SDOH and Cervical Cancer Screening Uptake: Barriers and Facilitators for Vulnerable and Marginalized Women in Canada

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Lakehead UNIVERSITY

Overview

- A Social Determinants of Health Framework for Indigenous Populations
- The Wellness Gap in First Nations
- Cervical Cancer Disparities among Indigenous Women
- Case Study: The Anishinaabek Cervical Cancer Screening Study (ACCSS)
- Barriers, Facilitators and Next Steps

Why Use a Social Determinants of Health Approach?

- Broadens the lens of analysis to include the historical and political context of health care -opportunities, power relations and decision making

-focus is on the social structures, environments, conditions, opportunities and challenges

-allows us to indentify the broader contextual factors shaping health and ill health for populations and individuals

-enables us to better understand both individual health behaviours and population health patterns

Social Determinants of Health for Canada's Indigenous Peoples

1. Proximal

(direct impact on physical, emotional, mental or spiritual health

- Physical environments
- Employment and income
- Health behaviours
- Education
- Food insecurity

2. Intermediate

(conditions shaping proximal problems)

- Health care systems
- Education systems
- Community infrastructure and resources
- Environmental Stewardship
- Cultural continuity

3. Distal Determinants

(political, economic and social contexts that frame intermediate and proximal context)

- Colonialism
- racism and social/exclusion
- lack of opportunities for self determination

(Loppie and Wien (2009) *Health Inequalities and Social* Determinants of Aboriginal Peoples' Health)

The Wellness Gap for Indigenous Peoples

"By whatever "objective" or "subjective" measures used, overall the health status of First Nations, Inuit and Metis people in Canada is disproportionately poor compared with Canadians as a whole" (Wellesley Report "First Peoples, Second Class Treatment" 2015)

- Lower life expectancy
- Higher rates of infectious disease
- Higher rates of chronic disease
- Higher rates of disability
- Higher suicide rates (15-20x the Canadian average)
- Higher rates of substance use and addictions
- Poorer self rated health

Additional Wellness Gap for Indigenous Women

- Higher burden of poverty (2-3x other women)
- More likely to be caring for dependents
- Higher rates of physical and sexual abuse
- Racism and social exclusion
- Limited access to health care and culturally sensitive care
- Social and emotional well being negatively impacted by colonial legacy and cultural disruption
- Reproductive health inequities – higher burden of cervical cancer, limited maternity and childcare options, “delivery away from home”

Cervical Cancer Disparities

- 83% reduction in cervical cancer mortality in Canada since introduction of provincial PAP screening programs in 1950s (7.3/100,000 to 2.2/100,0000)

- Primarily opportunistic screening which relies on primary health care provider contact

- Increasing evidence of inadequacy recruiting marginalized and underserved populations - those underserved by primary care

- Even where recall screening systems in place, PAP rates more commonly 50% compared with 85% for ever screened women

Cervical Cancer Disparities

- 2 – 20 times increased cervical cancer incidence and mortality among Indigenous women in Canada (Nishri et al., Int J Cancer 2015; Decker et al., Cancer Prev Res 2015; Colquhoun et al., Chron Dis CA 2010)

- Incidence rates reported of 1.73 fold higher in Ontario, 1.8 (in situ) and 3.6 (invasive) in Manitoba, and 20 times in two communities in N. Alberta

- Death rate for cervical cancer among Indigenous women also disproportionately high

- Similar disparities internationally (Maar et al. 2013)
  - Australian 2.4 times more likely to develop cancer, mortality 5X Australian average
  - Elevated risk and poorer outcomes also among Maori women in New Zealand, and among Native Americans and Alaskan Natives

Pilot Study - Fort William First Nation 2009

Pilot study with the Fort William First Nation (2009)

Goal: to increase cervical screening participation by offering **self-sampling for HPV** as an alternative to Pap testing.

Results:

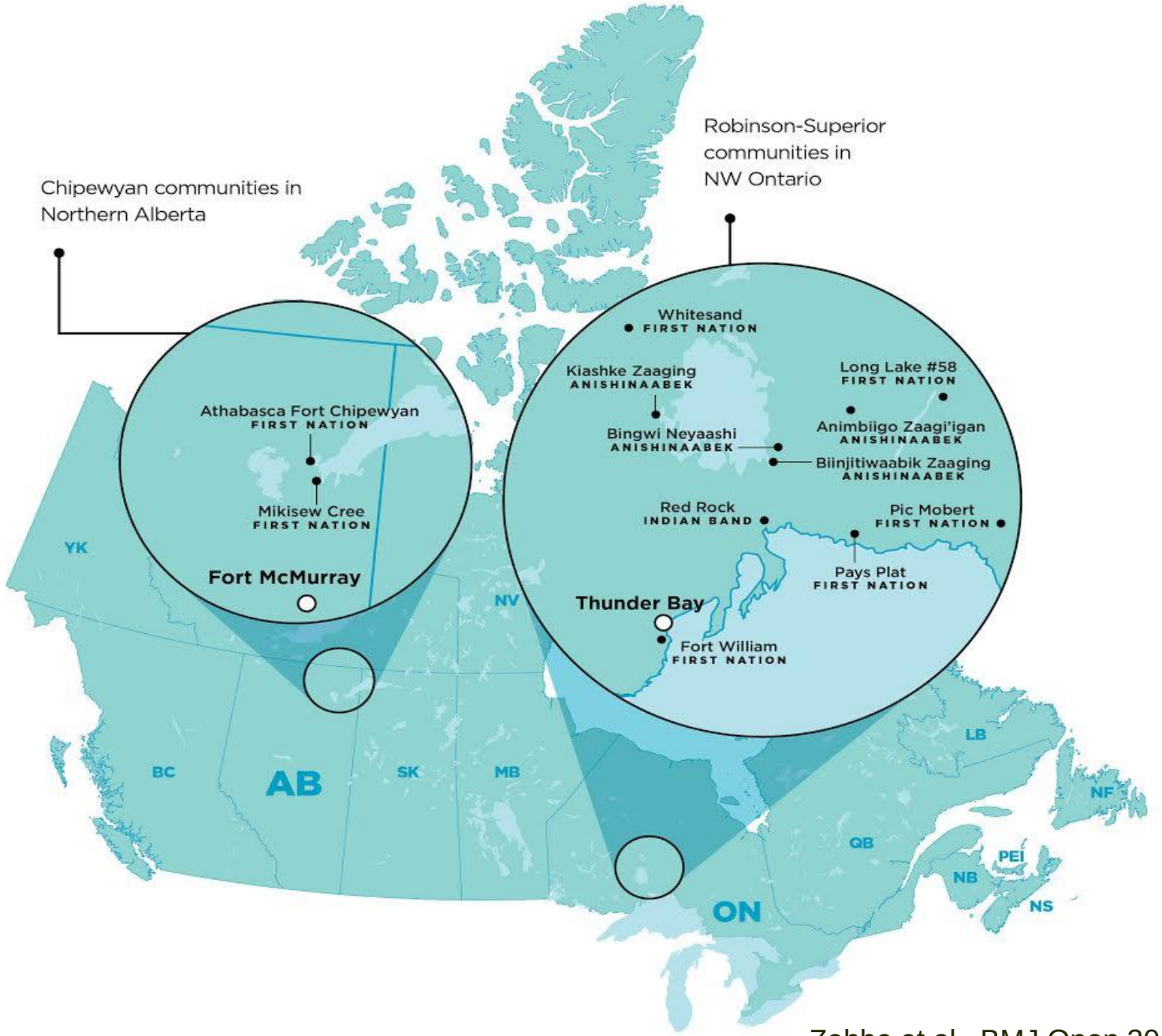
- 87% of women felt that self-sampling was a better option that would lead to increased screening participation
- Self-sample integrity was high (96%)
- 28.6% of samples were positive for HPV (both low and high risk types)
- 16.3% of samples were positive for HR-HPV (women were provided follow-up)

Conclusion:

- Success of the pilot led to an invitation to the All Chief's Meeting in 2010
- Larger study to include 10 First Nations called the **Anishinaabek Cervical Cancer Screening Study**

Wood et al (2014). Using community engagement to inform and implement a community-randomized controlled trial in the Anishinaabek Cervical Cancer Screening Study. Frontiers in Oncology, 427.

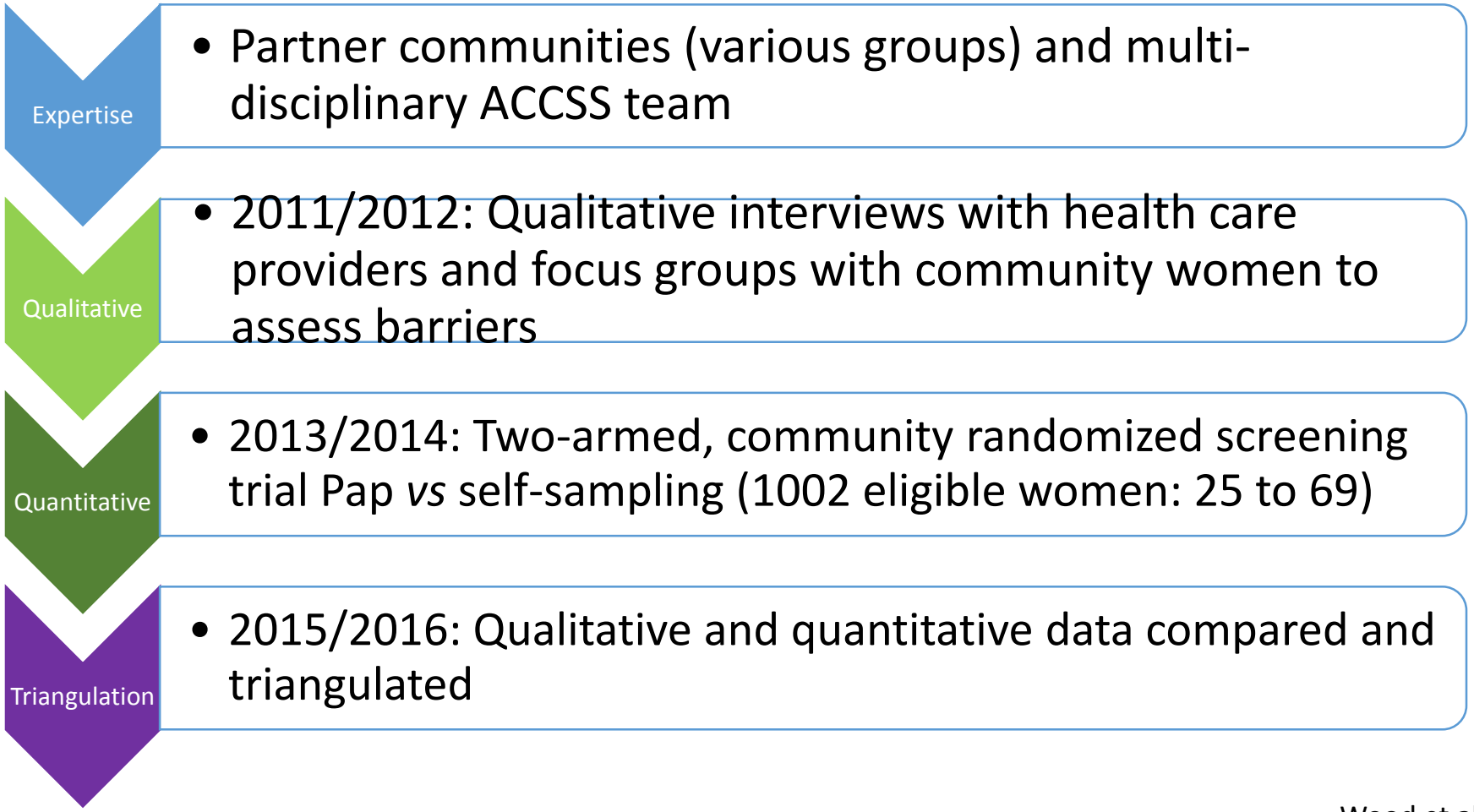
ACCSS partner communities



Zehbe et al., BMJ Open 2011 **(pilot study)**

- Animbiigoo Zaagi'igan Anishinaabek*
- Biinjitiwaabik Zaaging Anishinaabek
- Bingwi Neyaashi Anishinaabek*
- Fort William First Nation
- Kiashke Zaaging Anishinaabek
- Long Lake #58 First Nation
- Pays Plat First Nation
- Pic Mobert First Nation
- Red Rock Indian Band
- Whitesand First Nation

ACCSS approach: multi-disciplinary, mixed methods and community engagement



Wood et al., Front Oncol 2014

ACCSS – Community Engagement

The community leadership encouraged the research team members to:

- Attend community events to build a better relationship with local women
- Present at annual health fairs and cultural celebrations to raise awareness about the study and cervical cancer prevention in general
- Develop a clearly outlined process for HPV testing that was to remain blinded at the community level to give optimum privacy to participants
- Draft research agreements that could be tailored to the needs of the respective communities
- Community Steering Committee – provided guidance on cultural safety
- Publication Steering Committee – review of all publications, some writing

Workshop to Develop a Culturally Appropriate Brochure

- Engaged discussions about colonial legacy, cultural sensitivity and representations of Indigenous women's bodies

- Brochure collectively designed through workshops

- Issues of age, residential school histories, privacy and the body shaped the final design

  Fully clothed woman on the outside –
  images of PAP and self-sampling on the inside -
  to protect privacy

  (Zehbe et al. 2015)

ACCSS results

Qualitative

- Transportation barriers, access issues, education and socioeconomic inequalities, generational effects, colonial legacy; "*Education the biggest factor*"*

Quantitative

- Screening 1.8- (ITT) or 3-fold (PP) higher with self-sampling; 96% adequate self-tests; 19% HR HPV; 20% overall participation (range 0 to 62%)**

Triangulation

- *Women's voices*: unequivocal preference for self-sampling***; *trial questionnaires*: low participation caused low statistical power

*Maar et al., WHI 2013; HCWI 2014; Wakewich et al., CPH 2015; Zehbe et al., HEJ 2015; IJHPE 2016a
**Wood et al., Front Oncol 2014; Zehbe et al., 2016b (submitted)
*** Zehbe et al., 2016c (submitted)

Qualitative Data:
Interviews and focus groups

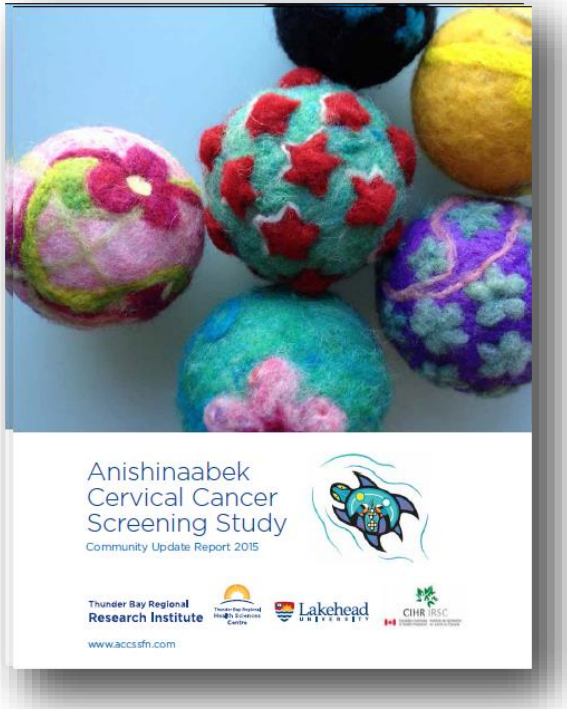
BARRIERS TO SCREENING:

- Shortage and high turnover of appropriate health care providers
- Trust issues with health care system
- Stigma and confidentiality
- Geographic and transportation barriers
- Education and socioeconomic inequalities
- Lack of culturally appropriate services
- Lack of a ‘notification system’ inviting/reminding eligible women to go for screening

NEED FOR EDUCATION:

Culturally tailored and age and gender specific education

Community Update Gathering October 2015



- 2 day event – sharing circles and discussion groups
- 2 members from each First Nation
- Stakeholders from Society of Obstetricians and Gynaecologists of Canada (SOGC) and Cancer Care Ontario (CCO)

Community update gathering

- Stakeholder meeting to review findings from the ACCSS trial
  - Community members, health care providers, policymakers, interdisciplinary research team

- Talking circle and World Café format
  - What worked and what could have been better?
  - What are the best approaches to deliver cancer screening and education in your community?
  - The project will be successful when _____?

What worked:

- Ethical space model
  - People felt heard and respected
  - Planning, education and decision making were shared
  - Cultural sensitivity was respected at all stages

  “We can sit down now and be one, rather than privileging one knowledge base over another”

- Persistence
  - Team’s commitment to keeping the project moving forward was positive

  “The fact that you’re trying continuously worked well”

- Self-sampling
  - Increased accessibility, more comfortable, respects privacy, “*Empowers women”*

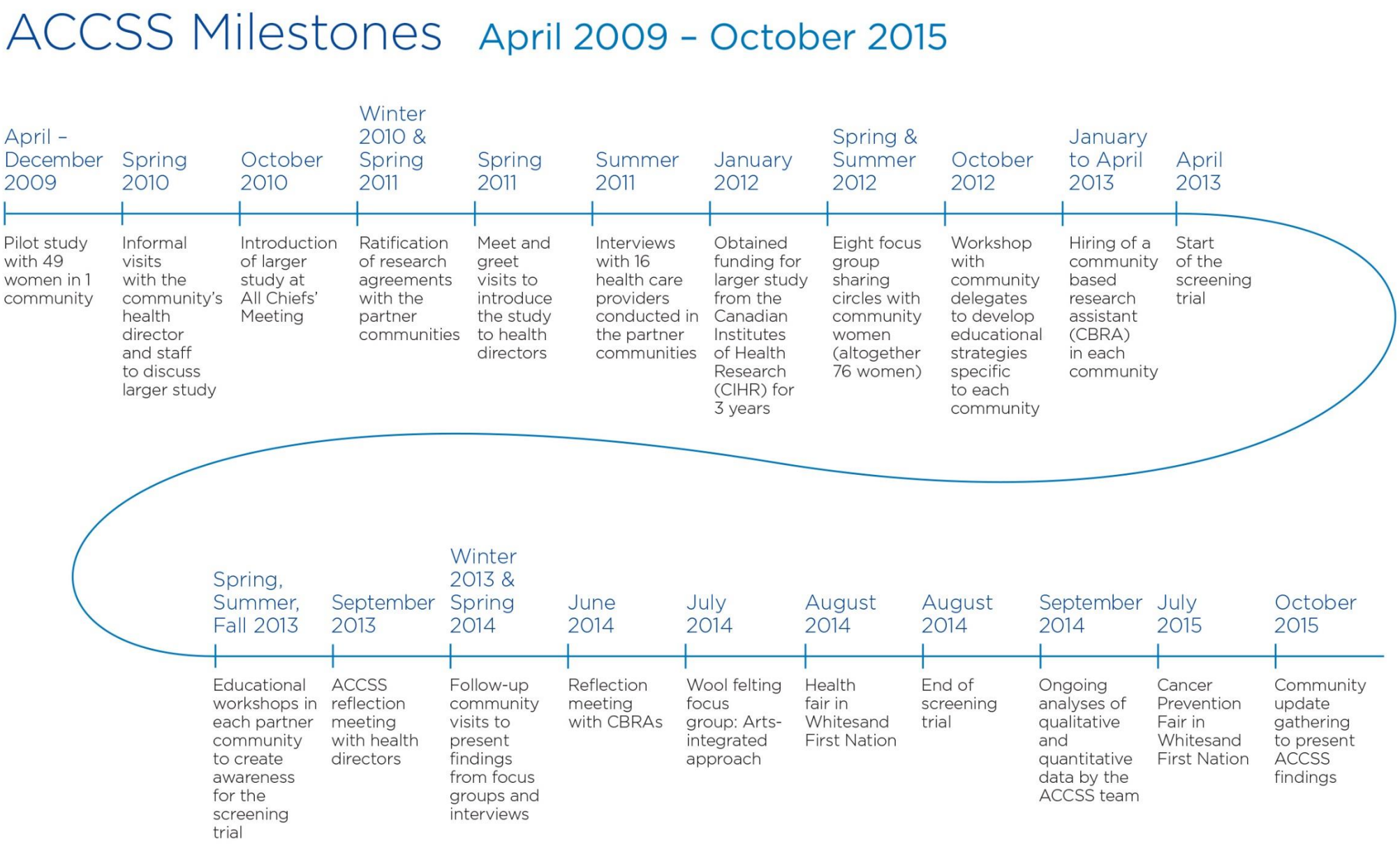
What we can improve:

- More tailored education
  - HCPs and community members
  - All ages and genders
  - *Start with young people*
  - Focus on well-being through the life course, rather than cancer *per se*
  - Expand the use of arts-integration – *"created a less hierarchical and safer environment to talk about personal issues and ask basic health questions"*

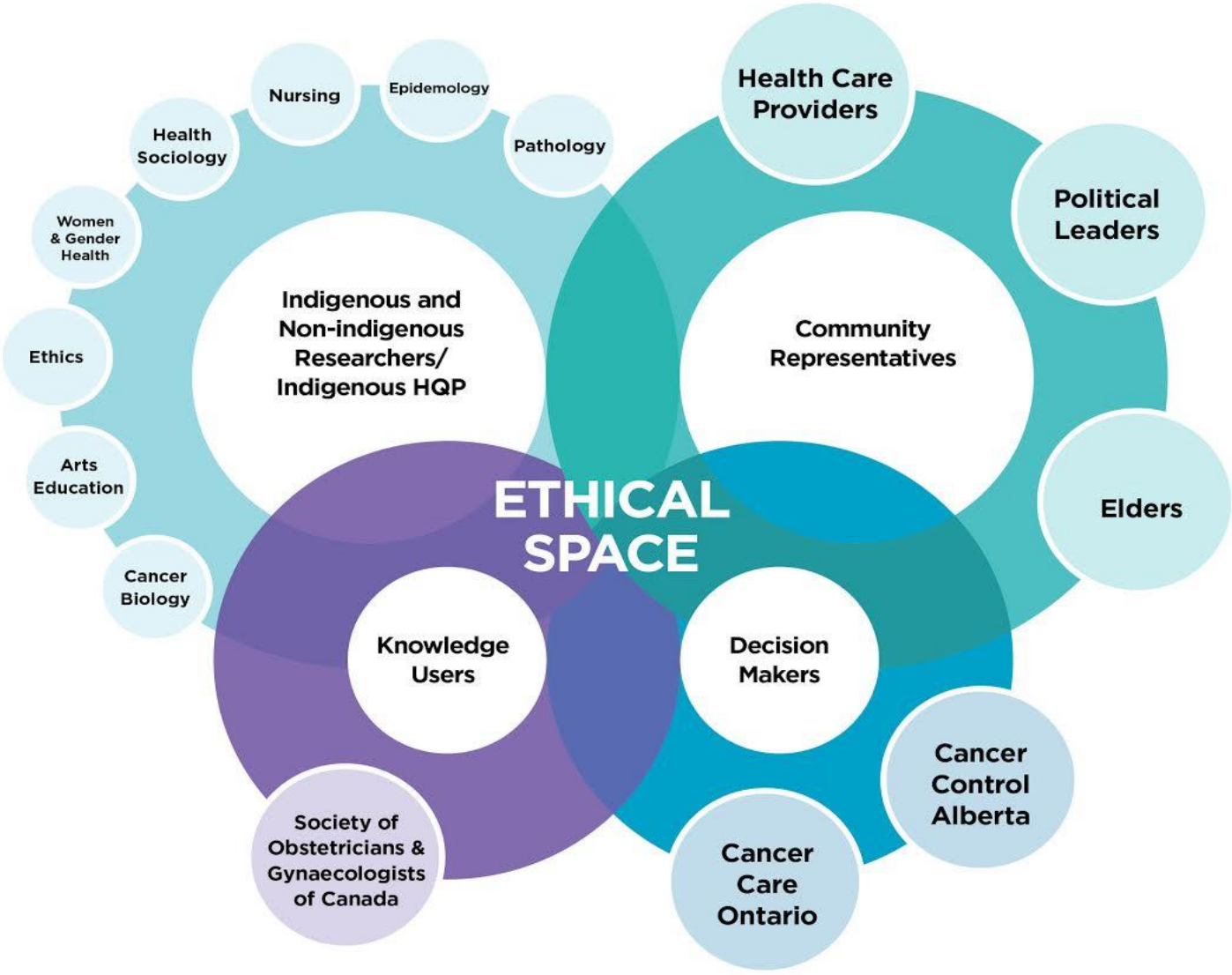
- More communication and time spent in communities
  - Ongoing relationship building, staff support during education and screening, keep project and team visible

- More flexible research design
  - Offer only self sampling
  - Screening at an earlier age
  - Screening kits continuously available

Challenges: Effective community engagement takes time



Facilitators: Getting all of the stakeholders to the table



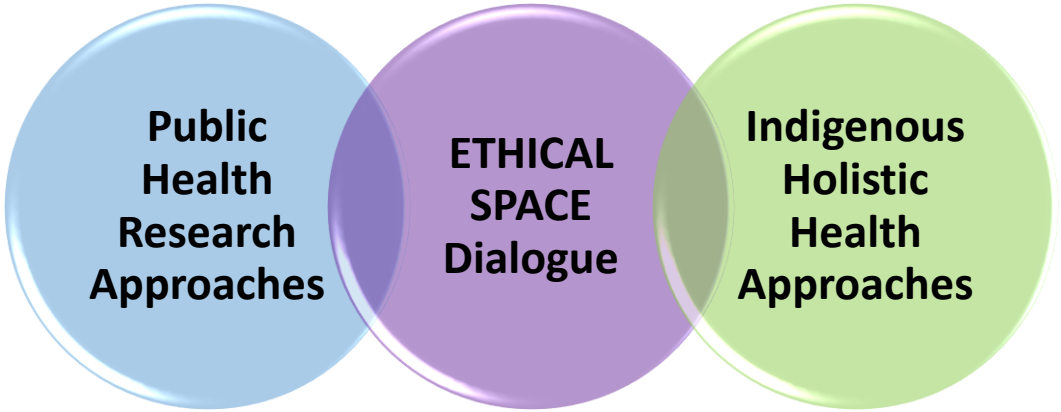
Zehbe et al., JAH 2012

Facilitators: respecting cultural sensitivity by using anEthical Space Model

Willie Ermine

ETHICAL SPACE:

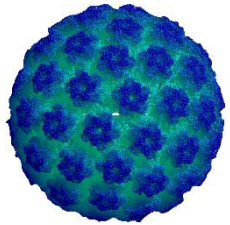
Builds bridges between disparate knowledge systems and cultures – a respectful form of engagement



Ermine, Indigenous Law J, 2007

Facilitators: Using the arts to build relations and understanding

Community HPV felting workshops



Sameshima et al., 2016

Workshop to co-design a screening brochure

Dialogic painting at the community update gathering

- Currently applying for funding to move into the implementation stages
- Community derived educational plans that can be maintained
- Including new communities in Northern Alberta as Pilot study to assess transferability of process
- Will only offer HPV testing
- Assessing the effectiveness of particular educational plans to increase uptake of cervical screening by self-sampling for HPV
- Recognize that creating awareness takes time – repeated education

- www.accssfn.com

Next steps …

- Community-tailored educational workshops
- Elder-led talking circles, health forums, retreats
- Arts-education initiatives for different ages and genders
- Crafting circles, T-shirt/video contest, boys & men's hunting retreat, moon-time girls
- HPV self-sampling trial in 2017/18

As the new ACCSS logo expresses:

- A more holistic focus *on well-being for life*…

www.accssfn.com

Acknowledgements

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The turtle logos for the Anishinaabek Cervical Cancer Screening were designed by **Mr. Kevin Belmore** from Kiashke Zaaging Anishinaabek.