

Improving HPV Prevention
Among Aboriginal Peoples
Workshop

December 9, 2008

Appendices

Appendix I

Participants and Organizations Represented

Workshop Participants

Anderson, Dr. Marcia	Manitoba Health
Barker, Dr. Kim	Assembly of First Nations
Belzak, Ms. Lisa	Public Health Agency of Canada
Brassard, Dr. Paul	McGill University
Brown, Ms. Crystal	International Centre for Infectious Diseases
Chartrand, Prof. Paul	University of Winnipeg
Demers, Dr. Alain	CancerCare Manitoba
Dinner, Ms. Katherine	Public Health Agency of Canada
Dubec, Ms. Bernice	Anishnawbe Mushkiki Lodge
Duguid, Mr. Terry	International Centre for Infectious Diseases
Dumaresq, Ms. Gina	FNIHB, Health Canada
du Plessis, Ms. Elsabé	National Collaborating Centre for Infectious Diseases
Elias, Dr. Brenda	University of Manitoba
Folz, Ms. Kelly	Public Health Agency of Canada
Hamilton, Ms. Sherry	Public Health Agency of Canada
Hammond, Dr. Gregory	International Centre for Infectious Diseases
Hart, Ms. Lyna	South East Resource Development Council
Hook, Ms. Ethel	International Centre for Infectious Diseases
Jayaraman, Dr. Gayatri	Public Health Agency of Canada
Kelly, Ms. Mary	Pauktuutit Inuit Women of Canada
Kettner, Dr. Joel	Manitoba Health
Kliewer, Dr. Erich	CancerCare Manitoba
Koh, Dr. Denise	Manitoba Health
Lavallee, Ms. Margaret	Winnipeg Regional Health Authority
Letendre, Dr. Angeline	CIHR – Aboriginal People’s Health
Maurice, Dr. Jacqueline	Federation of Saskatchewan Indian Nations
Medwick, Ms. Heather	International Centre for Infectious Diseases
Moor, Mr. Bruce	CIHR – Infection and Immunity

Morgan, Ms. Barbara	Manitoba Métis Federation
Mudry, Ms. Amanda	Native Women's Association of Canada
Nesic, Dr. Momir	FNIHB, Health Canada
Patterson, Ms. Colleen	National Aboriginal Health Organization
Poffenroth, Dr. Linda	FNIHB, Health Canada
Roland, Ms. Brenda	Winnipeg Regional Health Authority
Ronald, Dr. Allan	International Centre for Infectious Diseases
Schettler, Ms. Wendy	International Centre for Infectious Diseases
Senikas, Dr. Vyta	Society of Obstetricians and Gynecologists of Canada
Sevenhuysen, Ms. Claire	National Collaborating Centre for Infectious Diseases
Severini, Dr. Alberto	National Microbiology Lab, PHAC
Shaw, Mr. Souradet	National Collaborating Centre for Infectious Diseases
Sobol, Dr. Issac	Nunavut Health
Springer, Mr. Gregory	FNIHB, Health Canada
Stopera, Ms. Shelley	Manitoba Health
Templeton, Ms. Kimberly	CancerCare Manitoba
Tremblay, Dr. Paulette	National Aboriginal Health Organization
Turner, Dr. Donna	CancerCare Manitoba
Wiebe, Mr. Dan	Brokenhead Ojibway Nation
Wilson, Dr. Don	Physician
Wong, Dr. Thomas	Public Health Agency of Canada
Wurtak, Mr. George	International Centre for Infectious Diseases

Organizations Represented

Anishnawbe Mushkiki Lodge

Assembly of First Nations

Brokenhead Ojibway Nation

Canadian Institutes for Health Research – Aboriginal People’s Health

Canadian Institutes for Health Research – Infection and Immunity

CancerCare Manitoba

Centre for Aboriginal Health Education, Winnipeg Regional Health Authority

Federation of Saskatchewan Indian Nations

First Nation and Inuit Health, Health Canada

International Centre for Infectious Diseases

Manitoba Health and Healthy Living

Manitoba Métis Federation

McGill University

National Aboriginal Health Organization

National Collaborating Centre for Aboriginal Health

National Collaborating Centre for Infectious Diseases

Native Women’s Association of Canada

Nunavut Health

Pauktuutit Inuit Women of Canada

Public Health Agency of Canada

Society of Obstetricians and Gynecologists of Canada

South East Resource Development Council

University of Manitoba

University of Winnipeg

Appendix II

Participant Kits

At the registration desk each participant received a kit of materials for use during the day. Materials included documents describing the International Centre for Infectious Diseases and paper copies of the PowerPoint presentation slides from each presenter. Included in the kit were copies of:

- International Centre for Infectious Disease HPV programs descriptive postcard, and information sheets
- “Understanding HPV” slides – Dr. Paul Brassard
- “HPV Surveillance in Nunavut” slides – Dr. Isaac Sobol & Dr. Thomas Wong
- “Manitoba’s Population-based HPV Surveillance System” slides – Dr. Erich Kliewer
- “Implementation of the Manitoba HPV Immunization Program: Four Main Program Elements” slides – Ms. Shelley Stopera
- “Knowledge, Attitudes, Behaviours and Beliefs of HPV in First Nations Communities” slides – Dr. Kim Barker
- “HPV Programs at ICID” slides – Dr. Allan Ronald
- “Manitoba HPV Disease Prevention Secretariat” slides – Dr. Greg Hammond
- “First Nations, Inuit & Métis People in Canada” – Dr. Paulette Tremblay
- “Overview and Model of Intersecting HPV Research Areas” – Dr. Brenda Elias
- “HPV Immunization Program in First Nations Communities” – Ms. Gina Dumaresq
- “Gaps and Issues in HPV Program Implementation: Lessons Learned” – Dr. Vyta Senikas

Also made available to participants at the workshop were copies of:

- “Introduction of the Human Papillomavirus (HPV) Vaccine: A Review of the Literature. 2007” – with the permission of Dr. Kim Barker, Assembly of First Nations
- “It Could Save Your Life: Quick Facts on Cervical Cancer and the Pap Test”. First Nations Centre, National Aboriginal Health Organization.
- “Metis Cookbook and Guide to Healthy Living”. 2008. Metis Centre, National Aboriginal Health Organization.
- “Our Healthy Journey: A collection of First Nations Children’s Perspectives”. 2008. First Nations Centre, National Aboriginal Health Organization.

Appendix III
Presentation PowerPoint Slides

(See individual PDF documents)

Appendix IV

Break Out Discussion Group Flipchart Notes

Group 1: Understanding HPV

[Basic Research, Medical Issues, Health Services]

Members: Amanda Mudry (Facilitator & Rapporteur) Paul Brassard Angeline Letendre
Bruce Moor Momir Nestic Allan Ronald Dan Wiebe Don Wilson
Tom Wong

Gap Identification

1. Need for practitioners, CHW's, other health & research professionals to address the need for healing re: sexual abuse, intergenerational effects of Residential schools.
2. Long-term commitment to our community's healing processes – no more “helicopter research”
3. Not event-specific; more holistic approach to women's health promotion
4. Access to Pap testing – newer technology required
5. Knowledge of healthcare providers – quality of education- cultural/social/geographical, etc.; need to increase resources for frontline workers – more in-depth HPV/cervical cancer-specific training
6. Marketing/education that is culturally-relevant to promote health
7. Pap & Liquid Cytology Testing has limitations – HPV testing will eventually replace Pap testing (3-5 years est.)
8. Organize data so we know who's being screened
9. Aboriginal women too targeted - stop shaming/blaming
10. Political support? Are there \$\$\$? Demonstration projects – new approaches – population inclusive
11. Pap test uptake baseline study to measure results
12. Regional cervical screening registry
13. Aboriginal statistics lacking
14. Male as vector of HPV to women – Gardasil for men
15. Two spirited population
16. Increase of abuse against Aboriginal women – increase mistrust/fear of medical professionals
17. Cohorts that include Aboriginals & non-Aboriginals, and vaccinated & non-vaccinated populations; circulating types: are they different for different populations? And are the effects the same?
18. Programs to look for adverse effects – length of immunity (racial/community differences – factors)
19. Proper monitoring of large-scale population analysis

20. Increase basic knowledge of types
21. Risk-assessments
22. Type replacement
23. New vaccine being tested to cover 9 HPV types instead of 4
24. Cost of vaccine to youth, especially non-status First Nations
25. Development of research policies/protocols in First Nation communities – OCAP as a principle
26. Lack of urban/off-reserve/settlement lands research
27. Culturally relevant knowledge translation – gender inclusive analysis; for families & communities
28. Document gaps in levels of knowledge
29. Health disparities between North and South populations
30. Testing facilities in Northern/Rural/remote communities
31. Capacity development at the community level – need \$\$\$ to do this
32. Trust-based partnerships with Indigenous communities

Addressing the Gaps

- a) Capacity development to increase understanding of qualitative/statistical/medical research for community leaders – **Long Term**
- b) Healthy people, healthy communities – **Long Term**
- c) Increased sexual health awareness/education/research – **Long Term**
- d) Develop a national screening policy & database/registry for testing & vaccine recipients (increase standard of care) – and the ability to tailor this to the community level– **Extra Long Term**
- e) Demonstration projects:
 - a. culturally appropriate marketing; increase efficiency of Pap testing/HPV testing – **Short Term**
 - b. cervical cancer prevention plan – national – **Long Term**
- f) Reduce stigma of STI's to increase testing & vaccination in Aboriginal communities through education campaign – **Short Term & Long Term**
 - a. Face to face level by people who the community can relate to – cultural/social/economic layers – very complex to get information to the community level
 - b. Compound issue – very important who addresses it & how you approach it – “Knowledge Translation”
 - c. Tie it into other women's health-related messages (time efficient) – Health Pack – **Now**
 - d. Age-targetted, gender-specific programs
- g) Increase of health services in Northern communities
- h) Look at ethnic biological differences – how to ethically separate that data within small communities – difficult populations to access (for example, Nunavut); application of studies to Aboriginal communities – to increase implementation of programs
- i) Changing screening technologies – **Long Term**
- j) Targeting men for screening & vaccination – **Now**

Capacity Development

1. Increase understanding of qualitative/statistical/medical research for community workers
2. Increase funding – targeted – priority areas/groups
3. Train people in a variety of disciplines
4. Community-based research – development of community – researchers/health professionals
5. Increased sexual health awareness/education
6. Cultural awareness for all researchers & care providers – funders, academics, health education, Aboriginal communities, Aboriginal Health & Human Resource Initiative

Timeline: Now & On-going

Technology

1. Develop a national screening policy & database/registry for testing & vaccine recipients – increase standard of care
2. Implementation of new technologies or any technology for rural/remote communities
3. Developing standards – colposcopy
 - a. Hospitals, physicians, funding agencies, researchers & clinicians, provinces/territories, Canadian government/health agencies – Indian & Northern Affairs Canada

Timeline: with demonstration projects – 5 – 10 years

Community & Family Education

1. School-based program improvement
2. Educators & health professionals need to recognize issues – look at risk factors
3. Culturally appropriate training for new teachers from community knowledge holders
4. Community-level curriculum development
5. Development of age & gender specific health packs (wrap it into one for time-efficiency)
6. Reduce stigma of STI's to increase testing & vaccination in communities – must be face-to-face, community-level by people the community can relate to
7. Health people, healthy communities
8. Target men for screening & vaccination
 These initiatives to involve researchers, funding agencies, community health reps/directors/nurses, practitioners, ICID, schools, academics, families & community members, curriculum developers.

Timeline: NOW

Separation of Aboriginal statistics/information:

1. Ethics, protocols, policy development
2. Ethnic biological differences
3. Access to community health information
4. HPV type differences & vaccine effectiveness
5. INAC/NHB, Communities, Regional Health Services, Provincial providers

Demonstration Projects

Male as a vector of HPV to women

Group 2: Developing a Population Level Understanding of HPV

[Epidemiology, Surveillance, Monitoring]

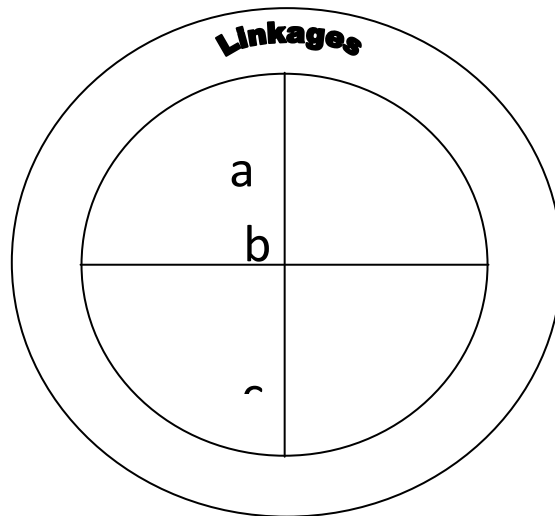
Members: Gaya Jayaraman (facilitator & rapporteur) Brenda Elias Erich Kliewer
 Brenda Roland Paulette Tremblay Shelley Stopera Alberto Severini

Gap Identification

1. Lack of basic (denominator) data to improve prevention
2. Not enough research with First Nation, Métis, Inuit populations
3. How to reach young people regarding SHSTI, including HPV?
4. How to improve public health communication to First Nation, Métis, Inuit populations?
5. How to reach out to those who were not part of residential schools?, e.g. adopted, didn't grow up in community
6. Gaps in infrastructure and data collection mechanisms (different systems, little standardization)
7. Difference in jurisdictional delivery of vaccine
8. Collecting/analyzing information relevant to clinical practice and "patient" needs/concerns
9. Negative media attention raises questions re: exposure to sex, adverse events, "DNA" testing; need appropriate data & messaging to address
10. Incorporating HPV messaging into arena of holistic approach to "wellness"
11. How to access First Nations, Métis, and Inuit individuals living in urban areas? (for data and messaging)
12. Capacity building (health care providers, data analysts, program delivery staff)
13. Need to design different approaches relevant for different communities including urban and reserve communities:
 - Risk factors
 - Mental health
 - Residential school survivors, etc
14. Community is still looking for status, recognition
15. How to approach sensitive topics (e.g. sexual abuse) in a "healing" way? How does one get through the silence?
16. Need to access individuals who don't read
17. Gap: burden of HPV genotyping (type replacement) following cohort that is vaccinated
18. How to identify First Nations, Métis, and Inuit population (for database) especially non-registered First Nations, Métis, and Inuit individuals
19. Lack of centralized/linkable databases
20. Need for data sharing agreements – important, but time consuming
21. Cost of vaccine (if not given in school) is prohibitive
22. Develop better female-centred way for Pap testing (type of exam; who performs it)

Solutions to Address the Issues

1. Develop registries within communities
2. Develop centralized (anonymous) or linkable registries (health, education, First Nation status, etc.)
3. Pap testing as part of annual wellness visits using nurse practitioners or physician assistants
 - focus on wellness
 - “Well adolescent clinic”
4. Improved delivery of services
 - E.g. a) Self Administration of Swabs
 - E.g. b) Pap testing
 - presence of a 3rd party
 - who performs the exam
 - type of exam
5. Linking information:
 - Linking Data
 - Linking Jurisdictions
 - Linking Organizations
 - Linking provider & community
 - Linking Messages (cancer, STI’s, vaccine, wellness)
 - Linking data analyses/surveillance to programs/policy
6. a) Improving messaging/communication to key partners
b) Capturing First Nations, Métis, Inuit - specific data
c) Linking data & service delivery systems
d) Improving service delivery (pap testing, STI) that is “wellness” focused



How Can Needs be Addressed:

1. Strengthen/create relationships with First Nations, Métis and Inuit peoples
 - Mother-child
 - Family
 - Communities
 - Service delivery
 - Nations
 - Regions
 - National
2. Building capacity at all levels (local, regional, national) and sectors
3. Developing culturally appropriate messaging with flexibility and adaptability to meet diverse needs
4. Demystifying medical terminology and recontextualizing

Who Could be Involved and What Timeframe?

1. A collaborative involving:
 - FNIHB, Health Canada
 - PHAC (including labs)
 - INAC
 - CCPAC
 - NAHO
 - F/P/T organizations (including labs)
 - SOGC and other professional organizations (e.g. CFPC)
 - Mothers and grandmothers
 - National Aboriginal organizations (political)
 - National Aboriginal CHW
 - Friendship centres

Timeframe: 6 months

2. Pilot/demonstration projects

Funding: Federal/Provincial/Territorial Treasury Boards

Group 3a: Developing Community Understanding & Program Implementation

(Vaccination, Educational Resources, Public Awareness)

Members: Kelly Folz (facilitator) Mary Kelly (Rapporteur) Kim Barker Paul Chartrand
 Alain Demers Bernice Dubec Greg Springer Lyna Hart
 Colleen Patterson

Gap Identification

1. Barriers:
 - Access
 - Transportation
 - Child care
 - Continuity of care
 - Cultural safety
 - Number of people without family physician
 - a) Must meet communities and individuals where they are at
 - b) Flexibility required
 - c) Understanding environmental & cultural factors
 - d) Fear of removal of children from family
 - e) Identification/ non-insured health benefits, provincial health cards
 - f) Language
 - g) Mobility
2. Lack of comprehensive sexual health education
3. Need to support community organizations already doing this work
4. Need to connect to social determinants of health
5. Traditional knowledge-based activities (e.g. midwives)
6. Need an HPV version of NACHA (National Aboriginal Council on HIV/AIDS (NACHA) – with nomination of representatives
7. There is a communication gap - information needs to filter down to community level
8. Service provider burn-out
9. Communication with youth
10. Need basic understanding of STI's (HPV, HIV, etc.)
11. Need clear mandates and scopes
12. There is a lack of resources dedicated to prevention
13. Need policies – e.g. condoms in schools
14. Projects need research for funding (need to include anecdotal information)
15. Multi-year funding (reduce fiscal funding gaps)
16. Integrated projects
17. Need access to provincial databases at Tribal Council level (e.g. access to MIMS)
18. Lack of Aboriginal Health Human Resources
19. Develop infrastructure & services in remote, rural & northern communities

Priority-setting : Group 3A:

Community mobilization

1. Pull together what's already been done (programming & resources) (e.g. Kanikanichik, U of MB Continuing Education – Marg Beaucage, Raimy Gaywish); Butterflies-Patterns of Light; Sexual Education Resource Centre
2. Identify what's working
3. Evaluation of projects/resources
4. Identify resources to support demonstration projects (HHR & \$\$)
5. Well-women's programs
6. Need to address stigma & discrimination
7. Develop community partnerships – need a community response
8. Need on-line resources
9. Need youth-driven projects
10. Need parent-friendly resources
11. Train-the-trainer approaches
12. Bringing people together in a non-threatening way
13. Involve fun, socialization, food
14. Celebrating community successes
15. Incorporate historical issues

Priority #1

Community capacity building & community mobilization (effective communication)

- Includes resources for more screening
- More vaccinations
- More education
- Contact, encourage attendance
- Follow-up
- Tie HPV issues into community programs – “Value Added”
- Form/develop the community – lead to self-determination

Priority #2

Appropriate Programming & Educational Resources

Priority #3

Research – e.g. OCAP (Ownership, Control, Access and Possession)

Other Priorities

- Aboriginal HHR
- Funding
- Access
- Traditional knowledge
- Cultural competency & safety

Group 3b: Developing Community Understanding & Program Implementation

(Vaccination, Educational Resources, Public Awareness)

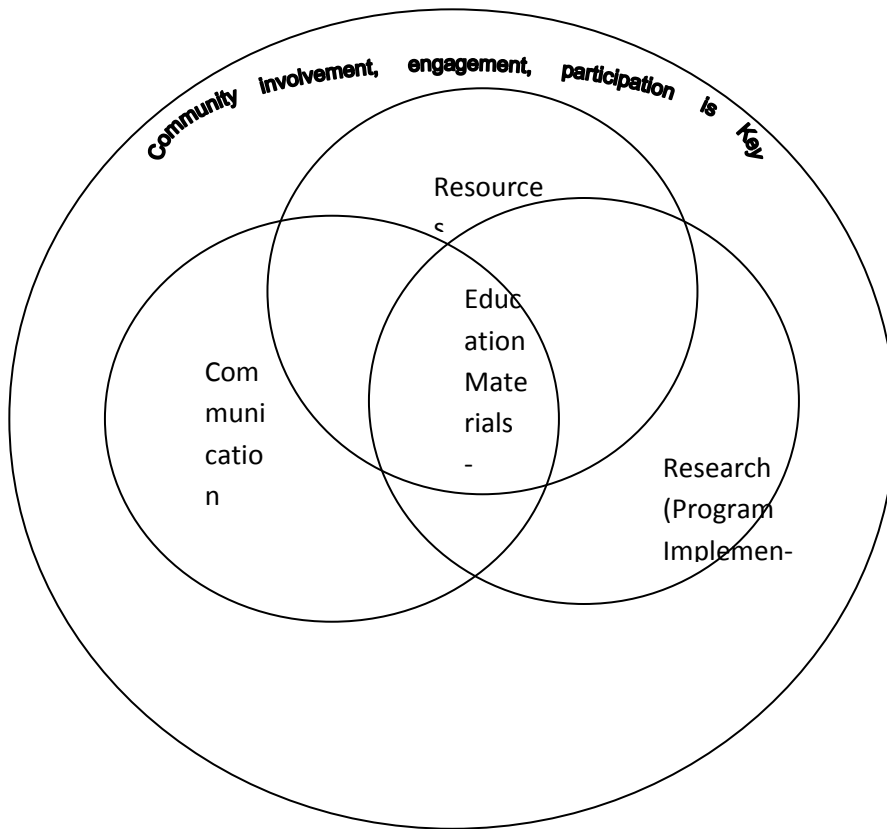
Members: Donna Turner (Facilitator & Rapporteur) Marcia Anderson
 Lisa Belzak Sherry Hamilton Isaac Sobol Kim Templeton

Issues/ Needs/ Gaps

1. Lack of access to services – for a variety of services & different populations (e.g. vaccine, Pap tests)
2. Human resources, financial resources, educational resources
3. Community engagement on resource/ program development....how to? What is the correct way to connect with the community? E.g. materials need to be developed from “scratch” – not just a late add-on; without this we may increase health disparities
4. SOGC - ?Aboriginal program
5. Integrate community voice in resource development
6. Nursing allocations: change workload “values” to calculate # of nurses needed
7. Not just the \$\$! Need a systems approach: what works in urban centres isn’t relevant to remote First Nations/ Métis/ Inuit communities
8. CHR’s (Community Health Representatives) also
9. Community buy-in to vaccine – but do we have the right vaccine? (HPV types)
10. Communicating the burden of disease (it’s importance)
11. Building of trust: the right people (who care), continuity
12. Appropriate location/ distribution of vaccine (school?? What age are you aiming at?)
13. Practical considerations - # of schools; parents’ perceptions
14. Different age of child – parents “ready” when children older
15. The same ages, or different?? - May be based on mainstream population, but can we build in flexibility to who/when?
16. Change management in Federal/Provincial government systems – e.g. Elders Councils; support word of mouth networks
17. We have a wealth of resources within the strengths of the community construct
 - e.g. - Councils
 - Community connectedness
 - Information transfer – e.g. DVD, but provided by Elders
 - The right info in the right format – not written
 - Community radio, TV, call-in show
 - PSA’s (public service announcements),
 - CD’s, DVD’s
 - need community & Elders specifically to be involved in the creation of messages (i.e. on CD’s, DVD’s)

18. No standard sex education curriculum in communities
 - Religious impact (Residential School effect)
19. Communities are diverse! Capitalize on this. Is there a basic message that can be delivered in various ways? E.g. Hip Hop
20. Is the lack of knowledge around HPV/cervical cancer affected by decreasing interest/aversion to talking about sex because of residential schools trauma?
21. Concern about the role of big Pharma
22. With big Pharma, the role of politics makes HPV vaccine use “suspicious” (influences trust)
23. Sustainability of funding for vaccine is in question
24. “Tyranny of the acute”
25. Benefit of HPV vaccine/ cervical cancer prevention is future
26. Ability to (meaningfully) evaluate programs is not clear or standard
27. Stigma towards women (because women are tested/ seen, #'s and rates of STI's are (or appear to be) higher
28. Groupings?
29. Priorities?
30. Steps to make change: Resources; Who; Timelines
31. NB: Community must be central – understand politics (drivers/champions, barriers)
 - Framing engagement opportunities are key (e.g. bigger picture, prevention & sexual health)
32. Education : materials, methods
 - Knowledge, Attitudes, Behaviours to Knowledge Translation
 - Grassroots: who's best-placed to deliver information?
 - First Nations, Métis, Inuit: community members to develop specific materials
33. Resources – sustainable HR & \$\$
34. Research – connecting education (“how”?) to program implementation with evaluation
35. Communicating risks, benefits, burden of disease – providers & individuals
36. Core messages, issues: common – but not appropriate delivery ; requires major community involvement

Priorities – group 3B



Engagement:

- National Collaborating Centres
- PHAC
- FNIHB
- Small research grants (e.g. MacArthur, CIHR-IAPH, CIHR- III, Grand Challenge)

Links to Communities: Who?

- National political organizations
- Professional organizations
- National Aboriginal Health Organization (NAHO)
- National Collaborating Centre for Aboriginal Health
- National Collaborating Centre for Infectious Diseases

Timelines:

- Less than 1 year:
 - APTN/ Hip Hop for HPV
 - build on outcomes of AFN report
 - Pilot(?) targeted research materials (need now with vaccine implementation)
- 1-3 years:
 - multi-media
 - multi-community distribution

Steps to make change:

- Resources: PHAC

Appendix V

Acknowledgements

The success of the workshop depended upon the involvement and contributions of members of the planning team (listed on page 7 of this report), as well as a number of capable staff and volunteer workers. Appreciation is expressed to Ms. Crystal Brown, Ms. Jennifer Allison, Ms. Jane Nikkel, Ms. Ethel Hook, Ms. Elsabé du Plessis, Ms. Claire Sevenhuysen, Mr. Souradet Shaw, Mr. Terry Duguid and Ms. Heather Medwick for their support.