential speakers, logistical arrangements, evaluation, and how best to facilitate communication among individuals interested in Indigenous HPV issues.

Members of the Symposium Planning Committee

Representatives of several governmental and non-governmental organizations assisted in the planning and implementation of the Symposium, including:

- Dr. Marcia Anderson DeCoteau, Medical Officer of Health, Public Health Specialist, Manitoba First Nations Public Health Improvement Pilot Project, Manitoba Health
- Ms. Katherine Dinner, Health and Social Services Advisor, Community Acquired Infections Division, Centre for Communicable Disease & Infection Control, Public Health Agency of Canada
- Ms. Martine Dubuc, Nurse Advisor, Vaccine Preventable Diseases & Immunization Communicable Disease Control Division, First Nation and Inuit Health Branch, Health Canada
- Dr. Erich Kliewer, Consulting Epidemiologist, Epidemiology & Cancer Registry, CancerCare Manitoba
- Mr. Robert Lerch, Head, Knowledge Development and Research, Community Acquired Infections Division, Centre for Communicable Disease & Infection Control, Public Health Agency of Canada
- Ms. Colleen Patterson, Senior Communications Officer, Communications Unit, National Aboriginal Health Organization

- Ms. Olivia Remes, Junior Analyst, Community Acquired Infections Division, Centre for Communicable Disease & Infection Control, Public Health Agency of Canada
- Dr. Allan Ronald, Senior Scientific Advisor, International Centre for Infectious Diseases
- Ms. Wendy Schettler, Director of Public Health Programs, International Centre for Infectious Diseases
- Ms. Joyce Seto, Research Analyst, Sexual Health and STI Section, Public Health Agency of Canada
- Ms. Shelley Stopera, STI/BBP Program Specialist/HPV Project Manager, Communicable Disease Control Branch, Public Health and Primary Health Care, Manitoba Health
- Ms. Stephanie Totten, Epidemiologist, Community Acquired Infections Division, Centre For Communicable Diseases & Infection Control, Public Health Agency of Canada
- Dr. Thomas Wong, Director, Community Acquired Infections Division, Centre for Communicable Disease & Infection Control, Public Health Agency of Canada
- Mr. Cory Woodyatt, Project Officer, Community Acquired Infections Division, Centre for Communicable Diseases & Infection Control, Public Health Agency of Canada
- Mr. George Wurtak, Manager, HPV Programs, International Centre for Infectious Diseases

Elder Blessing

The Symposium Planning Committee supported the conference organizers in having the full conference opened by an Elder of the traditional territory where the conference would be held in Canada. The region around Montreal is traditional Mohawk territory, and a respected Elder from the community known as Kahnawake (which means “By the water”) on the St. Lawrence River was approached to provide the opening blessing for the IPV Conference. The Elder, Amelia Tekwatonti McGregor is a Kanienkehaka woman, and is a Bear Clan member of the Kahnawake Mohawk Territory. The Elder also participated in the Indigenous HPV Symposium and shared information with many symposium participants and speakers.

Symposium Design

One member of the Symposium Planning Committee served as Master of Ceremonies (MC) for the event. Ms. Colleen Patterson facilitated the symposium and introduced speakers, monitored presentation times, and moderated the question and answer period.

The Planning Committee organized the Symposium presentations into two broad themes to address a range of presentation topics:

1. Researching the Burden of HPV Disease, Immunization, and Cervical Screening among Indigenous Populations

2. Primary and Secondary Prevention of HPV Diseases, Cervical and other cancers among Indigenous Populations: Promising Interventions and Wise Practices

The first theme was intended to provide a snapshot of known information and new research findings with respect to the burden of HPV and related diseases, and taking a holistic approach to health and well-being, to include and acknowledge related health issues and the determinants of health in Indigenous populations.

The second theme was intended to serve as a sharing of current practices and new interventions that show promise by contributing to the reduction of HPV and related diseases amongst Indigenous Populations.

In addition to the four invited speakers, the Planning Committee wished to share with the international audience an overview of the situation with respect to HPV and Canada's Aboriginal peoples. Consequently, Dr. Paulette C. Tremblay, Chief Executive Officer of the National Aboriginal Health Organization, was invited to present an opening address to the participants.

Invited Speakers, Topics and Presentation Titles

Opening Address

Presentation Title: **Aboriginal Peoples and HPV Prevention**

Dr. Paulette C. Tremblay
Chief Executive Officer
National Aboriginal Health Organization
Ottawa, Canada

Topic 1: Researching the burden of HPV disease, immunization, and cervical screening among Indigenous populations

Presentation 1: **WHINURS HPV genotype prevalence in Australian women pre-vaccination: what differences might there be for Indigenous women?**

Professor Suzanne Garland
Director of Microbiological Research and Head of Clinical Microbiology and Infectious Diseases, Royal Women's Hospital, Senior Consultant Microbiology, Royal Children's Hospital; Professor Faculty of Medicine, Dentistry and Health, Department of Obstetrics and Gynaecology, University of Melbourne, Australia

Presentation 2: **Burden of HPV disease in Nunavut**

Dr. Isaac Sobol (Canada) MD, CCFP, MHSc
Chief Medical Officer of Health,
Dept. of Health and Social Services,
Government of Nunavut, Iqaluit, Canada

Topic 2: Primary and secondary prevention of HPV diseases, cervical and other cancers among Indigenous populations: promising interventions and wise practices

Presentation 3: **Prevention of HPV diseases in Indigenous populations: examples of promising interventions and activities among Alaska Natives and American Indians**

Dr. Eileen F. Dunne (USA) MD, MPH
Medical Epidemiologist
Epidemiology and Surveillance Branch
Division of Sexually Transmitted Disease Prevention,
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
U.S. Centers for Disease Control
Atlanta, Georgia, USA

Presentation 4: **Service providers of HPV vaccination for Aboriginal and Torres Strait
Islander Australian females**

Ms. Telfia Joseph (Australia)

National Indigenous Immunisation Co-ordinator

The National Centre for Immunisation and Surveillance

Kids Research Institute at The Children's Hospital at Westmead,

New South Wales, Australia

A number of HPV research projects involving Indigenous peoples in northern Quebec, Canada have been undertaken or are in process. In order to share information on these projects and his expertise in the area, Dr. Paul Brassard was invited to participate in the panel during the Question and Answer period following the presentations:

Dr. Paul Brassard, MD

Departments of Medicine, Epidemiology & Biostatistics,

McGill University;

Division of Clinical Epidemiology, McGill University Health Center

Montreal, Quebec, Canada

Speaker biographies may be found in Appendix 7.

Speaker Presentations

Opening Remarks: Aboriginal Peoples & HPV Prevention in Canada

Dr. Paulette C. Tremblay opened the Symposium by acknowledging the people of the traditional territory in which the conference was being held, including the Mohawk Elder, Amelia Tekwatonti McGregor, who was present. Dr. Tremblay outlined the mission of Canada's National Aboriginal Health Organization, and provided a definition for good health for all Aboriginal people which embraces a holistic approach to health. A map showed the distribution of Aboriginal peoples across Canada, and population characteristics and distribution figures were provided. Approximately 1.2 million people (4% of Canada's population) have First Nation, Inuit or Métis heritage, and a substantial proportion live in Canada's 633 Aboriginal communities.

HPV and cervical cancer incidence rates in Canada were described, and the paucity of information regarding HPV incidence, screening and cervical cancer rates amongst First Nations, Inuit and Métis peoples in Canada was noted. Findings of regional studies indicate that there is a higher prevalence of HPV infection among Aboriginal peoples compared to other Canadians within the age range 13-20 showing the highest rates. Also, cervical cancer prevalence among Aboriginal populations is up to three times the rate of other Canadians, and cervical cancer mortality rates up to four times that of other Canadian women.

A number of challenges were described, including the absence of HPV knowledge within communities, a lack of health services, difficulties with accessing services, transportation and distance issues, low participation rates in cervical cancer screening, negative encounters with health care providers, communication, language and cultural barriers, funding limitations and shortages of female and Aboriginal health care providers.

Improving the situation would involve filling the information gap in various areas, developing culturally appropriate educational materials and services, improving cooperation of service providers and all stakeholders, working towards a disease prevention approach, recruiting Aboriginal women into cervical screening programs, and the undertaking of research studies on HPV and cervical cancer among Aboriginal populations.

Key Messages:

- There is a paucity of information regarding HPV incidence, screening and cervical cancer rates amongst First Nations, Inuit and Métis peoples in Canada.
- A higher prevalence of HPV infection and cervical cancer (3x), and increased cervical cancer mortality (4x) is experienced in Aboriginal populations compared to other Canadians

- Opportunities to address the many challenges include: filling the information gap in various areas; developing culturally appropriate educational materials and services; improving service access; and addressing barriers to screening including transportation and distance issues
- Innovative approaches should be considered to: recruit Aboriginal women into screening programs; work towards a disease prevention approach; improve cooperation of all stakeholders; and to undertake research studies on HPV and cervical cancer among Aboriginal populations.

Presentation 1: WHINURS HPV genotype prevalence in Australian women pre-vaccination: what differences might there be for Indigenous women?

Professor Suzanne Garland described the WHINURS - Women's HPV Indigenous Non-Indigenous Urban Rural Study (pronounced "winners") – a project which was started well prior to the government funded school based HPV vaccination programme and which therefore establishes a baseline for the prevalence of HPV overall together with HPV type-specific data among various populations presenting for Pap cytology screening and including those in isolated regions. Cervical cancer incidence and mortality rates have been declining since 1982 in Australia, but Aboriginal mortality rates are three times that of other Australian women. The Indigenous population - Aboriginal and Torres Strait Islanders – comprise 2.3% of Australia's 21 million population, and in the Northern Territory account for nearly 30% of the population. Cervical cancer incidence and mortality rates for Aboriginal women from the Northern Territory are five times the national average. Rates of other STI's (chlamydia, gonorrhoea and syphilis) are also many fold higher in the Indigenous populations.

The Australian government funded a school based quadrivalent HPV vaccination program starting in April 2007 with 12-13 year old females (on-going) and 13-18 year old females as part of a catch-up program (2 year period from July 2007 to December 2009). During 2007, the program was expanded to include community based general practitioner administered vaccination of 18-26 year old females and 12-18 year old females who are missed in the school program (ending in 2009). Within the school program coverage rates are 75-80% for the first dose (70% in rural areas), 96% return rates for the second dose, and 87% course completion rates.

The WHINURS project aims to estimate the prevalence of type-specific genital HPV infection prior to vaccination in the Australian female population by age group, Indigenous status, cervical Pap smear status, and region of residence (urban, rural, remote). The project recruited 1000 Indigenous and 2000 Non-Indigenous women from across Australia. The differences in HPV types, multiple versus single type infections, and the most frequently detected HPV types between Indigenous and Non-Indigenous women were described. Finally, the value of HPV vaccination and Pap screening for all women was emphasized.

Key Messages:

- While cervical cancer incidence and mortality rates have been declining since 1982 in Australia, Aboriginal mortality rates are three times that of other Australian women; and cervical cancer incidence and mortality rates for Aboriginal women from the Northern Territory are five times the national average
- The Australian government funded a school-based quadrivalent HPV vaccination program starting in 2007 for 12-13 year old females, and a one year period catch up program for 13-18 year olds. School program coverage rates are 75-80% (first dose) with a 96% return rate for the second dose, and 87% course completion rates
- Approximately 1000 Indigenous and 2000 non-Indigenous women were recruited for the WHINURS project, which aims to estimate the prevalence of HPV types prior to vaccination in the Australian female population, stratified by age group, Indigenous status, cervical Pap smear status, and region of residence (urban, rural, remote)
- The results from WHINURS show that there is equal value in HPV vaccinations and Pap screening for all women, indigenous and non-indigenous.

Presentation 2: **Burden of HPV disease in Nunavut**

Dr. Isaac Sobol provided background information on the population of Nunavut; population 30,000, 85% of which are Inuit, and 50% are under the age of 21. Inuktitut and Innuinaqtun are spoken by 80% of the population, and by 2020 the functioning language of government will be Inuktitut. Nunavut has 25 remote communities, all of which are only accessible by air or sea (no roads).

Cervical cancer decreased in Nunavut between 1994 and 2000, and in 2005, 79.3% of women had undergone Pap screening within the last three years. All cervical cancer screening is accomplished in public facilities (none in private clinics). The publicly funded, school based vaccination program for grade 6 girls (12 year olds) was initiated in March 2010. Vaccine uptake has been approximately 58% since the initiation of the program. A communications plan and the implementation of a catch up program to increase uptake are under consideration.

In 2008, a collaborative project between Nunavut and the Public Health Agency of Canada was undertaken. It aimed to provide evidence for decision-making around the HPV vaccine in Nunavut, to examine differences in HPV prevalence in Inuit and non-Inuit women, and to contribute to the national baseline of HPV prevalence.

In this study involving 4,043 women, HPV (any type) was found in 29.9% of the women; 9.5% had multiple HPV types; 22.1% had a high risk HPV type, and 4.9% had multiple

high risk types. The most common high risk HPV types were 16 (6.4%) and 31 (3.1%), with eight other high risk types, including type 18, falling in the 1% to 2% range.

Key Messages:

- Human papillomavirus is a significant public health issue in the territory of Nunavut, with a large proportion of the women who present for Pap testing in Nunavut are infected with the virus.
- This surveillance is the first to compare type-specific HPV prevalence in Inuit to non-Aboriginal females in Nunavut, and answers questions about the role of non-vaccine-targeted HPV types in the development of cervical cancer.
- These data provide a baseline of HPV prevalence in an unvaccinated population, and will enable evaluation of population-based HPV immunization programs in Nunavut.

Presentation 3: Prevention of HPV diseases in Indigenous populations: Examples of promising interventions and activities among Alaska Natives and American Indians

Dr. Eileen Dunne began by describing the diverse cultures of American Indians and Alaska Natives (AI/AN), the complexities involved in sovereignty, self-governance, health care delivery and federal-tribal relationships. The similarity of issues across continents was noted. Most prevention opportunities are within the health care settings. There are 560 federally recognized tribes in 35 states, but many tribes are not recognized. The Indian Health Services (IHS) provides health services for 1.9 million AI/AN, which constitutes 57% of the healthcare provided to Indigenous populations in the USA.

There are regional differences in cervical cancer rates, with the highest rates in the Southern Plains (14.1 per 100,000) and Northern Plains (12.5 per 100,000). Overall, Indigenous women have higher rates of cervical cancer than non-Hispanic white women (9.4 per 100,000) and are more likely to be diagnosed at a later stage of disease.

Interventions to prevent cervical cancer include HPV vaccine program implementation and cervical cancer screening programs. The status of the vaccine program as of early 2010 was described, as was the school based vaccine implementation project, and an evaluation of the HPV vaccine impact in Alaska Natives.

The National Immunization Survey of the USA reported that as of 2008 approximately 38% of US adolescent females received at least one vaccine dose, and 17.9% completed the three doses, a relatively low HPV vaccine uptake rate. In comparison, the publicly funded HPV vaccine uptake (all three doses) by the Indian Health Services was approximately 40%, and approximately 70% receiving at least one dose.

Dr. Dunne described the Fort Berthold HPV Vaccine Implementation Project, which involved five school districts in three Tribal areas. The project was described as multi-focused

and included components related to nutrition, exercise and HPV vaccination. 138 girls completed the vaccination series, with 453 doses distributed. The intention is to expand this program in the next school year.

A description was then provided by Dr. Dunne of the CDC, Arctic Investigations Program (AIP), which has a successful collaboration with the Alaska Native Tribal Health Consortium (ANTHC). AIP in collaboration with ANTHC are evaluating HPV vaccine in AN communities by a project that measures HPV vaccine impact, including HPV genotype distribution, long-term duration of immunogenicity, and HPV type distribution contributing to cervical cancers. Dr. Dunne described the results of a study intended to identify HPV types causing cervical cancers in Alaska Native Women using archived cervical cancer specimens. This study found that HPV type 16 was identified in 51% of cervical cancers, followed by type 18 (12%), HPV 16 + 18 (4%) and other HPV types (33%).

Another project for American Indians is the Northern Plains Cervical Cancer Screening Project, which is evaluating if a cervical self-sampler can improve experiences of cervical cancer screening in Northern Plains American Indian women. It will also assess the validity of samples and determine if screening rates improve through the use of self sampling techniques at home, 30 and 90 days following the first traditional clinical Pap smear and HPV testing. Finally, a survey of Indian Health Service providers is underway to determine intentions to vaccinate boys.

Key Messages:

- There are opportunities for cervical cancer prevention in AI/AN communities.
- AI/AN communities have higher cervical cancer rates, especially in certain regions.
- HPV Vaccine implementation through the Vaccine for Children Program appears to have higher coverage for AI/AN adolescents.
- Ongoing studies and evaluations of HPV vaccine and cervical cancer are seeking to improve prevention activities in AI/AN communities.

Presentation 4: Service providers of HPV vaccination for Aboriginal and Torres Strait Islander Australian females

Ms. Telfia-Leanne Joseph provided a description of Indigenous populations in Australia, the HPV vaccine delivery program, and the challenges and factors that may have affected the HPV vaccine service provision for Indigenous females in Australia. Two distinct groups comprise Indigenous Australians – Aboriginals and Torres Strait Islanders. The majority of Indigenous peoples live in rural areas in half of the Australian states; in the Northern Territory the majority of the Indigenous population resides in remote areas; and urban Indigenous residents make up a large minority of the population in half the states, and the

majority of Indigenous people in South Australia live in urban areas. This population is often considered to be primarily located in remote or rural regions, but this is not the case in several states which have large urban populations of Indigenous peoples.

Cervical cancer rates among Indigenous women are at least four times greater than among non-Indigenous women. There is inconsistent, late or non-presentation for Pap testing among Indigenous women, despite Australia's well-established cervical screening program and Pap register. The poor screening rates of Indigenous women make HPV vaccination an important prevention tool. The vaccination program in Australia has been in place since 2007 and has included three distinct tiers since its inception, including an annual school based program for 12-13 year olds (on-going), a school-based catch-up program for 13-18 year olds (ended in late 2009) and a general practice and community provider program for 16-18 year olds not at school and for 18-26 year olds (ended in late 2009).

Indigenous communities access health services through the government-funded Aboriginal Medical Services (AMS) system, public health and through general practice clinics. Factors affecting HPV vaccination for 15-26 year olds in the AMS systems included issues related to service provision, individuals outside of the school system, and H1N1. The facilitators to vaccination included the belief of staff in the vaccine, their knowledge of the community, and the Patient Information Recall System (PIRS). Factors affecting HPV vaccination in the school based program include low attendance rates (73% at 15 years; 36% by 17 years), inconsistent attendance, and return rates of consent forms. In communities with large Aboriginal populations, public health staff, Aboriginal health workers, and Aboriginal liaison education staff shared resources and knocked on doors to achieve a 94% consent rate.

Challenges experienced in vaccinating 15-26 year olds within General Practice offices include the identification of Indigenous status, and barriers including limited cultural comfort and physical access. Knowing the community, making good use of medical software, and persisting in Indigenous identification are positive ways to improve vaccine uptake.

It was more difficult to target urban Indigenous populations than rural/remote populations. The vaccine uptake rate for Indigenous people in urban areas (70%) is lower than in rural areas, and this is also true for non-Indigenous Australians. The more remote areas had better - nearly full vaccine coverage.

Key Messages:

- The vaccination program for Indigenous Australians is a success as a result of:
 - a multi-pronged approach to vaccinating different age ranges,
 - fully funded vaccine coverage,
 - having community buy-in,
 - having staff who believe in the vaccine, and
 - having the PIRS e-health tracking system whereby recall mail outs and targeted approaches could be used, in addition to patients presenting themselves.

- Working with Indigenous people rather than taking a more patriarchal intervention approach is recommended.
- Education and mentoring supported the program - WHINURS engaged and empowered a lot of women relating to HPV and found that women knew more than their doctors about HPV.

Materials Distributed at the Symposium

HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations: an annotated bibliography

An environmental scan/ background document on the current level of research and understanding of HPV and Indigenous populations was completed and distributed by the symposium planning committee and led by Ms. Olivia Remes of PHAC. The purpose of the document was to share information on HPV research from around the world, and to serve as a starting point for the Symposium discussion. The annotated bibliography is entitled “HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations”. It was prepared by the Symposium Planning Committee. The document was handed out at the Symposium entrance, and has been made readily available via the ICID (www.icid.com) and NAHO (www.naho.ca) websites, and is attached to this report (Appendix 1).

Improving HPV Prevention among Aboriginal Peoples – Canadian Workshop Report

The executive summary of the final report for this workshop, held in Winnipeg, Canada on December 9, 2008, was distributed to Symposium participants prior to commencement of the event (Appendix 2). Objectives for this workshop included sharing information on HPV and Aboriginal populations in Canada, identifying HPV research gaps and priorities, and identifying HPV vaccine implementation challenges and program improvement strategies. This workshop report is also available on the ICID website (www.icid.com).

National Aboriginal Health Organization Fact Sheet

The “Human Papillomavirus or HPV” fact sheet describes HPV, risks and protection, and offers information about the HPV vaccine (Appendix 3a), available at www.naho.ca.

First Nations and Inuit Health Branch - Medical Staff Continuing Education Program

The “HPV and Aboriginal Women in Canada” educational program provides information on HPV infections in Aboriginal populations in Canada, the epidemiology, clinical manifestations, prevention and management of HPV infection. It also discusses anogenital warts and approaches to improve communication among Aboriginal peoples (Appendix 3b).

Contact Cards

These cards were utilized to collect name, organization and contact coordinates of symposium participants who were interested in receiving electronic copies of materials, and to stay in contact in order to continue communications and dialogue on the topic of HPV and Indigenous populations (Appendix 4). Of the approximately 100 delegates attending the symposium, over 80 participants provided their contact details.

Evaluation Questionnaire

In order to gather feedback on the symposium and to provide an opportunity for participants to share their comments, suggestions and ideas for continuing dialogue, an evaluation questionnaire was distributed (Appendix 5).

Symposium Follow Up

The following actions will be undertaken by members of the planning committee:

- a. Distribute the annotated bibliography (“HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations), the executive summary of the Winnipeg workshop (“Improving HPV Prevention among Aboriginal Peoples”), and the Indigenous HPV Symposium final report to all participants who provided contact details
- b. Request permission to include names/contact details in a networking list
- c. Share list of contact information provided by participants with all participants, once approval is gained from participants
- d. Request examples of educational products, descriptions of innovative practices, and research projects to share with the participant list
- e. Request additional items to add to the annotated bibliography

Concluding Remarks

Issues of HPV and related diseases affecting Indigenous populations are of great concern to health workers in many countries. The fact that conference delegates from 19 different countries around the world chose to attend the HPV and Indigenous Peoples Symposium demonstrated the high level of interest. Delegates came to learn about the burden of disease experienced by Indigenous populations and innovative approaches in implementing or improving an immunization program in their home countries.

Speakers provided valuable information on Indigenous populations and HPV in their regions and offered a number of key messages:

- HPV is a significant public health issue within Indigenous populations in the jurisdictions described; a higher prevalence (up to five times) of HPV infection and cervical cancer,

and increased cervical cancer mortality is experienced in Indigenous populations in certain regions of Australia, Canada and the United States compared to other populations in these countries

- There is a lack of information regarding HPV incidence, screening and cervical cancer rates amongst Indigenous peoples in some countries/regions; new surveillance research is being conducted in some jurisdictions to identify HPV types in Indigenous populations prior to vaccinations that will enable evaluation of population-based HPV immunization programs; a number of ongoing studies and evaluations of HPV vaccine and cervical cancer are being implemented in order to improve HPV prevention activities
- HPV programs in the jurisdictions described include publicly funded school based HPV immunization programs, and some have fully funded catch-up and multi-pronged programs; school program coverage rates are up to 80%, and in some areas Indigenous female vaccination exceeds that of the general female population; e-health tracking systems that allow for recall mail outs and targeted approaches have been very useful
- There are many opportunities for cervical cancer prevention in Indigenous communities to address the many challenges, including: filling the information gap in various areas; developing culturally appropriate educational materials and services; improving service access and addressing barriers to screening including transportation and distance issues; working with the Indigenous communities rather than taking a patriarchal intervention approach
- Innovative approaches should be considered to: recruit Aboriginal women into screening programs; work towards a disease prevention approach; improve cooperation and vaccine buy-in of all stakeholders including staff and community members; and to undertake research studies on HPV and cervical cancer among Aboriginal populations.

Following the presentations, 43 participants submitted completed evaluation questionnaires (Appendix 6). Participants reflected a number of occupational groups including physicians, nurses, researchers and public health officials. The majority of participants agreed or strongly agreed that the symposium: **identified promising interventions and wise practices for addressing prevention of HPV disease among Indigenous populations; and provided new and relevant information related to the burden of HPV among Indigenous populations.** Almost all participants (95%) were interested in continuing dialogue on HPV issues with respect to Indigenous populations.

The symposium as well as the internationally focused background document point to some key areas for ongoing and future activities. Included among these activities is the need for facilitation of ongoing dialogue through the formation of collaborative networks supported by dedicated secretariats. These collaborative partnerships can help to facilitate knowledge exchange and application by supporting:

- a. The development of new and innovative interventions and methods which better engage Indigenous communities in HPV disease prevention
- b. The gathering and sharing of HPV educational materials that are culturally appropriate and effective in raising awareness amongst Indigenous populations
- c. The sharing of information on practices that have led to improvements in HPV vaccine uptake rates and cervical cancer screening rates within Indigenous populations
- d. The promotion of dialogue between interested parties individually, and at conferences and events related to HPV, health services and indigenous populations

Additionally, international collaborations and networks focused on the planning and implementation of programs and research projects have the potential to respond to information gaps and expand our understanding in key areas including:

- a. the identification of contributing / risk factors to explain the increased burden of HPV and HPV related disease, including high grade lesions, within Indigenous populations
- b. the distribution of circulating HPV types among different Indigenous populations and the contributing / risk factors which explain variations in these distributions
- c. knowledge, attitudes, and beliefs of Indigenous peoples with respect to HPV and HPV disease, cervical screening, HPV vaccines, and related issues
- d. the burden of HPV disease in male Indigenous populations
- e. the value and cost-effectiveness of introducing advanced screening technologies such as HPV testing, and self-sampling within Indigenous populations
- f. improvements in data collection and quality through the use of medical software and systems

The community members and non-governmental organizations participating in the symposium were supportive of the development of a mechanism to advocate for additional programs and research leading to a reduction in the burden of HPV disease in Indigenous populations and the implementation of publicly funded high risk vaccination programs for Indigenous peoples with direct input and direction from Indigenous communities.

It was not possible at this symposium to develop a specific mechanism to move forward on additional programs and research into HPV disease in Indigenous populations. However, the strong interest shown by participants in ongoing dialogue and collaborative partnerships could serve as a starting point towards the development of innovative strategies to address these needs.

Acknowledgements

The Symposium Planning Committee would like to acknowledge the assistance and guidance provided by Dr. Marc Steben, Chair of the IPV 2010 Conference Local Organizing Committee, and the support provided by the organizations involved in the planning and implementation of this highly successful symposium. Appreciation is expressed to the Assembly of First Nations (AFN) for allowing the presentation of the HPV video, and to the Society of Obstetricians and Gynaecologists of Canada (SOGC), and to the National Aboriginal Health Organization (NAHO), for providing and permitting distribution of printed information on HPV. The planning committee also expressed appreciation to the speakers who so willingly provided their experiences and insights: Dr. Paulette C. Tremblay, Prof. Suzanne Garland, Dr. Isaac Sobol, Dr. Eileen Dunne, Ms. Telphia Joseph, and Dr. Paul Brassard.

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1. PHAC 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>, and World Health Organization. "HPV and Cervical Cancer in the World: 2007 Report". Vaccine 25.3 (2007): C1-C230. Print.
2. Health Canada (2006). Screening for Cervical Cancer. http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/cervical-uterus_e.html
3. HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations: an annotated bibliography. Draft manuscript. Public Health Agency of Canada. July, 2010.
4. Modified from the UNESCO statement on Wise Coastal Practices, <http://www.unesco.org/csi/wise/progress.htm>

Appendix 1

HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations: An annotated bibliography:

HPV Infections, Cervical Cancer and Cervical Cancer Screening Practices in Indigenous Populations

Executive Summary

The World Health Organization estimates that approximately 493,243 women worldwide acquire cervical cancer each year and 273,505 die from this disease. It is the second most common malignancy among females, particularly those between 15 to 44 years of age.¹ Prior infection with the sexually transmitted human papillomavirus (HPV) leads to the development of cervical cancer, and in some populations, over 20% acquire an oncogenic HPV during their lifetime. Oncogenic HPV genotypes 16 and 18 are responsible in most studies for about 70% of cases of invasive cervical cancer globally with the remainder due to about 15 less commonly acquired HPV oncogenic types. Cervical cancer occurs in 1% to 2% of individuals who have become infected with an oncogenic HPV type. Cancer seems to develop only if the virus persists in the cervix for years.^{2,3}

Strategies to prevent the consequences of HPV infection include screening for cervical cytological abnormalities or oncogenic HPV types, and HPV immunization (the quadrivalent vaccine protects against oncogenic HPV types 16 and 18 and non-oncogenic types 6 and 11, mainly associated with anogenital warts⁴). Limited data are available on screening rates and immunization of Indigenous groups.

Who are Indigenous Peoples?

According to the United Nations Permanent Forum on Indigenous Issues, Indigenous peoples are identified as “the inheritors and practitioners of unique cultures and ways of relating to other people and to the environment. Indigenous peoples have retained social, cultural, economic and political characteristics that are distinct from those of the dominant societies in which they live.”⁵ As cited by Hall et al. and according to the International Work Group for Indigenous Affairs (IWGIA),

¹ World Health Organization. "HPV and Cervical Cancer in the World: 2007 Report." *Vaccine* 25.3 (2007): C1–C230. Print.

² Castle PE, et al. "Short Term Persistence of Human Papillomavirus and Risk of Cervical Precancer and Cancer: Population Based Cohort Study." *British Medical Journal* 339 (2009). Print.

³ Rodríguez AC, et al. "Longitudinal Study of Human Papillomavirus Persistence and Cervical Intraepithelial Neoplasia Grade 2/3: Critical Role of Duration of Infection." *Journal of the National Cancer Institute* 102.5 (2010): 315-324. Web.

⁴ Shefer A, et al. "Early Experience with Human Papillomavirus Vaccine Introduction in the United States, Canada and Australia." *Vaccine* 26.10 (2008): K68-75. Print.

⁵ UN Permanent Forum on Indigenous Issues. "ABOUT UNPFII and a Brief History of Indigenous Peoples and the International System." 2006. Web. <<http://www.un.org/esa/socdev/unpfii/en/history.html>>.

Indigenous peoples constitute approximately 5% of the world's population. The ninth annual IWGIA 2008 report provides the following regional breakdown of Indigenous populations worldwide⁶:

Table 2: Indigenous Populations by Region (millions)

China	105.23
South Asia	94.90
Former Soviet Union	0.40
Southeast Asia	29.84
South America	19.53
Africa	21.98
Central America/Mexico	19.07
Arabia	15.41
USA/Canada	3.29
Japan/Pacific Islands	0.00
Australia/New Zealand	0.46
Greenland/Scandinavia	0.10
Total	310.21

Source: IWGIA 2008

Health Status of Indigenous Peoples:

Several studies indicate that Indigenous populations are disproportionately affected by HPV infections and are at greater risk for HPV-related genital cancers than the general population. In comparison with non-Indigenous populations, they are more likely to be diagnosed at a later stage in the disease process and less likely to survive a diagnosis with cervical cancer. Several factors, such as sociocultural and access barriers contribute to this issue.

Scope of Annotated Bibliography:

A literature review was undertaken to determine the burden of HPV and health-related consequences among Indigenous peoples in Canada, the United States, New Zealand, Australia, Argentina, Brazil, Venezuela and Greenland. Although HPV-related anogenital warts represent a significant health burden, Indigenous-specific research examining this issue is scarce and therefore not included. Peer-reviewed literature was retrieved from the Scopus database and results are presented in an annotated format (conference abstracts have not been included in this document).

The following sections will be presented in this annotated bibliography:

1. Cervical cancer
2. HPV infections
3. Cervical cancer screening

⁶ Hall G, et al. "Indigenous Peoples, Poverty and Development, Draft Manuscript". 2010. Print.

1.1 Cervical Cancer

AUSTRALIA

- *Prior, D. "The Meaning of Cancer for Australian Aboriginal Women; Changing the Focus of Cancer Nursing." *European Journal of Oncology Nursing* 13.4 (2009): 280-6.*

Interpretive ethnography was used to investigate why Aboriginal women of Australia present for screening, but then are less likely to return for further follow-up and are less inclined to follow recommended treatment regimens. In addition, attitudes, perceptions, and beliefs regarding cancer as a general term/disease as well as cervical cancer were examined by the author. Data was gathered over a two-year period via 'participant-observation', 'fieldwork' during which the researcher observed everyday life in the study setting, a mixed focus group, and interviews with Aboriginal females in 2 rural Queensland communities (n=48).

The study sample was comprised of 48 participants ages 18+ (the majority of participants were of Aboriginal origin; however, 10 subjects were health care workers of Aboriginal/non-Aboriginal ethnicity). Findings demonstrated that Aboriginal females had fearful attitudes towards cancer and regarded it as a "killer disease". Some of the common themes that emerged include:

- Cancer is one disease and the outcome is fatal, therefore treatment has little value.
- Biomedical treatment methods do not align with cultural concepts of holistic care; the woman's body is sacred and should not be violated by invasive treatment methods such as surgery.
- CIN diagnosis is associated with cancer and immoral behaviour
- One acquires cancer as a result of a curse, payback for past evil deeds, relationship disharmony, etc...
- Women feel ashamed to discuss their sexual health with health care workers, as it is a private matter.

- *Condon, J. R., et al. "A Cluster of Vulvar Cancer and Vulvar Intraepithelial Neoplasia in Young Australian Indigenous Women." *Cancer Causes and Control* 20.1 (2009): 67-74.*

Condon et. al examined cases of vulvar cancer or high-grade vulvar intraepithelial neoplasia among females of the Northern Territory in Australia. The authors identified 71 cases (32 with vulvar cancer and 39 with high-grade VIN) diagnosed between January 1, 1996 and December 31, 2005.

The majority of the cases identified were females of Indigenous origin, younger than 50, and living in the East Arnhem region.

Among those 0-49 years of age, the incidence rate of vulvar cancer was higher among Indigenous females of the East Arnhem region in comparison with the general population (national Australian rate):

- Age-adjusted incidence rate for Indigenous women: 31.1/100,000 [95% CI 13.1-49.1]
- Age-adjusted incidence rate for general Australian population during 1996-2001 (national rate): 0.4/100,000 [95% CI 0.4-0.5]

In addition, the incidence rate of vulvar intraepithelial neoplasia (VIN) was higher among Indigenous females of the East Arnhem region in comparison with Indigenous females living in other regions of the Top End (located in the Northern Territory). Among those 0-49 years of age, the following incidence rates of VIN were obtained:

- Age-adjusted incidence rate for Indigenous women of East Arnhem: 34.7/100,000 [95% CI 15.2-54.3]
- Age-adjusted incidence rate for Indigenous women in other regions of the Top End: 6.7/100,000 [95% CI 2.0-11.4]
- Age-adjusted incidence rate for non-Indigenous women of the Top End: 1.9/100,000 [95% CI 0.8-3.1]

The results indicate that a cluster of vulvar cancer and VIN exists among Indigenous women living in the East Arnhem district. The authors suggest various causes for these findings, such as, genetic susceptibility to HPV or high prevalence of high-risk HPV types among these women.

➤ *Luke, C., et al. "Benchmarking Epidemiological Characteristics of Cervical Cancer in Advance of Change in Screening Practice and Commencement of Vaccination." Australian and New Zealand Journal of Public Health 31.2 (2007): 149-54.*

The study authors examined 1977-2004 data from the South Australian Cancer Registry (death data was available from State records, the National Death Index, and cancer registries). Of 1,920 cases of invasive cervical cancer and 644 deaths identified during the 1977-2004 period, the authors found that the case fatality rate from cervical cancer in South Australia was 2.14 times higher among Aboriginal/Torres Strait Islanders compared to other women. This suggests that cervical cancer survival was lower among Indigenous females.

The following results are from the article:

Relative risks of case fatality from cervical cancer: South Australia, 1977-2003	
Race	Relative risk
Other (reference) (n=1,820)	1.00
Aboriginal/Torres Strait Islander (n=30)	2.14 [95% CI 1.17-3.92]

Relative ratios of glandular cancers to squamous cell carcinomas: invasive cervical cancers: South Australia, 1977-2004	
Race	Relative ratio
Other (reference) (n=1,620)	1.00
Aboriginal/Torres Strait Islander (n=30)	0.12 [95% CI 0.02-0.86]

- *Condon, J. R., et al. "Cancer in Indigenous Australians: A Review." *Cancer Causes and Control* 14.2 (2003): 109-21.*

Indigenous Australian populations have a higher incidence rate of cervical cancer in comparison to other Australians. These results were apparent in a review of the literature conducted by Condon et. al which examined cancer in Indigenous Australian populations. The following themes emerged:

- Indigenous Australians were more likely to die and less likely to survive a diagnosis with cancer than other Australians.
- Factors contributing to the higher mortality and lower survival among Indigenous Australians may include diagnosis of cancer at a later stage and poorer treatment of disease.
- Certain forms of cancer, such as cancer of the cervix, were more common among Indigenous women, a trend which has persisted across time.

Incidence of cervical cancer among indigenous women may be underreported due to problems with complete case ascertainment. Incomplete identification of cases as indigenous is likely and therefore, true incidence values may be higher than those reported in the literature.

- *O'Brien, E. D., R. S. Bailie, and P. L. Jelfs. "Cervical Cancer Mortality in Australia: Contrasting Risk by Aboriginality, Age and Rurality." *International journal of epidemiology* 29.5 (2000): 813-6.*

Death records, with cervical cancer as the primary cause of death, were retrieved from the Australian Institute of Health and Welfare, which collects data from death registers of South Australia, Western Australia and the Northern Territory; death records were used to examine

cervical cancer mortality in these three regions for the period 1986-1997. Population data were obtained from the Australian Bureau of Statistics.

During this period, a total of 727 deaths from cervical cancer occurred (76 Aboriginal and 651 non-Aboriginal deaths). The authors completed their analysis on 702 of the death records (73 Aboriginal and 629 non-Aboriginal deaths).

The following results were obtained:

Crude annual mortality rate (/100,000) of cervical cancer in Southern Australia, Western Australia and the Northern Territory, by place of residence and ethnicity: 1986-1997		
	Aboriginal females	Non-Aboriginal females
Metropolitan	6.4	3.8
Rural	11.6	3.0
Remote	14.9	1.4
Total, all areas	12.3	3.5

Aboriginal women who lived in metropolitan areas had a 4.3 times greater risk of death from cervical cancer compared to non-Aboriginal women; the risk of death increased for rural and remote areas:

- Standardized mortality ratio (SMR) for cervical cancer of Aboriginal vs. non-Aboriginal females living in metropolitan areas = 4.3
- SMR for cervical cancer of Aboriginal vs. non-Aboriginal females living in rural areas = 9.7
- SMR for cervical cancer of Aboriginal vs. non-Aboriginal females living in remote areas = 18.3

The mean age at death from cervical cancer for individuals living in metropolitan areas was 48.7 for Aboriginal women and 61.9 for non-Aboriginal women.

Aboriginal women living in rural or remote regions had approximately a two-fold greater risk of dying from cervical cancer compared to Aboriginal women living in metropolitan areas; the opposite trend is observed in non-Aboriginal women:

Standardized mortality ratios for cervical cancer in Southern Australia, Western Australia and the Northern Territory by place of residence and ethnicity: 1986-1997		
	Aboriginal females	Non-Aboriginal females
Metropolitan	1.0	1.0
Rural	1.7 [95% CI 0.90-3.3]	0.81 [95% CI 0.67-0.98]
Remote	2.1 [95% CI 1.6-2.8]	0.52 [95% CI 0.32-0.82]

These findings suggest that there are geographic disparities in cervical cancer mortality in Australia among Aboriginal women.

- *Bailie, R., et al. "Data for Diagnosis, Monitoring and Treatment in Indigenous Health: The Case of Cervical Cancer." Australian and New Zealand Journal of Public Health 22.3 (1998): 303-6.*

Bailie et. al reviewed published data on Indigenous populations of Australia, concluding that research among this population is insufficient and the quality of existing data is poor.

Research suggests that the incidence rate of cervical cancer is 2-5 times greater among Indigenous women than non-Indigenous women in Australia. In addition, the mortality rate from cervical cancer is 8-10 times greater among those of Indigenous origin. Furthermore, the recording of Indigenous status in various Australian databases may be inaccurate, leading to an underestimate of cases. Therefore the true incidence and mortality rates of Aboriginal and Torres Strait Islanders may be higher than those reported.

In reference to Indigenous populations, the quality of incidence and mortality data varies across Australian states, and information on screening participation is limited. The authors conclude that "consistent recording, transfer and reporting of information on Aboriginality" is needed.

- *Mak, D., and J. A. Y. Straton. "Effects and Sustainability of a Cervical Screening Program in Remote Aboriginal Australia." Australian and New Zealand Journal of Public Health 21.1 (1997): 67-70.*

Mak et. al used a population-based cervical cytology register to determine screening rates of Aboriginal females living in the Fitzroy Valley area, Western Australia. Aboriginal women residing in the Fitzroy Valley who underwent Pap smears between January 1, 1991 and December 31, 1992 and who were eligible to be on the Fitzroy Valley Pap Smear Register comprised the study sample. The cohort, consisting of 545 Aboriginal females ages 13-78 years, was followed from the date of the first/index Pap smear (the first date occurred between 1991-1992) until December 31, 1994. Mortality data was retrieved from the Fitzroy Crossing Community Health Services and the Western Australian Death Register. The following results were obtained (per 545 index smears):

- 88% of the Pap smears were considered normal
- 7.5% of the Pap smears presented 'mild atypia'
- Prevalence of CIN in the sample was 1.8% [95% CI 0.7-2.9]
- 1.8% [95% CI 0.7-2.9] of the women in the sample had HPV

The follow-up period of 545 females was 47 months: during this time, 65.3% or 356 women (out of 545) had a second Pap smear; 189 women did not have a second Pap smear (7 of these had died and 10 did not receive further invitations to participate).

The Pap Smear Register and Cervical Screening Programme of the Fitzroy Valley were established in 1989 and coordinated by the Community Medical Officer from July 1989 until February 1993. Following program establishment, an increase in the number of women undergoing cervical screening procedures was reported; however, participation declined following the departure of the coordinator in 1993.

CANADA

- *Louchini, R., and M. Beaupré. "Cancer Incidence and Mortality among Aboriginal People Living on Reserves and Northern Villages in Québec, 1988-2004." International journal of circumpolar health 67.5 (2008): 445-51.*

Data from the Quebec tumour and mortality files were used to determine the incidence and mortality of cancer for the Aboriginal population living on Indian reserves and in Northern villages of Quebec from the period 1988 to 2004. These data were compared with the incidence and mortality of the general Quebec population for the same time interval. Population estimates were retrieved from the Canadian Census. The following results were obtained:

- Age-standardized cervical cancer incidence rate of Aboriginal females: 17.0/100,000 [95% CI 11.9-22.1]. Age-standardized cervical cancer incidence rate of the Quebec general population: 6.7/100,000 [95% CI 6.5-6.9].
 - Age-standardized cervical cancer mortality rate of Aboriginal females: 6.3/100,000 [95% CI 3.0-9.6]. Age-standardized cervical cancer mortality rate of the Quebec general population: 1.6/100,000 [95% CI 1.5-1.7].
- *Healey, G. K., and L. M. Meadows. "Inuit Women's Health in Nunavut, Canada: A Review of the Literature." International journal of circumpolar health 66.3 (2007): 199-214.*

A MEDLINE review of the literature was conducted to determine the available research on the health of Inuit women in Nunavut and associated determinants of health. The literature suggested high rates of sexually transmitted infections such as Chlamydia among the Inuit female population as well as sexual and reproductive health-related issues such as premature delivery. There is a

paucity of data regarding the health and wellness of this population, and further research is needed to examine determinants of health among the Inuit.

- *First Nations Centre, National Aboriginal Health Organization. Cancer of the Cervix in North American Indian Women: A Literature Review., 2006. Print.*

A literature search was conducted for the ten year period prior to the review and 30 articles on cervical cancer rates, associated determinants and screening practices among Aboriginal females in Canada were retrieved. Results indicated that the incidence of cervical cancer is high among Aboriginal women. In addition, poor screening practices and inadequate follow-up of abnormalities detected during screening procedures contribute to high mortality rates among Aboriginal groups. Several reasons are provided for these findings including lack of awareness and discomfort regarding screening, fear of being diagnosed with cancer and associated psychological and financial burdens that entail following diagnosis. Culturally-sensitive interventions and health promotion strategies are recommended.

- *Marrett, L. D., and M. Chaudhry. "Cancer Incidence and Mortality in Ontario First Nations, 1968-1991 (Canada)." Cancer Causes and Control 14.3 (2003): 259-68.*

Indian and Northern Affairs Canada files were linked with the Ontario cancer registry and mortality files to determine the patterns in cancer incidence and mortality in a cohort of 141,290 Ontario First Nations people between 1968 and 1991. Cervical cancer was the second most common malignancy among First Nations women and the sixth most common among the general female population of Ontario. Although cervical cancer incidence declined significantly between 1968-1975 and 1984-1991, First Nations women continued to be disproportionately affected.

Compared to the general female population of Ontario, the age-standardized cervical cancer incidence was 1.73 times greater among the First Nations population during the 1968-1991 time period (RR=1.73, 95%CI 1.48-2.03].

- Age-standardized cervical cancer incidence rate of Ontario Status Indians: 20.12/100,000. Age-standardized cervical cancer incidence rate of the general provincial population: 11.60/100,000.

Compared to the general female population of Ontario, the age-standardized cervical cancer mortality was 2.03 times higher among the First Nations group during the 1968-1991 time period [RR=2.03, 95%CI 1.54-2.64].

- Age-standardized cervical cancer mortality rate of Ontario Status Indians: 7.38/100,000. Age-standardized cervical cancer mortality rate of the general provincial population: 3.63/100,000.

- *Healey, S. M., et al. "Oncogenic Human Papillomavirus Infection and Cervical Lesions in Aboriginal Women of Nunavut, Canada." Sexually transmitted diseases 28.12 (2001): 694-700.*

This study examined high-risk HPV types and SIL among pap-screened women in the Baffin and Keewatin regions of Nunavut. Liquid-based Thin-Prep cytology was used to detect low and high grade SIL and the Hybrid Capture II assay was used to test for HPV DNA. During the period from May 1 to December 31, 1999, 1,855 women presented for a Pap test and of these, 1,290 samples were adequate and retained for further testing and analysis. Of the 1,290 study participants aged 13-79 years, Inuit women constituted 86% of the sample.

The prevalence of high-risk HPV genotypes was 25.8% [95%CI 23.8-27.9] and the prevalence of squamous intraepithelial lesions (SIL), any grade, was 6.9% [95%CI 5.5-8.3]. HPV prevalence was highest among younger groups, particularly those under the age of 30, and declined thereafter. The following results are from the article:

Age-specific prevalence of oncogenic HPV and SIL by region and ethnicity							
		Inuit			Non-Inuit		
Region	Age group (years)	Subjects (n)	HPV*	SIL**	Subjects (n)	HPV*	SIL**
Baffin	13-20	100	43.0	11.0	3	66.7	0.0
	21-30	182	34.1	7.1	29	44.8	13.8
Keewatin	13-20	28	35.7	0.0	3	33.3	0.0
	21-30	74	29.7	12.2	11	27.3	9.1

* % of women with oncogenic HPV

** % of women with SIL

The odds for infection with HPV were highest for 13-20 year old females, lower for 20-30 year olds, and lowest for those over 30.

Females in the youngest age group also exhibited markedly higher HPV viral loads in comparison with those aged 20 years and older. A very high viral load, defined as relative light units (RLU) greater than 500, was present among 31% of HPV-positive females aged 20 and younger. The greater the HPV viral load, the stronger the association between SIL and the human papillomavirus

(for RLU > 500, the age-adjusted odds ratio for SIL was 152.52 [95% CI 62.3-373.4]). In this study, more than 90% of the women who received a SIL diagnosis also tested positive for HPV infection.

- *Young, T. K., et al. "Monitoring Disease Burden and Preventive Behavior with Data Linkage: Cervical Cancer among Aboriginal People in Manitoba, Canada." American Journal of Public Health 90.9 (2000): 1466-8.*

The Manitoba Cancer Registry was linked to the Manitoba Health Services Insurance Plan population registry to determine the incidence of invasive and in situ cervical cancer diagnosed in a cohort of Manitoba-resident females (First Nations vs. non-First Nations) during the 1984-1997 period.

Study findings indicated that Indigenous people had higher rates of both in situ and invasive cervical cancer in comparison with non-Indigenous people, and the risk of developing invasive cancer was substantially greater among the Indigenous group. The following results are from the article:

In situ cervical cancer:

- Age-standardized incidence rate of First Nations females from 1984-1997: 110.1/100,000. Age-standardized incidence rate of non-First Nations females from 1984-1997: 60.3/100,000.

Invasive cervical cancer:

- Age-standardized incidence rate of First Nations females from 1984-1997: 34.1/100,000. Age-standardized incidence rate of non-First Nations females from 1984-1997: 9.5/100,000.

Screening:

- 42.6% of First Nations women and 60.4% of non-First Nations females had one or more Pap tests during the 1993-1996 period.

- *Band, P. R., et al. "Rate of Death from Cervical Cancer among Native Indian Women in British Columbia." Canadian Medical Association journal 147.12 (1992): 1802-4.*

Death records on "Registered Indians" of federally recognized tribes were obtained from the British Columbia Division of Vital Statistics, and population figures were obtained from the Department of Indian and Northern Affairs, the British Columbia Division of Vital Statistics, and Statistics Canada.

The authors examined the rate of death from cancer of the cervix among native Indian women of British Columbia; this was compared to the death rate among non-native females (primarily comprised of Caucasian individuals) of the same region.

Among native Indian women, the relative rate of death from cervical cancer compared to non-native women has shown an increase across time periods and fluctuations across age groups. The relative rate (native:non-native ratio of age-standardized death rates) increased steadily from 3.56 in 1953-62 to 4.24 in 1963-72 and finally to 4.72 in 1973-84. Of particular interest is the sharp rise in the relative rate among females between the ages of 20 and 64 years: the relative rate increased from 3.83 in 1953-62 to 6.53 in 1973-84. On the other hand, women aged 65 and older experienced a decline in the rate, particularly from the period of 1953-62 to the period of 1963-72 (3.56 to 2.25); a slight increase occurred thereafter (2.86 in 1973-84). During the entire study period, no deaths were recorded in British Columbia for either native Indian or non-native Indian females under the age of 20.

Age-standardized death rate (/100,000) from cervical cancer (all ages): British Columbia, 1953-1984		
Time period	Registered native Indian women	Non-native women
1953-1962	42.27	11.88
1963-1972	40.53	9.56
1973-1984	26.12	5.53

CIRCUMPOLAR

- *Circumpolar Inuit Cancer Review Working Group, et al. "Cancer among the Circumpolar Inuit, 1989-2003. II. Patterns and Trends." International journal of circumpolar health 67.5 (2008): 408-20. Web.*

Regional cancer registries were used to identify cancer cases diagnosed during the 1989- 2003 period (2002 for Greenland) among the Inuit inhabiting Alaska, Canada, and Greenland. The following results were obtained:

Region	Age-standardized incidence rate (/100,000) for cancer of the cervix uteri among Inuit women
Alaska	8.2 [95% CI 4.9-11.5]
Canada	14.7 [95% CI 9.0-20.3]
Greenland	33.7 [95% CI 27.5-39.9]
Circumpolar	20.1 [95% CI 17.1-23.2]

The age-standardized incidence rates for cervical cancer have declined in Alaska, Canada and Greenland to less than half the rates which were seen during the 1970s and 1980s.

NEW ZEALAND

- *McKenzie F, Brewer N, Wong KC, Ellison-Loschmann L. "Monitoring Report 29: National Cervical Screening Programme January to June 2008." Print.*

The National Cervical Screening Program (NCSP) was initiated in 1990, it is coordinated by the National Screening Unit of the Ministry of Health, and its goal is to it diminish cervical cancer incidence and mortality rates among New Zealand-resident females (the success of the program is measured against national targets). The Register contains cytology and histology records of women participating in NCSP.

The National Screening Unit provided researchers at Massey University with records retrieved from the NCSP Register, and these were used to calculate screening rates among Maori, Pacific, and non-Maori/non-Pacific females. The study sample comprised 5,446 high-grade cytology cases (females ages 20-69 years) entered in the NCSP Register between July 1, 2006 and June 30, 2007. Results indicated that the proportion of women who obtained a histology specimen following a high grade cytology result varied by ethnicity. The following results are from the article:

Timeliness in histological follow-up among women with a high grade cytology result, by ethnicity						
Time period	Maori women		Pacific women		Non-Maori/non-Pacific women	
	n	Proportion (%)	n	Proportion (%)	n	Proportion (%)
Within 12 weeks ¹	507	65.3	126	62.4	3,406	76.2
13-26 weeks	105	13.5	23	11.4	430	9.6
27-52 ² weeks	58	7.5	26	12.9	193	4.3
More than 52 weeks	17	2.2	5	2.5	65	1.5
<i>Subtotal</i>	<i>687</i>		<i>180</i>		<i>4,094</i>	
No histology recorded on NCSP Register	89	11.5	22	10.9	374	8.4
<i>Total</i>	<i>776</i>		<i>202</i>		<i>4,468</i>	

"Difference between ethnic groups P<0.001"

Screening targets: ¹ 90% of females enrolled in NCSP should obtain histology specimen within 12 weeks of high grade smear result; ² 99% of females enrolled in NCSP should obtain histology specimen within 52 weeks of high grade smear result

➤ *Robson, B., D. Cormack, and G. Purdie. Unequal Impact: Maori and Non-Maori Cancer Statistics 1996-2001., 2006. Print.*

Data on cancer registrations and deaths recorded during the period of January 1, 1996 through to December 31, 2001 were retrieved from the New Zealand Health Information Service (NZHIS). Population estimates were obtained from Statistics New Zealand. Among Maori females, cervical cancer was the third most common cancer type and the fourth most common cause of cancer deaths. Among non-Maori females cervical cancer was the ninth most common cancer and noted as a rare cause of cancer deaths.

Some variation was noted by age group, with the highest incidence occurring among Maori females ages 45-64 years and among non-Maori females ages 65+. Further, Maori women were more

frequently diagnosed with distant stage cancer and more likely to die of it in comparison with their non-Maori counterparts. Over the time period, 1997-2000, the incidence rate for Maori women decreased by 21% whereas the rate among Non-Maori women remained relatively static.

The following results were reported:

Female cancer registrations: age-standardized rate per 100,000 and rate ratio (Maori/Non-Maori), 1996-2001			
Site	Maori rate	Non-Maori rate	Rate ratio
Cervix uteri	14.2	6.3	2.27 [95% CI 1.97-2.62]

Female cancer deaths: age-standardized rate per 100,000 and rate ratio (Maori/Non-Maori), 1996-2001			
Site	Maori rate	Non-Maori rate	Rate ratio
Cervix uteri	6.6	1.4	4.85 [95% CI 3.87-6.06]

➤ *Lewis, H. Achieving Equity in Cervical Screening. Print.*

The National Cervical Screening Programme was introduced in New Zealand in 1990 and a substantial decrease in cervical cancer incidence and mortality occurred thereafter as an increasing number of women began undergoing screening tests.

The following results are reported:

Age-standardized cervical cancer incidence rates (/100,000): 1996-2003			
Year	Maori	Pacific	Total population
1996	19.9	22.3	9.7
1997	18.9	15.8	8.4
1998	12.6	17.4	8.2
1999	16.0	5.2	9.1
2000	13.8	6.8	8.5
2001	11.8	9.1	7.9
2002	13.2	8.4	6.9
2003	10.6	12.9	7.0

"Source: NZHIS June 2006; data for 2003 provisional; ASR: rates per 100,000 age standardised to Segi's world population"

Age-standardized cervical cancer death rates (/100,000): 1996-2003			
Year	Maori	Pacific	Total population
1996	11.3	4.1	3.4
1997	8.0	1.6	2.8
1998	9.7	5.7	2.9
1999	9.7	9.6	2.7
2000	8.1	3.1	2.5
2001	6.1	1.2	2.1
2002	5.2	1.2	2.2
2003	3.1	4.8	1.8

“Source: NZHIS 2006; data for 2003 provisional; ASR: rates per 100,000 age standardised to Segi’s world population”

➤ *Cormack, D., et al. Access to Cancer Services for Maori., 2005. Print.*

Routinely collected data on cancer deaths and registrations in New Zealand from January 1, 1996 to December 31, 2001 were analysed. The following themes emerged:

- Cervical cancer occurred more frequently among the Maori than the non-Maori
- Survival from cervical cancer is poorer among the Maori than the non-Maori
- Stage of cervical cancer at diagnosis is less likely to be recorded in Maori cancer registrations than in those of non-Maori populations
- Maori are more likely than non-Maori groups to be diagnosed with cervical cancer at a later stage in the disease process
- 1996-2001: Among Maori females, 6.3% of all cancer registrations were for those of the cervix
- Among Maori females, 5.4% of all cancer deaths were those of the cervix
- Cervical cancer screening programs are not reaching Maori women adequately or equitably

The following results were reported:

Cervical cancer registrations and deaths for 1996-2001 - age-standardized incidence and death rates (/100,000)				
	Registrations		Deaths	
	Maori	non-Maori	Maori	non-Maori
	14.2	6.3	6.6	1.4

POLYNESIA

- *Dachs, G. U., et al. "Cancer Disparities in Indigenous Polynesian Populations: Māori, Native Hawaiians, and Pacific People." *The Lancet Oncology* 9.5 (2008): 473-84.*

Polynesia comprises New Zealand, Hawaii, and the Pacific islands. The trends in cancer (i.e. cervical cancer) incidence, mortality, and survival among Indigenous Polynesian populations vary and are different from the numerically dominant populations of those regions (usually of European origin). Research on Indigenous populations of New Zealand and Hawaii is available. Nevertheless, cancer data is rather limited for people of the Polynesian Pacific islands, and there is a paucity of research regarding cancer survival in numerous groups of the Polynesian islands. The same lack of information with respect to screening, stage of disease, treatment (by ethnicity), and outcome is observed. In addition, the undercounting of Indigenous cases presents significant challenges.

UNITED STATES

- *Day, G. E., et al. "Cancers of the Breast, Uterus, Ovary and Cervix among Alaska Native Women, 1974-2003." *International journal of circumpolar health* 69.1 (2010): 72-86. Web.*

Alaska Native Tumour Registry (ANTR) data from 1974-2003 were used to calculate the incidence of various cancer types. Since 2001, ANTR has been included as a SEER (Surveillance, Epidemiology and End Results Program of the National Cancer Institute, US) registry. Data for Alaska Native women were compared to data on American white women retrieved from SEER data files.

Cancer incidence ranking:

- 1974-1983: cancer of the cervix uteri ranked 3rd among Alaska Native women and 7th among U.S. white women
- 1999-2003: cancer of the cervix uteri ranked 9th among Alaska Native women and 13th among U.S. white women

The following results are from the article:

Age-adjusted incidence rates (/100,000) and rate ratios for invasive cervical cancer			
Year of diagnosis	Alaska Native women	U.S. white women	Rate ratio
1974-78	30.5	9.8	3.11 [95% CI 2.11-4.60]
1979-83	31.1	7.9	3.95 [95% CI 2.87-5.43]
1984-88	17.7	7.5	2.38 [95% CI 1.63-3.48]
1989-93	14.7	7.6	1.92 [95% CI 1.32-2.80]
1994-98	5.0	6.8	0.74 [95% CI 0.41-1.32]
1999-03	6.4	5.8	1.12 [95% CI 0.70-1.79]

- *Mahoney, M. C., et al. "Fifty Years of Cancer in an American Indian Population." *Cancer* 115.2 (2009): 419-27. Web.*

A retrospective cohort study was undertaken to determine cancer incidence among the Seneca Nation of Indians (SNI) of the New York State, United States from January 1, 1955 to December 31, 2004. "Tribal roll book listings" were used to identify registered tribal members and a match with the New York State Cancer Registry data files was conducted to determine incident cases of cancer in this population. A dynamic cohort was utilized, accounting for births and deaths. The cohort was comprised of 3935 males and 4193 females.

During the study period, 233 primary malignancies were detected in males and 256 malignancies in females. Cervical cancer had been diagnosed in 19 women (7%).

- Standardized incidence ratio for cervical cancer among SNI females during the 1995-2004 time interval was 162 [95% CI 98-254]

- *Mahoney, M. C., et al. "Changes in Cancer Incidence Patterns among a Northeastern American Indian Population: 1955-1969 Versus 1990-2004." *The Journal of rural health: official journal of the American Rural Health Association and the National Rural Health Care Association* 25.4 (2009): 378-83. Web.*

A retrospective cohort study was undertaken to determine cancer incidence among the Seneca Nation of Indians (SNI) of the New York State, United States during the period 1955-1969 and 1990-2004. "Tribal roll book listings" were used to identify registered tribal members and a match with the New York State Cancer Registry records was conducted to determine incident cases of cancer in this population. The period from 1970 through 1980s was excluded, during which time shifts in medical facilities on reservations were occurring.

A dynamic cohort was used to account for births and deaths, with a total of 54,473 person-years from 1955-1969 and 83,266 person-years from 1990-2004. The following results were reported:

- SIR for cervical cancer among SNI females during the 1955-1969 time interval was 201 [95% CI 87-397]
- SIR for cervical cancer among SNI females during the 1990-2004 time interval was 115 [95% CI 31-295]

➤ *Wiggins, C. L., et al. "Cancer among American Indians and Alaska Natives in the United States, 1999-2004." *Cancer* 113.5 Suppl (2008): 1142-52. Web.*

Data were retrieved from U.S. population-based cancer registries that are part of the Surveillance, Epidemiology and End Results (SEER) Program and/or the National Program of Cancer Registries (NPCR). Cancer registry records were linked with Indian Health Service data files to determine the number of incident cancer cases that occurred among American Indians and Alaska Natives (AI/AN) and non-Hispanic whites (NHW) during the time period 1999-2004. Incidence rates were calculated for those living in American counties, CHSDA counties, and Indian Health Service regions. Population estimates were obtained from the U.S. Bureau of the Census.

The following results were reported:

CHSDA counties:

- The age-standardized incidence rate of cancer of the cervix uteri for AI/AN females from 1999-2004 was 9.4/100,000
- The age-standardized incidence rate of cancer of the cervix uteri for NHW females from 1999-2004 was 7.4/100,000
- AI/AN:NHW rate ratio was 1.28 [95% CI 1.15-1.42]

All counties:

- The age-standardized incidence rate of cancer of the cervix uteri for AI/AN females from 1999-2004 was 6.9/100,000

- The age-standardized incidence rate of cancer of the cervix uteri for NHW females from 1999-2004 was 7.7/100,000
- AI/AN:NHW rate ratio was 0.90 [95% CI 0.82-0.99]

IHS regions:

- Rate ratios (AI/AN:NHW) varied by region with significant results for the Northern Plains (RR 1.69), Southern Plains (RR 1.54), and all regions combined (RR 1.28).

➤ *Becker, T. M., et al. "Regional Differences in Cervical Cancer Incidence among American Indians and Alaska Natives, 1999-2004." Cancer 113.5 SUPPL. (2008): 1234-43.*

Becker et. al determined the incidence of cervical cancer among American Indians (AI) and Alaska Natives (AN) of federally recognized tribes living in Contract Health Service Delivery Area (CHSDA) counties. The study authors linked cancer registry data with Indian Health Service (IHS) data to analyse trends from the period 1999 through 2004. The following table compares the cervical cancer incidence among American Indian and Alaska Native people with non-Hispanic white (NHW) people, by Indian Health Service regions:

Age-adjusted cervical cancer incidence rates (/100,000) for AI/AN and NHW, by IHS region		
	CHSDA Counties	
Indian Health Service Region	AI/AN women	Non-Hispanic white women
Northern Plains	12.5 [95% CI 9.6-16.1]	7.4
Alaska	8.4 [95% CI 5.1-13.2]	6.2
Southern Plains	14.1 [95% CI 11.6-16.9]	9.1
Pacific Coast	6.9 [95% CI 5.2-8.9]	7.0
East	7.1 [95% CI 3.9-11.8]	7.3
Southwest	7.8 [95% CI 6.2-9.6]	7.3
Total	9.4 [95% CI 8.5-10.4]	7.4

The incidence rate of cervical cancer among American Indian and Alaska Native populations of all regions combined was 9.4/100,000, whereas the incidence rate among non-Hispanic white women was substantially lower at 7.4/100,000.

Further, the study indicated that the age distribution in AI/AN women was different than that in NHW women:

- The incidence rate of invasive cervical cancer in NHW was highest among those ages 30-49 years [6.3/100,000, 95% CI 6.1-6.5].
- The incidence rate of invasive cervical cancer in AI/AN was highest among those ages 65+ years [10.0/100,000, 95%CI 7.6-13.0].
- Disparities in the incidence rates of invasive cervical cancer between the two populations increased with age.

The mean age at diagnosis for AI/AN and NWH females was 47.3 and 50.1 years, respectively. The stage of disease at diagnosis also differed between these two groups: American Indian and Alaskan Native women were more likely to be diagnosed with regional and distant stage cervical cancer than non-Hispanic white women.

➤ *Espey, D. K., et al. "Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives." Cancer 110.10 (2007): 2119-52. Web.*

Data from the U.S. National Cancer Institute, the Centers for Disease Control and Prevention National Program of Cancer Registries and National Vital Statistics System, the American Cancer Society and the North American Association of Central Cancer Registries were used to determine the status of cancer among American Indians/Alaska Natives (AI/AN), non-Hispanic Whites (NHW) and other ethnicities from 1975-2004. In order to reduce misclassification of AI/AN, medical records from cancer registries were linked with the Indian Health Service patient registration database; this linkage was conducted for cases diagnosed between 1995 and 2004. Data from the U.S. Census Bureau and the Behavioral Risk Factor Surveillance System were used to determine screening rates by geographic region and ethnicity.

The following results were reported:

Cancer of the cervix uteri: Age-adjusted incidence rate per 100,000 and rate ratios by Indian Health Service Region and Contract Health Service Delivery Area (CHSDA) Counties in the U.S., 1999-2004			
	American Indian/Alaska Native Rate	Non-Hispanic White Rate	Rate ratio
U.S. CHSDA counties	9.4	7.5	1.25 [95% CI 1.11-1.39]
Northern plains	11.3	7.5	1.50 [95% CI 1.07-2.06]
Alaska	9.2	6	1.52 [95% CI 0.88-2.51]

Southern plains	14.1	9.2	1.53 [95% CI 1.25-1.86]
Pacific coast	6.9	7	0.98 [95% CI 0.74-1.27]
East	8.2	7.7	1.07 [95% CI 0.62-1.71]
Southwest	7.9	7.5	1.06 [95% CI 0.83-1.33]

Death rates per 100,000 for 2000-2004 and fixed-interval trends for 1995-2004 for cancer of the cervix uteri							
All races/ethnicities	White	Black	American Indian/Alaska Native	AI/AN	AI/AN (CHSDA counties)	Hispanic	Non-Hispanic
2.6	2.3	4.9	2.4	2.7	4.0	3.3	2.5

Results further indicated that American Indian/Alaska Native women were less frequently diagnosed with localized cervical cancer in comparison with Non-Hispanic White women. Further, proportionally less American Indian/Alaska Native women (82.4%; 95% CI 80.1-84.5) over 18 years of age had completed a pap test within the last three years compared to Non-Hispanic white women (86.4%; 95% CI 86.2-86.6).

- *Benard, V. B., et al. "Race-Specific Results of Papanicolaou Testing and the Rate of Cervical Neoplasia in the National Breast and Cervical Cancer Early Detection Program, 1991-1998 (United States)." *Cancer Causes and Control* 12.1 (2001): 61-8.*

The cervical screening and biopsy results of women who participated in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) were analysed and stratified by ethnicity. The study authors examined results of 628,085 females enrolled in NBCCEDP who underwent screening procedures between July 1991 and March 1998; 'first program screens' refer to the first round of screening that occurred during this time period.

Findings indicate that 69.6% of all females in the sample had a Pap test prior to study entry (the same was true for 47.6% of the 50,368 American Indian or Alaska Native women who participated in the study). For first program and subsequent screens during the 1991-1998 period, the following results were obtained:

Proportions that had abnormal Pap test results of LSIL, HSIL, and squamous cell cancer, by ethnicity (results are age-adjusted)		
Ethnicity	First screening round (%)	Subsequent screening rounds (%)
American Indian or Alaska Natives	4.4 [95% CI 4.2-4.6]	4.1 [95% CI 3.9-4.4]
Blacks	3.2 [95% CI 3.0-3.3]	2.7 [95% CI 2.4-2.9]
Whites	3.0 [95% CI 2.9-3.0]	2.2 [95% CI 2.1-2.3]
Hispanics	2.7 [95% CI 2.6-2.8]	2.1 [95% CI 1.9-2.2]
Asians or Pacific Islanders	1.9 [95% CI 1.6-2.1]	1.8 [95% CI 1.3-2.3]

Following the first program screens, 24,188 females with normal and abnormal Pap tests had a diagnostic evaluation.

For first program and subsequent screens during the 1991-1998 period, the following results were further reported:

Age-adjusted biopsy detection rates (/1000 Pap tests) of high-grade lesions (biopsy results of CIN II, CIN III, CIS, or invasive cancer), by ethnicity		
Ethnicity	First screening round	Subsequent screening rounds
American Indian or Alaska Natives	6.7 [95%CI 5.9-7.4]	4.2 [95%CI 3.5-4.9]
Blacks	7.1 [95%CI 6.5-7.7]	4.0 [95%CI 3.1-4.9]
Whites	9.9 [95%CI 9.5-10.2]	5.6 [95%CI 5.1-6.0]
Hispanics	7.6 [95%CI 7.1-8.0]	3.8 [95%CI 3.3-4.3]
Asians or Pacific Islanders	5.4 [95%CI 4.2-6.6]	1.9 [95%CI 0.9-3.0]

Of the 628,085 women who had a pap test during the 1991-1998 period, 50,368 were American Indian or Alaska native, 329,557 were white, 90,844 were black, 18,055 were Asian or Pacific Islander, and 128,616 were Hispanic.

- Schiff, M., et al. "Contraceptive and Reproductive Risk Factors for Cervical Intraepithelial Neoplasia in American Indian Women." *International journal of epidemiology* 29.6 (2000): 983-98.

Schiff et. al did a case-control study of 628 American Indian women ages 18-45 to determine contraceptive and reproductive risk factors for the development of cervical intraepithelial neoplasia (CIN). The cases and controls were enrolled through New Mexico Indian Health Service facilities, and recruitment occurred from November 1994 to October 1997. The cases consisted of females diagnosed with CIN I, II, or III and were recruited from colposcopy clinics. The controls were women with a normal cervical epithelium and documented normal Pap tests. PCR was used to detect HPV DNA. The following risk factors were significantly associated with CIN II/III in American Indian females:

- HPV DNA
- Annual family income < US\$10,000 / year
- vaginal deliveries ≥ 3
- Infertility and past infection with STD

Past/current use of an intrauterine device was associated with CIN II/III.

Infection with HPV was found to be a strong risk factor for the development of cervical intraepithelial neoplasia.

- Of 326 controls, 99 females were positive for HPV
- Of 190 women with CIN I, 111 females were positive for HPV
- Of 112 women with CIN II/III, 87 females were positive for HPV

- Schiff, M., et al. "Risk Factors for Cervical Intraepithelial Neoplasia in Southwestern American Indian Women." *American Journal of Epidemiology* 152.8 (2000): 716-26.

Schiff et. al did a case-control study of southwestern American Indian women to determine risk factors for CIN. Cases consisted of 190 females with CIN I, 70 females with CIN II, and 42 females with CIN III, while controls consisted of 326 women with normal cervical epithelium and documented normal Pap tests. The participants were recruited from Indian Health Service clinics and hospitals in the United States. Tests for various STIs, such as gonorrhea, Chlamydia, *Treponema pallidum*, herpes simplex, hepatitis B and C, and HPV (PCR-based test) were performed, and a brief history on sexual health and tobacco consumption was obtained from the participants. The following risk factors were significantly associated with CIN II/III:

- Infection with HPV of any type

- Infection with HPV 16
- Low annual income, particularly if less than \$10,000 / year
- Past STI infection

➤ *Baquet, C. R. "Native Americans' Cancer Rates in Comparison with Other Peoples of Color." *Cancer* 78.7 Suppl (1996): 1538-44. Web.*

The term 'Native Americans' refers to American Indians, Alaska Natives, Native Hawaiians, and American Samoans. Age-adjusted incidence and mortality data from 1977-1983 and survival data from 1975-1984 are presented.

- Cervical cancer incidence rates for females, 1977-1983:

New Mexico/Arizona SEER data – age adjusted incidence rate (/100,000)		
American Indians	African Americans	Caucasians
20.5	19.5	8.6

Data provided by Dr. Lanier and colleagues, Alaska Area Native Medical Centre – age adjusted incidence rate (/100,000)		
Alaska Natives	African Americans	Caucasians
28.0	19.5	8.6

Hawaii SEER data –age adjusted incidence rate (/100,000)		
Native Hawaiians	African Americans	Caucasians
15.2	19.5	8.6

- Age-adjusted cervical cancer mortality rates for females, 1977-1983:

American Indian mortality data (/100,000)*		
American Indians	African Americans	Caucasians
5.5	8.7	3.2

* Source US National Cancer Centre for Health Statistics/Bureau of Census.

Alaska Native mortality data (/100,000)*		
Alaska Natives	African Americans	Caucasians
12.5	8.7	3.2

* Source Dr. Lanier and colleagues, Alaska Area Native Medical Centre

Native Hawaiian mortality data (/100,000)*		
Native Hawaiians	African Americans	Caucasians
5.6	8.7	3.2

* Source US National Cancer Centre for Health Statistics/Bureau of Census.

- SEER 5-year relative survival data for females, 1975-1984: Cervical cancer data not provided.

Literature reviews and consultations with health professionals revealed that data on American Samoans is limited. Available data suggests that cervical cancer is a problem in this community as incidence and mortality rates from invasive cervical cancer are high and screening rates are low. Culturally-appropriate intervention strategies are recommended.

1.2 HPV Infections

ARGENTINA

- *Tonon, S. A., et al. "Human Papillomavirus Type 16 Molecular Variants in Guarani Indian Women from Misiones, Argentina." International Journal of Infectious Diseases 11.1 (2007): 76-81.*

Guarani Indians, a tribal group in South America, have been fairly isolated from urban communities in the past and contact with the rest of the Argentinean peoples has been limited. In the last ten years, however, this has changed and economic factors have caused Guarani Indian males to seek work in rural surroundings and thus come into contact with Caucasians living in those areas. Indian males began having sexual relations with Caucasian Argentinean females leading to changes in their sexual health and disease patterns. An increase in sexually transmitted infections among Guarani Indian males was observed. The authors further noted that Guarani Indian women have their sexual debut at very young ages and screening is not a common practice in this population.

A cross-sectional study was conducted on a group of females ages 15-45 years screened for HPV infections and cervical disease (i.e. in situ carcinoma) from nine Indian communities located in Misiones, Argentina. Seventy HPV 16 DNA samples were retained for analysis. Of the 70 cervical specimens analysed, the following results were observed:

- 37 specimens had normal cytology
- 18 specimens had LGSIL
- 15 specimens had HGSIL

Further analysis of HPV 16 variants was conducted and the following prototypes were found:

- 51% were EP (European)
- 32% were E-350G
- 9% were Af1-a (African 1)
- 4% were E-6862C
- 3% were Af2-a
- 1% were AA-a (Asian American)

➤ *Picconi, M. A., et al. "Human Papillomavirus Type-16 Variants in Quechua Aboriginals from Argentina." Journal of medical virology 69.4 (2003): 546-52.*

Quechua Aboriginals, a semi-closed group of Indigenous people, are located in the Jujuy Province of Argentina. A cross-sectional study was conducted on a group of females from the Puna and Quebrada region. 271 cervical specimens were obtained and 106 tested positive for HPV 16. Of the 106 HPV-16 positive samples, the following results were observed:

- 33 LSIL cases
- 28 HSIL cases
- 9 invasive cervical cancer cases

AUSTRALIA

➤ *Bowden, F. J., et al. "Estimating the Prevalence of Trichomonas Vaginalis, Chlamydia Trachomatis, Neisseria Gonorrhoeae, and Human Papillomavirus Infection in Indigenous Women in Northern Australia." Sexually transmitted infections 75.6 (1999): 431-4.*

Bowden et. al used data from two community-based studies of 1090 Indigenous females ages 12-73 from the 'Top End' region of Australia, which includes Darwin, Katherine, and East Arnhem. HPV DNA testing was performed using PCR techniques and results demonstrated that the overall prevalence ("proportion of women infected") of cervical HPV infection was 0.42. When results were stratified by age the following was observed:

Proportion of females positive for HPV infection by age group	
Age group	Proportion of women with HPV
11-15	0.5 [95% CI 0.12-0.88]
16-20	0.62 [95% CI 0.47-0.76]
21-30	0.42 [95% CI 0.34-0.5]
31-40	0.41 [95% CI 0.3-0.53]
> 40	0.23 [95% CI 0.12-0.37]
All ages	0.42 [95% CI 0.37-0.48]

A decrease in the prevalence of infection among older age groups was observed. The study authors suggest that, although prevalence decreases with age, HPV infection is acquired at young ages.

BRAZIL

➤ Brito, E. B., S. J. Martins, and R. C. Menezes. "Human Papillomaviruses in Amerindian Women from Brazilian Amazonia." *Epidemiology and Infection* 128.3 (2002): 485-9.

Bruto et al. determined the HPV status of Parakana Amerindians of the Southeastern Brazilian Amazonia. Interviews were conducted with 79 female participants aged 10-73 years from the Parakana Amerindian tribe. Of the 79 participants, pap smears were done on 78 women and samples for HPV PCR testing were collected from 42. "Cytological signs of HPV infection were observed in 11 patients; 6 of these were probed for HPV infection".

- PCR-based tests indicated an overall HPV prevalence of 14.3%
- 3 Parakana women had high-risk HPV types:
 - 2 cases infected with HPV 16
 - 1 case of co-infection with HPV 16 and 58

In 1991, the first cervical cytology screening program was developed for Parakana Amerindians. Although this population is relatively isolated from the rest of society, sexually transmitted diseases

are existent among people of this tribe; therefore, health promotion activities, such as cervical cancer screening, are encouraged.

CANADA

- *Demers A, Shearer B, Dawood M, Severini A, Lotocki R, Kliewer EV, Stopera S, Jayaraman G, Wong T. "Distribution of Human Papillomavirus (HPV) Types, Screening History, and Risk Factors for Infection in Manitoba." Print.*

In October 2008, 642 Pap screened women ages 18+ were recruited from 53 clinics located in Manitoba. The women completed a questionnaire and PCR-based tests were used to detect HPV DNA. Of the recruited females, 592 were retained for participation in the study and comprised the final sample. Overall, 19.4% of the women were infected with HPV, and 8.3% had high-risk types. 19.7% of infections involved HPV 16. One of the risk factors for HPV infection was Aboriginal ethnicity. Aboriginal participants were more likely to have had cervical abnormalities in comparison with the rest of the study sample ($p=0.006$).

- *Hamlin-Douglas, L. K., et al. "Prevalence and Age Distribution of Human Papillomavirus Infection in a Population of Inuit Women in Nunavik, Quebec." *Cancer Epidemiology Biomarkers and Prevention* 17.11 (2008): 3141-9.*

This study examined the prevalence of HPV among Inuit females of Nunavik, Quebec. The sample consisted of 554 women ages 15 to 69 years, who were recruited between January 2002 and December 2007 from clinics of four communities. Pap smears were conducted and HPV DNA tests were performed using the PGMY-Line blot assay.

The overall prevalence of HPV infection in the sample was 28.9%. Thirty-two types were detected in the cervical specimens – the most frequently occurring genotypes were HPV 16 (5.6%), HPV 31 (3.6%), HPV 61 (3.6%), and HPV 84 (3.1%). 25% of all HPV infections were caused by HPV 16 or 18. Other common high-risk types identified were HPV 58 (2.7%) and HPV 52 (2.3%). HPV 11 was not detected in this population. Other common low-risk types identified were HPV 62 (2.9%) and HPV 67 (2.2%).

Among 523 women with baseline cytology, 6.5% had an abnormal Pap smear result, such as ASCUS, LSIL or HSIL. Among the women with normal cytology, HPV prevalence was found to be 25.4%; if the cytology result was LSIL or HSIL, HPV prevalence was 94.1%; and if the result was ASCUS, HPV

prevalence was 64.7%. Specimens classified as low-grade and high-grade commonly involved HPV 16, HPV 31, and HPV 58.

- *Toffolon-Weiss, M., et al. "Alaska Native Parental Attitudes on Cervical Cancer, HPV and the HPV Vaccine." International journal of circumpolar health 67.4 (2008): 363-73.*

The study was undertaken using a convenience sample of male and female Alaska Native parents ages 21 years and older and who resided in hub (n=23), urban (n=24), and village (32) communities. A hub community was identified as "a commercial, medical, educational and transportation" center for nearby villages. The entire sample was comprised of Alaska Native parents/guardians who had children between the ages of 9 and 18 years. The parents participated in 11 qualitative focus groups (Jan-Mar 2007) and completed quantitative surveys. The scope of the study was to assess parental knowledge and attitudes towards HPV, the HPV vaccine, and cervical cancer.

Quantitative survey results:

Of the participants, 70% were aware that the Pap test is useful in screening for cervical cancer and 56% knew that a vaccine against HPV is available. Many parents were unaware of the link between infection with HPV and subsequent development of cervical cancer. 74% of the parents living in hub communities, 63% of parents residing in urban communities, and 36% of parents living in villages were aware of the HPV transmission mechanisms. 38% of urban and hub-based parents and 6% of village-based parents knew that HPV is also a risk factor for genital warts.

Qualitative focus group results:

The participants did not express concern about the vaccine promoting or condoning sexual behaviour in their children. Parents were more likely to accept the vaccine if they believed it would have a protective health effect, especially as their daughters grew older and would become sexually active and thus susceptible to STI. Parents who had less favourable attitudes towards HPV immunization expressed concern about the lack of research conducted on the side effects of the vaccine. Nevertheless, the majority of the parents had a positive attitude towards the HPV vaccine. Of interest is that parents of hub communities possessed greater knowledge regarding HPV, the vaccine, and cervical cancer than parents of urban and village communities.

- *Ogilvie, G. S., et al. "Parental Intention to have Daughters Receive the Human Papillomavirus Vaccine." Canadian Medical Association journal 177.12 (2007): 1506-12.*

In the context of the potential implementation of an HPV vaccine program targeting grade 6 schoolgirls, a national survey was undertaken to assess parental knowledge and attitudes towards HPV immunization. From June 2006 to March 2007, 2083 male and female parents aged 19+ years, living in Canada, and who had children between the ages of 8 and 18 years were recruited into the study using random-digit dialling methods (these participants completed the study survey). Of 1350 parents with female children, 73.8% [95% CI 71.5-76.1] were considering vaccinating their daughters against HPV. Intention to vaccinate was analysed by region and the following results were reported:

- 82.6% [95% CI 80.6-84.6] of the parents in Atlantic Canada and 62.8% [95% CI 60.2-65.4] of those in British Columbia/Yukon Territory intended to vaccinate their daughters.

Several factors were associated with parental intention to vaccinate; however, the strongest predictor was having a positive attitude towards immunizations. Parental decision to vaccinate was not influenced by cultural and religious background/beliefs.

- *Young, T. K., P. McNicol, and J. Beauvais. "Factors Associated with Human Papillomavirus Infection Detected by Polymerase Chain Reaction among Urban Canadian Aboriginal and Non-Aboriginal Women." Sexually transmitted diseases 24.5 (1997): 293-8.*

During the period from November 1992 to March 1995, 1,696 females living in Winnipeg who requested/were recommended to undergo a Pap test were recruited from a community health centre offering primary care. The study design was cross-sectional. Demographic, behavioural, sexual/reproductive health information was collected through interviews; and HPV, Chlamydia and gonorrhoea infections were detected through laboratory tests. Of the 1,696 women recruited, 1,477 completed the study questionnaire and were retained for further testing and analysis; 42% of the women in the final study sample (n=1,477) were of Aboriginal origin and 73% were younger than 30 years.

14% of the specimens were inadequate and could not be tested for HPV; of the 1,263 specimens considered adequate, 33% were HPV DNA positive. There was no significant difference in HPV prevalence by ethnicity (Aboriginal/non-Aboriginal). The following results were further reported:

- Among Aboriginal females, HPV 18 was the most frequently occurring genotype with a prevalence of 15%. Among non-Aboriginal females, HPV 16 was the most common genotype with a prevalence of 13%.

- Several factors were associated with HPV positivity such as “number of lifetime sexual partners.”
- Aboriginal women with 20+ lifetime sexual partners were compared with Aboriginal women who had ≥ 1 sexual partners, and the following odds ratio for HPV infection was reported: 1.90 [95% CI 1.66-2.17]. Non-Aboriginal women with 20+ lifetime sexual partners were compared with non-Aboriginal women who had ≥ 1 sexual partners, and the following odds ratio for HPV infection was observed: 1.54 [95% CI 1.36-1.73].

➤ *Pearce, W. G., et al. "Conjunctival Papillomas in Northern Canadian Natives." Canadian Medical Association journal 112.12 (1975): 1423-7.*

Pearce et. al retrieved conjunctival papilloma records from the pathology departments of Edmonton hospitals (that received Indian and Inuit cases from northern Alberta and the Mackenzie and Inuvik regions of the Northwest Territories) as well as records of non-native cases from Edmonton hospitals. Hospitals that received conjunctival papilloma cases included the Royal Alexandra, Misericordia, Edmonton General, University of Alberta, and Charles Camshell. Compared to non-native individuals, tumours were more common among Inuit of the Western Arctic. The following estimations are provided by the authors:

Conjunctival papilloma incidence rates by ethnicity:

Number of conjunctival papilloma cases, incidence per year, and incidence per 100,000 population, for non-native, Indian, and Inuit people				
Race	Number of cases	Population	Incidence/year	Incidence / 100,000 population
Non-native	8	630,000	1.20	0.19
Indian*	2	59,000	0.50	0.85
Inuit**	5	6,000	1.20	20.00

* Indian cases: 1 female age 14 years from Rivière Qui Barre examined on September 22, 1971; 1 female age 42 years from Edmonton examined on November 15, 1972

** Inuit cases: 1 female age 11 years from Cambridge Bay examined on March 10, 1973; 1 female age 25 years from Aklavik examined on March 31, 1973; 1 female age 9 years from Inuvik examined on December 19, 1973; 1 male age 12 years from Inuvik examined on March 25, 1974; 1 female age 42 years from Cambridge Bay examined on November 25, 1974.

CIRCUMPOLAR

- *Sebbelov, A. M., et al. "Comparison of Human Papillomavirus Genotypes in Archival Cervical Cancer Specimens from Alaska Natives, Greenland Natives and Danish Caucasians." *Microbes and Infection* 2.2 (2000): 121-6.*

The computerized pathology register of the University Hospital of Copenhagen was used to identify cases of cervical cancer from 1983 to 1987. 34 cases of squamous cell carcinoma diagnosed in Greenland natives and 36 cases of squamous cell carcinoma diagnosed in Danish Caucasians were selected. The mean age at diagnosis for Greenland natives was 44.1 years (range of 23 to 79 years), and that of Danish Caucasians was 47.4 years (range of 20 to 81 years).

32 cases of squamous cell carcinoma diagnosed in Greenland natives were retained for further analysis. Of these, 27 were positive for HPV. Of the HPV positive cases, 96.3% involved HPV 16, and 3.7% involved HPV 31 or 33.

34 cases of squamous cell carcinoma diagnosed in Danish Caucasians were retained for further analysis. Of these, 29 were positive for HPV. Of the HPV positive cases, 82.8% involved HPV 16, and 6.9% involved HPV 33.

From the period 1980-1989, 65 cases of invasive cervical cancer were diagnosed in the Alaska Native population. The US population-based registry of Alaska Native people was used to identify 54 cases of squamous-cell carcinoma. Of these, 52 involved HPV DNA. The order of genotype prevalence was: HPV 16 (78.8%), HPV 33 (30.8%), HPV 31 (21.2%), and HPV 18 (3.8%). Multiple HPV types were present in this population, and were observed to be more common in Alaska Native people than Greenland Natives and Danish Caucasians. Among the Alaska Native population, individuals classified as 'Eskimos' were more likely to exhibit infection with multiple types than those classified as 'Indians' and 'Aleuts'.

NEW ZEALAND

- *HPV Project Team, New Zealand Ministry of Health. "The HPV (Human Papillomavirus) Immunization Programme – National Implementation Strategic Overview." 2008. Print.*

The HPV Project Team of the Population Health Directorate (New Zealand Ministry of Health) prepared this document in an effort to inform individuals about New Zealand's HPV Immunisation Programme as well as those potentially involved in the planning, implementation, and delivery of

the proposed program. Information on program development and implementation was provided as part of the program description. A brief literature review on cervical cancer and ethnic disparities in disease burden provided context for the proposed program. The authors stated that Maori women were two times more likely to develop cervical cancer than non-Maori women. Further, Maori females were three times more likely to die from this malignancy than non-Maori females. The authors noted that Maori populations have a very high risk of developing cervical cancer, have the lowest immunization rates in the country, and live in deprived areas. The authors stressed that efforts to implement an "equitable immunisation program" are needed.

UNITED STATES

- *Bell, M. C., et al. "There is a High Prevalence of Human Papillomavirus Infection in American Indian Women of the Northern Plains." *Gynecologic oncology* 107.2 (2007): 236-41.*

Cervical samples, collected over a 2.5 year period, were extracted from 287 American Indian women ages 18-75 years attending an outpatient clinic located on a Northern Plains American Indian Reservation. PCR-based tests were used to detect HPV DNA and the following results were reported:

- Among 287 females in the sample, 61 tested positive for HPV and of these, 25 had multiple type infections. Of the 61 HPV-positive women, 41 and 20 females had oncogenic and non-oncogenic genotypes, respectively.
- In the entire sample, HPV 16 and HPV 59 were the most prevalent types and were present in 13 and 8 women, respectively.
- In comparison with those over the age of 25, the incidence of HPV was significantly ($p < 0.005$) higher among younger patients, especially those under 24 years of age
 - 41% of the HPV positive females were under 24
- Women infected with oncogenic genotypes had significantly ($p = 0.001$) higher incidences of abnormal Pap test results such as ASCUS and LSIL/HSIL in comparison with women who were HPV-negative or who had non-oncogenic genotypes.
- No correlation ($p = 0.33$) was found between HPV positivity and season

- *Miller, B. A., et al. "Human Papillomavirus Type 16 DNA in Esophageal Carcinomas from Alaska Natives." *International Journal of Cancer* 71.2 (1997): 218-22.*

During the 1958-1988 period, 50 Alaska Native males and females ages 43-88 years were diagnosed with esophageal cancer. Of the 50 individuals, tumour samples from 32 patients with esophageal

squamous cell carcinoma (SCC) and 3 patients with esophageal adenocarcinoma (AC) were retained for further analysis.

Of the 35 cases, 22 SCC and 3 AC cases provided adequate specimens for PCR testing. The following results were reported:

- 10/22 esophageal SCC and 0/3 esophageal ACC cases contained HPV L1 DNA
- 8/14 males and 2/8 females with esophageal SCC were infected with HPV ($p=0.08$). The mean age of HPV-infected patients was 63.6 years.

VENEZUELA

- *Azocar, J., et al. "Prevalence of Cervical Dysplasia and HPV Infection According to Sexual Behavior." *International Journal of Cancer* 45.4 (1990): 622-5.*

Uterine cervical specimens were taken from a sample of 46 "monogamous" Indigenous females of Piaroa communities and 119 "non-monogamous" Venezuelan women with multiple sex partners. The study sample comprised 165 females who had been tested for HPV infection and cytological abnormalities.

Among the sample of Indigenous women of Piaroa communities, no abnormal cervical cytology was detected and there was no evidence of HPV infections. Of the "non-monogamous" females, 11% presented with carcinoma or cervical intraepithelial neoplasia and 8% were infected with HPV. The results may be explained by a cultural pattern of monogamy in Piaroa communities, and isolation from urban populations.

1.3 Cervical Cancer Screening

AUSTRALIA

- *Read, C. M., and D. J. Bateson. "Marrying Research, Clinical Practice and Cervical Screening in Australian Aboriginal Women in Western New South Wales, Australia." Rural and remote health 9.2 (2009): 1117.*

The scope of the Women, Human papillomavirus prevalence, Indigenous, Non indigenous, Urban, Rural Study (WHINURS) was to examine the HPV status of Aboriginal and non-Aboriginal women undergoing cervical screening in New South Wales, Australia. Study participants were recruited from clinics where cervical screening was performed. The Family Planning New South Wales (FPNSW) organization agreed to recruit Aboriginal and non-Aboriginal women to WHINURS. The aim of FPNSW was to enlist 200 non-Aboriginal females attending a clinic in southern Sydney; and 100 non-Aboriginal and 50 Aboriginal women attending the Dubbo clinic in western NWS (age range of participants: 18-40 years). This study reported strategies used to recruit Aboriginal women attending the FPNSW clinic at Dubbo.

Between January and December 2006, FPNSW managed to recruit only 1 Aboriginal female to WHINURS. The study protocol required the women who underwent Pap smears at the Dubbo clinic to be tested for HPV on the same day of Pap test; this was challenging as few Aboriginal women presented for screening. Thus, culturally appropriate strategies were devised to increase the participation of Aboriginal females, such as the employment of an 'Aboriginal community liaison worker'/ Aboriginal 'health promotion officer' who helped to promote FPNSW and WHINURS services to Aboriginal women; in addition, the flexibility of clinic schedules was increased, and Aboriginal women who agreed to take part in the study were provided with monetary compensation for travel and babysitting. Between January and April 2007, FPNSW managed to successfully recruit 41 Aboriginal women.

- *Binns, P. L., and J. R. Condon. "Participation in Cervical Screening by Indigenous Women in the Northern Territory: A Longitudinal Study." Medical Journal of Australia 185.9 (2006): 490-4.*

A retrospective study was undertaken to determine the biennial cervical screening participation among the female population of the Northern Territory, Australia between the period of January 1997 to December 2004. Women ages 20-69 years who had been Pap tested at least once during

the 1997-2004 time interval and who were listed in the Northern Territory Pap Smear Register were analysed. Results indicated that women residing in the Top End of Australia were less likely to be screened in comparison with those living in Central Australia, and females living in urban communities exhibited higher screening levels than those of rural/remote areas.

The following screening participation percentages of Indigenous women living in 9 rural/remote areas (where "Indigenous women comprise 70% or more of the total female population") of the Northern Territory were indirectly estimated:

- 1997-1998: 33.9% [95% CI, 32.6% - 35.2%] for Indigenous women versus 63.9% [95% CI, 63.8% - 63.9%] for the general Australian population
- 1999-2000: 44.0% [95% CI, 42.7% - 45.4%] for Indigenous women
- 2003-2004: in comparison with previous period, there was almost no increase in the participation rates of Indigenous people; screening rates for Indigenous groups were 18%-19% lower than those for the general Australian population.

Screening rates of all women (Aboriginal and non-Aboriginal) living in the Northern Territory:

- In comparison with national rates, screening rates of NT-resident females have recently been higher in Darwin and Alice Springs.
- Rural/remote regions report lower screening rates than the general Australian population.

➤ *Coory, M. D., et al. "Participation in Cervical Cancer Screening by Women in Rural and Remote Aboriginal and Torres Strait Islander Communities in Queensland." *Medical Journal of Australia* 177.10 (2002): 544-7.*

Data were retrieved from the Queensland Health Pap Smear Registry to determine the percentage of Aboriginal and Torres Strait Islander females ages 20-69 years (n=7795) who participated in cervical cancer screening during a two-year period, from March 1999 to February 2001. The study subjects resided in 13 Indigenous communities in Queensland, Australia. The age-standardized biennial cervical screening percentages (proportion of females who had been Pap tested at least once during the 1999-2001 period) were the following: 41.1% for females residing in Indigenous communities and 59.1% for women living in the rest of Queensland. The Indigenous:non-Indigenous risk ratio was 0.70 [95% CI 0.67-0.72]. Variation in screening participation across the 13 Indigenous communities ranged from 19.9% to 63.5%. Four communities had participation percentages over 50%. In such communities, cervical screening was included as part of primary health care, practitioners received adequate training, and local databases were properly maintained. Indigenous communities with lower screening percentages did not exhibit such characteristics.

CANADA

➤ *Assembly of First Nations. Access to Cancer Screening and First Nations. 2009. Print.*

To determine access, participation, and barriers (i.e. sociocultural, logistical) in accessing cancer screening programs for cervical, breast and colorectal cancers among First Nations people in Canada the peer-reviewed and grey literature was examined. As well, interviews were conducted with individuals coordinating and involved in screening programs at all levels as well as health workers in First Nations communities. In general, the incidence of cancer is increasing and survival is poor among First Nations populations. Reasons for this include later stage at diagnosis and lower rates of participation in screening programs in comparison with the general Canadian population.

However, since 2000 cervical cancer incidence among First Nations populations in Ontario, Nunavut and the North-West Territories (regions in which significant proportions of the female population are Aboriginal) appears to be decreasing. Although rates among these population groups appear to be decreasing, the incidence of cervical cancer has historically been greater among Aboriginal women compared to non-Aboriginal women in Canada. Literature on American and Australian indigenous populations has noted similar trends. With the current data it cannot be demonstrated whether this is an accurate picture of all Aboriginal women in Canada and representative of all regions.

➤ *O'Brien, B. A., J. Mill, and T. Wilson. "Cervical Screening in Canadian First Nation Cree Women." Journal of transcultural nursing : official journal of the Transcultural Nursing Society / Transcultural Nursing Society 20.1 (2009): 83-92. Web.*

The study used focused ethnography to determine beliefs and attitudes towards cervical cancer as well as screening among First Nation Cree females living in a rural reserve community in Canada. Data was collected for 8 First Nations Cree women using in-depth interviews and participant observation undertaken by a First Nations community health representative. Of the participants, 3 women had cervical cancer and the remaining five had at least one previous Pap test completed. The following themes emerged:

- Support and encouragement are important in helping women deal with their fear of cancer and being diagnosed with this disease.
- There is utility in combining traditional and Western healing.

- First Nation Cree females are embarrassed about undergoing pelvic examinations and talking about their sexual health with health care providers; they preferred to be screened by a female health provider.

Study participants had positive attitudes towards the dissemination of information on cervical cancer and screening and the educating of First Nation Cree women on this issue.

- *Amankwah, E., E. Ngwakongnwi, and H. Quan. "Why Many Visible Minority Women in Canada do Not Participate in Cervical Cancer Screening." *Ethnicity & health* 14.4 (2009): 337-49. Web.*

Data from cycles 1.1 and 2.1 of the Canadian Community Health Survey (CCHS) was used to determine the Pap screening history of Canadian women ages 18-69 years. Among those who had not been Pap screened, the reasons for not having undergone screening were analysed using a logistic regression model. The study sample consisted of 76,214 individuals (women with hysterectomies were excluded). CCHS did not include women on Indian Reserves, Canadian Forces Bases, and in some remote areas.

The following results were reported:

"Percentage of different Canadian ethnic women who have never had a Pap test or have had one in different time periods, Canada"			
	Pap test		
	Never	≥ 3 years	< 3 years
Ethnicity	%	%	%
Caucasian	8.9	4.6	86.5
Aboriginal	10.5	4.2	85.3
Visible minority	19.2	3.9	76.9
Chinese	27.3	2.2	70.5
South Asian	22.4	3.4	74.1
Filipino	22.0	4.6	73.3
Other Asian	18.8	6.8	74.4
Black	7.7	3.8	88.5
Latin American	2.5	6.8	90.7

The women most likely to not have been Pap screened were visible minority women, particularly those who were recent immigrants. Common reasons cited for not having undergone this procedure included: lack of time and the belief that Pap screening is not necessary.

➤ *Assembly of First Nations. Access to Cancer Screening and First Nations. 2009. Print.*

To determine access, participation, and barriers (i.e. sociocultural, logistical) in accessing cancer screening programs for cervical, breast and colorectal cancers among First Nations people in Canada the peer-reviewed and grey literature was examined. As well, interviews were conducted with individuals coordinating and involved in screening programs at all levels as well as health workers in First Nations communities. In general, the incidence of cancer is increasing and survival is poor among First Nations populations. Reasons for this include later stage at diagnosis and lower rates of participation in screening programs in comparison with the general Canadian population.

However, since 2000 cervical cancer incidence among First Nations populations in Ontario, Nunavut and the North-West Territories (regions in which significant proportions of the female population are Aboriginal) appears to be decreasing. Although rates among these population groups appear to be decreasing, the incidence of cervical cancer has historically been greater among Aboriginal women compared to non-Aboriginal women in Canada. Literature on American and Australian indigenous populations has noted similar trends. With the current data it cannot be demonstrated whether this is an accurate picture of all Aboriginal women in Canada and representative of all regions.

➤ *Hislop, T. G., et al. "Cervical Cytology Screening: How can we Improve Rates among First Nations Women in Urban British Columbia?" Canadian Family Physician 42.SEP. (1996): 1701-8.*

The authors used band membership lists, Department of Indian Affairs files, Medical Service Plan files and the Cervical Cytology Screening Program (CCSP) registry to determine the rates of Pap smear screening among 3794 First Nations females of 27 bands located in various regions of British Columbia. Of the 3794 women, 1971 lived on reserves, 310 in Vancouver, and 1513 resided outside reserves elsewhere in the province. Women were identified as 'current participants' if they had a Pap test within the 1990-1992 period and as 'ever participants' if they ever had a Pap smear. Results were reported for 3120 ever participants and 2285 current participants:

Current participants:

- Age-standardized Pap screening rates for those living on reserves, in Vancouver, and elsewhere in BC were 62%, 62%, and 58%, respectively. Age-standardized Pap screening rates for the general B.C. population was 84%.

Ever participants:

- Age-standardized Pap screening rates for those living on reserves, in Vancouver, and elsewhere in BC were 84%, 81%, and 80%, respectively. Age-standardized Pap screening rates for the general B.C. population was not reported.

Semi-structured interviews were carried out with a purposive sample of 11 First Nations females ages 18-69 years, living in Vancouver to determine knowledge and attitudes towards the Pap smear; current and ever participants were included. The following themes emerged:

- The Pap test was not openly discussed and caused discomfort among First Nations females.

In order to improve screening rates among First Nations women, Pap tests should be performed by female physicians and more information on Pap smears should be disseminated.

- *McDonald, J. T., and R. Trenholm. "Cancer-Related Health Behaviours and Health Service use among Inuit and Other Residents of Canada's North." *Social science & medicine* (1982) 70.9 (2010): 1396-403. Web.*

McDonald et. al analysed the influence of demographic, socioeconomic and geographic factors on health behaviours and the use of screening services among Inuit, First Nations, Métis, and non-Aboriginal people ages 21-65 living in Nunavut, the Northwest Territories, Labrador, Nunavik and Jamesie, northern Saskatchewan, and northern Manitoba. The Canadian Community Health Survey (2000-2001 and 2004-2005) and the Aboriginal Peoples Survey (2001) were used to determine cancer related health behaviours and the use of health services.

CCHS 2000-2001 and 2004-2005 data (sample size: 921 Inuit, 784 Métis, 954 First Nations, and 9634 non-Aboriginals):

- Pap test within the last 12 months: 52.5% of Inuit, **49.2%** of Métis, 55.0% of First Nations, and 55.4% of non-Aboriginal people
- Pap test within the last 3 years: **75.4%** of Inuit, 80.2% of Métis, 80.6% of First Nations, and 80.1% of non-Aboriginal people

“Coverage for the CCHS data includes Nunavut, NWT, the northern parts of Newfoundland and Labrador, Saskatchewan and Manitoba, and the northern part of Quebec excluding Nunavik and Jamesie. Individuals residing on-reserve are also excluded. Bold indicates that the difference between the aboriginal group specified and non-Aboriginals is significant at the 5% level.”

In the logistics regression models for cancer screening, health service utilization,

Inuit women were less likely than non-aboriginal female Northern residents to have had a Pap test in the previous three years (OR: 0.63; 95% CI: 0.40–0.98).

NEW ZEALAND

- *Bramley, D., et al. "Disparities in Indigenous Health: A Cross-Country Comparison between New Zealand and the United States." American Journal of Public Health 95.5 (2005): 844-50. Web.*

The health status of American Indians/Alaska Natives was compared with the 'numerically dominant population' in the United States. Similarly, the health status of the Maori population was compared with the 'numerically dominant population' in New Zealand. Several health indicators were assessed. 1999 mortality data were derived from the US National Centre for Health Statistics and the New Zealand Health Information Service. Screening coverage data on women ages 20-69 years for 2002-2003 were obtained from the New Zealand Ministry of Health; in the United States, self-reported data from women ages 18+ years were obtained through the 1998 National Health Interview Survey. If a woman underwent a Pap test in the preceding 3 years, she was included in the sample – this was true for both the U.S. and New Zealand.

The tables below indicate the cervical cancer mortality rate and screening coverage by ethnicity in New Zealand and the United States.

Cervical cancer age-adjusted mortality rate (/100,000)						
	New Zealand			United States		
	Maori	European	All races	American Indian/Alaska Native	White	All races
	6.5	1.2	1.9	1.0	1.3	1.5

Preventive services coverage: Cervical cancer screening in the United States and New Zealand – (%)				
	New Zealand		United States	
	Maori	European	American Indian/Alaska Native	White
	46.0	68.0	72.0	79.0

UNITED STATES

- *Tangka, F. K., et al. "Meeting the Cervical Cancer Screening Needs of Underserved Women: The National Breast and Cervical Cancer Early Detection Program, 2004-2006." *Cancer causes & control* : CCC 21.7 (2010): 1081-90. Web.*

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides free screening services to low-income, uninsured females ages 18-64 in the United States. Data from the U.S. Census Bureau was used to determine the number of women eligible for NBCCEDP services, which was adjusted for hysterectomy status according to the National Health Interview Survey and the Behavioral Risk Factor Surveillance System. NBCCEDP records from January 2004 through to December 2006 were used to determine the number of women who underwent Pap screening at least once during this time interval.

Results indicated that 775,312 females were NBCCEDP Pap screened from 2004 to 2006. There was significant variation in the number of NBCCEDP women screened by state. The following results were reported for women screened at least once during the study period:

Race and ethnicity	% of NBCCEDP-eligible women screened*
Hispanic	7.3 [90% CI 6.9–7.6]
Non-Hispanic	9.3 [90% CI 8.9–9.6]
White, non-Hispanic	9.7 [90% CI 9.3–10.1]
Black, non-Hispanic	6.5 [90% CI 6.1–6.9]
Non-Hispanic American Indian/Alaska Native	36.1 [90% CI 27.3–44.9]
Non-Hispanic non-Hispanic Asian and Native Hawaiian and Other Pacific Islander	9.0 [90% CI 7.8–10.2]
Non-Hispanic race combinations	4.6 [90% CI 3.4–5.8]

* *"Percent of all US women 18–64 years of age in a given age, racial and ethnic groups who are eligible and who were provided with NBCCEDP funded Pap tests".*

- *Guadagnolo, B. A., et al. "Assessing Cancer Stage and Screening Disparities among Native American Cancer Patients." Public health reports (Washington, D.C.: 1974) 124.1 (2009): 79-89. Web.*

A community-based survey was administered to recently diagnosed cancer patients to determine their knowledge and beliefs regarding screening and cancer management. Sociodemographic and cancer related information was retrieved from medical records. The survey was completed by 165 patients aged 18+ of whom 52 were Native American and 113 were non-Hispanic whites. Study participants were selected from the Cancer Care Institute of the Rapid City Regional Hospital in South Dakota, United States during the period of February 2005 to October 2007. Native American participants had a lower socioeconomic status and lived further away from the recruitment site than non-Hispanic whites.

In comparison with non-Hispanic whites, Native American patients were more likely to have been diagnosed with advanced stage cancer (this is true for those cancers for which screening is available, such as breast and cervical), had lower levels of knowledge regarding screening and more negative attitudes towards cancer treatment (i.e. belief that treatment causes people to feel sick and one's hair to fall out). Nevertheless both groups acknowledged the benefits of early detection with respect to survival following a cancer diagnosis.

Appendix 2

Final Report of the Improving HPV Prevention among Aboriginal Peoples Workshop

Winnipeg, Canada
December 2008



Final Report

Improving HPV Prevention among Aboriginal Peoples Workshop

December 9, 2008

George Wurtak
HPV Program Manager
International Centre for Infectious Diseases

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-focussed organizations and agencies that serve Aboriginal populations.

Following an opening blessing and smudge conducted by Elder Margaret Lavallee, 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.

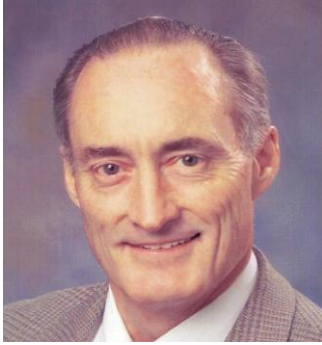


- Dr. Vyta Senikas, Associate Executive Vice-President, Society of Obstetricians and Gynaecologists of Canada. Presentation title: “Gaps and Issues in HPV Program Implementation: Lessons Learned”. A background covering HPV, Pap smear rates and vaccine timeline was provided, followed by a description 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
- $\frac{1}{2}$ status children (FN + Caucasian) have First Nations status; but $\frac{1}{4}$ FN children ($\frac{1}{2}$ 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.



Appendix 3

Materials Distributed at the Symposium

A. National Aboriginal Health Organization

Human Papillomavirus, or HPV Fact Sheet

See: <http://www.naho.ca/english/factSheets/HPV.pdf>

B. Continuing Medical Education Program:

HPV and Aboriginal Women in Canada Program

www.AdvancingIn.com

Appendix 4

Contact Cards

Enhancing HPV Prevention among Indigenous Populations:
International Perspectives on Health and Well-Being Symposium

Name/Nom:

Title/Titre:

Organization/Organisation:

Country/Pays:

Email/Courriel:

Contact details will be used to distribute electronic copies of today's materials and for future communication related to HPV in Indigenous populations.

Ces renseignements seront utilisés pour distribuer des copies électroniques des documents présentés aujourd'hui et pour partager d'autres informations sur le VPH chez les peuples autochtones.

Appendix 5

Evaluation Questionnaire

Enhancing HPV Prevention among Indigenous Populations: International Perspectives on Health and Well-being Symposium

Evaluation Questionnaire

Your feedback is important to us. Thank you for taking the time to fill out this form.

Country/Region: _____

Occupation (check all that apply):

- | | | | |
|---------------------------|--------------------------|---------------------------|--------------------------|
| Physician | <input type="checkbox"/> | Outreach Worker | <input type="checkbox"/> |
| Nurse | <input type="checkbox"/> | Program Coordinator | <input type="checkbox"/> |
| Researcher/Epidemiologist | <input type="checkbox"/> | Educator | <input type="checkbox"/> |
| Student | <input type="checkbox"/> | Other (specify):
_____ | |
| Public Health Official | <input type="checkbox"/> | | |

Affiliation (check all that apply):

- | | | | |
|----------------------------|--------------------------|---------------------------------------|--------------------------|
| Government | <input type="checkbox"/> | Non-Governmental Organization | <input type="checkbox"/> |
| Hospital/Clinical Facility | <input type="checkbox"/> | University/College/Research Institute | <input type="checkbox"/> |
| Industry | <input type="checkbox"/> | Other (specify):
_____ | |

Please rate the following aspects of the symposium:

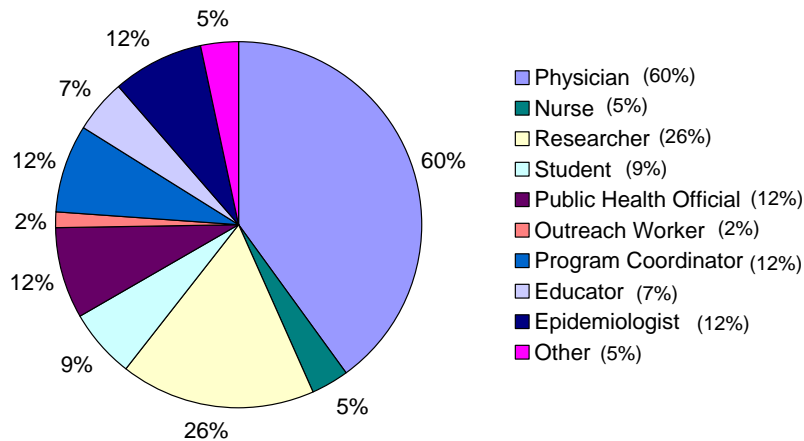
	Strongly Agree	Undecided	Disagree	Strongly Disagree
The symposium provided new and relevant information related to the burden of HPV among Indigenous populations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The symposium identified promising interventions and wise practices for addressing the prevention of HPV disease among Indigenous populations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The knowledge gained today will inform my work/practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The materials distributed today will be useful in my work setting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is need for continued international dialogue on HPV issues with respect to Indigenous populations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 6 Evaluation Results

Following the presentations, 43 participants submitted completed evaluation questionnaires.

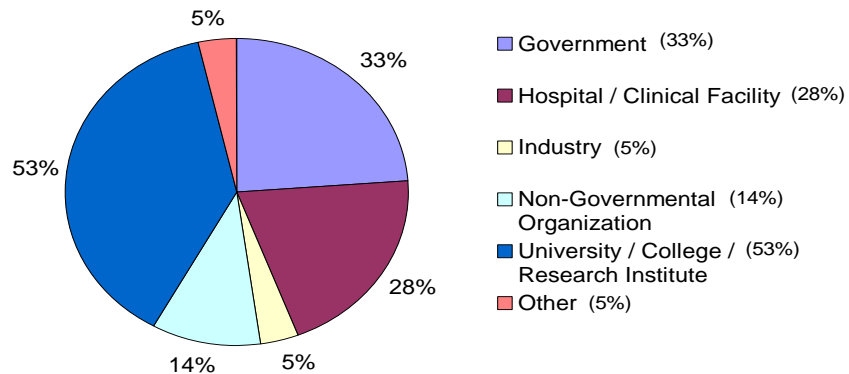
1. Occupation of Participants

The main occupations of the respondents were: Physician (26), Researcher (11), Public Health Official (5), Program Coordinator (5) and Epidemiologist (5). Other occupations included: Student, Educator, Outreach Worker, Marketer, Industry/Public Health Manager.



2. Affiliation of Participants

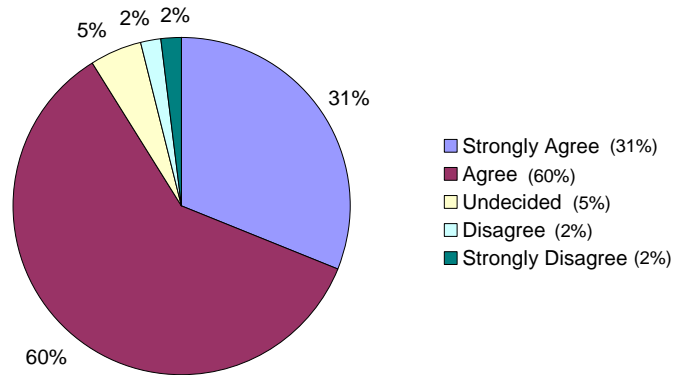
The affiliations of the 43 respondents included: University/College/Research Institute (23), Government (14), Hospital/Clinical Facility (12), Non-Governmental Organization (6), Industry (2), and Health Centre (1).



3. Ratings of Aspects of the Symposium

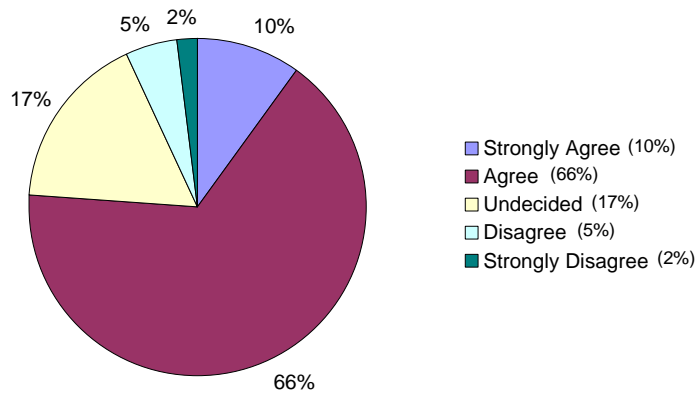
a) Provided new and relevant information related to the burden of HPV among Indigenous populations

Of the 42 responses received, 91% agreed or strongly agreed that the symposium provided new and relevant information.



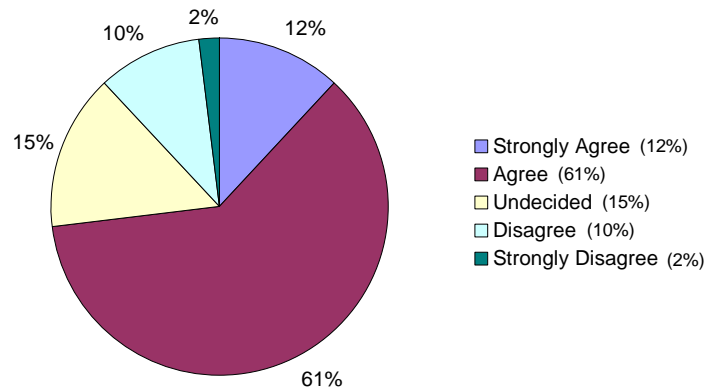
b) Identified promising interventions and wise practices for addressing prevention of HPV disease among Indigenous populations

76% of respondents agreed or strongly agreed that the symposium identified promising interventions and wise practices for HPV prevention.



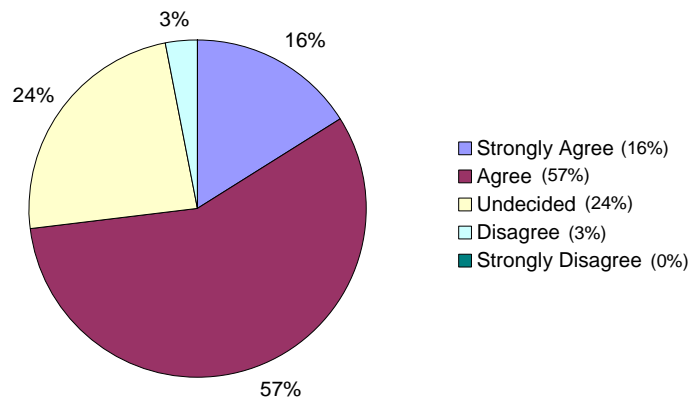
c) Knowledge gained will inform my work or practice

73% of the respondents agreed that the Symposium provided knowledge that will inform their work or practice.



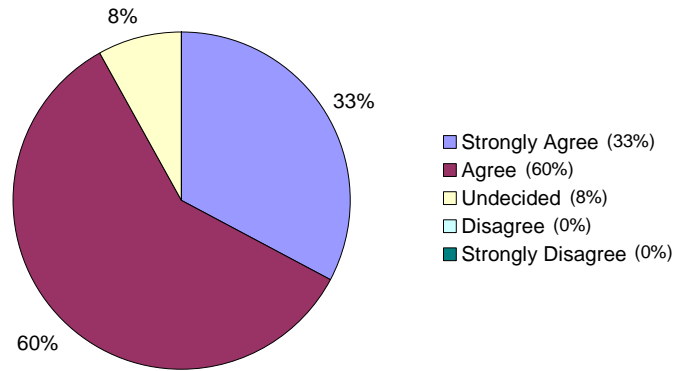
d) The materials distributed today will be useful in my work setting

Of the 37 responses received, 73% agreed or strongly agreed that the materials distributed at the symposium will be useful to them in their work.



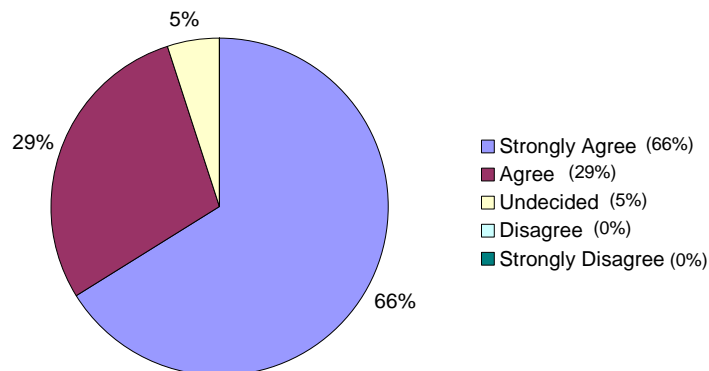
e) The presenters demonstrated a thorough understanding of the subject

93% of the 40 respondents agreed or strongly agreed that the presenters were highly knowledgeable and demonstrated a thorough understanding of the topic.



f) There is a need for continued international dialogue on HPV issues with respect to Indigenous populations

95% of the participants agreed or strongly agreed that there is a need for continued dialogue on this topic.



Appendix 7: Speaker Biographies

Moderator(s): Colleen Patterson & Paulette C. Tremblay - National Aboriginal Health Organization

Paulette C. Tremblay

Paulette C. Tremblay, Ph.D.
Chief Executive Officer
National Aboriginal Health Organization (NAHO)
Ottawa, Canada

Paulette C. Tremblay, Ph.D. is the Chief Executive Officer for the National Aboriginal Health Organization. She is a Mohawk from Six Nations of the Grand River Territory in Southern Ontario and a veteran, who served in the American Navy during the Vietnam War. Dr. Paulette C. Tremblay has had a diverse and accomplished career. In her former post, she served as Director of Education at the National Aboriginal Achievement Foundation. Prior to that, she held the positions of Senior Executive Officer with the Six Nations Council and Director of Education for the Assembly of First Nations. She has represented the Federation of Saskatchewan Indian Nations as the National Liaison for the Chiefs of Saskatchewan in Ottawa. Tremblay has also worked as a researcher for the University of Ottawa, a consultant for the private and public sectors, a policy analyst for the federal government, and a high school teacher and counsellor in the Yukon. Tremblay holds Doctor of Philosophy in Education and a Master of Arts in Education from the University of Ottawa. She also has a Bachelor of Education from Dalhousie University in Halifax, N.S. and a Bachelor of Arts in Sociology from Wilfred Laurier University in Waterloo, Ontario.

Suzanne Garland, MD

Suzanne Garland, MD FRCP(C) MBBS
Director of Microbiological Research, Head of Clinical Microbiology and Infectious Diseases,
Royal Women's Hospital, Melbourne, Australia

Suzanne M. Garland is a Clinical Microbiologist and Sexual Health Physician and holds the following appointments: Director of the Royal Women's Hospital, Microbiology and Infectious Diseases Department and Women's Research Centre Infectious Diseases, Senior Consultant Microbiology Royal Children's Hospital, Honorary Research Fellow Murdoch Children's Research Institute and Professor, University of Melbourne. Her research interests include infectious diseases in reproductive health, sexual health as well as neonatal health, rapid techniques of diagnosis, a special interest in human papillomavirus and cervical cancer, particularly at the public health vaccine level.

Isaac Sobol, MD

Isaac Sobol, MD
Chief Medical Officer of Health
Dept. of Health and Social Services, Government of Nunavut,
Iqaluit, Canada

Dr. Isaac Sobol is the Chief Medical Officer of Health for Nunavut and holds an appointment as Clinical Assistant Professor in Family Practice at UBC. He obtained his MD and Family Practice training at Queen's University at Kingston, and his Community Medicine training at UBC. Dr. Sobol is the Chair of the Council of Chief Medical Officers of Health (Canada), the Nunavut representative on the Public Health Network Council, and the P/T Co-Chair of the Surveillance and Information Expert Group of Public Health Network. Additionally, Dr. Sobol sits on the Advisory Board of the National Collaborating Centre on Aboriginal Health and also on the Advisory Board of the Institute of Aboriginal Health-CIHR. His medical career has focused in the area of Aboriginal health, working with Métis, First Nations, and now Inuit communities. Each year, he leads a team of volunteers to provide free medical clinics for the poor in eastern Tibet, on behalf of Rokpa International, whose Canadian branch he founded in 1992.

Eileen F. Dunne, MD

Eileen F. Dunne MD, MPH, Medical Epidemiologist,
Division of STD Prevention, Centers for Disease Control
Atlanta, USA

Dr. Dunne is an infectious diseases board certified physician who joined CDC in 1998 as an EIS officer. Dr. Dunne joined the Division of STD Prevention in 2001 as a research epidemiologist with a focus on HPV and HSV. Dr. Dunne has been conducting research on Chlamydia among men, patient-delivered partner therapy for Chlamydia in California, HPV among men, and she was the principal investigator for an RCT to evaluate the effect of suppressive acyclovir on HIV and HSV shedding in co-infected women living in Chiang Rai, Thailand. Dr. Dunne is a member of the HPV ACIP workgroup and helped develop the ACIP recommendations for the quadrivalent and the bivalent HPV vaccine for girls and women, and the quadrivalent HPV vaccine for men. Dr. Dunne has over 30 publications on infectious diseases, epidemiology and STDs.

Telphia Joseph:

Telphia Joseph, National Indigenous Immunisation Co-ordinator
The National Centre for Immunisation and Surveillance,
Kids Research Institute at The Children's Hospital at Westmead
NSW, Australia

Telphia Joseph, a Yamitji woman from Western Australia, has qualifications in Community Development which led to her initial interest in environmental health and otitis media. Telphia has a qualitative research base and now acts in a liaison position between the National Immunisation Committee and Aboriginal Community Controlled Health Services and other service providers offering immunisation programs for Aboriginal and Torres Strait Islander people. Telphia has developed a continued interest in HPV after working with Professor Suzanne Garland on Women, Human Papillomavirus, Urban, Non-Urban, Remote Study (WHUNURS).

Paul Brassard, MD:

Paul Brassard, MD
Departments of Medicine, Epidemiology & Biostatistics, McGill University;
Division of Clinical Epidemiology, McGill University Health Center
Montreal, Canada

Dr. Brassard is a community medicine physician with graduate training in parasitology and epidemiology. He has been involved with research in the Canadian Arctic and sub-Arctic since 1979. Areas of expertise include infectious diseases control mainly tuberculosis and Aboriginal health. The main tools used to perform this research are surveillance data, epidemiologic investigations and molecular epidemiology. Main research aims to define the natural history of the human papillomavirus infection in Inuit women from Nunavik, Quebec. Research also looks into the transmission of tuberculosis in Quebec using molecular markers, human genealogy and historical geography techniques.