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| **Title of Symposium** International Indigenous Cohort Collaborative: Wise practices in undertaking Indigenous cohort studies |
| **General Objective**Despite significant differences in the circumstances of Indigenous people globally, including Indigenous peoples in Australia, Canada and New Zealand, there are shared experiences in the persistent inequities across health outcomes and determinants (1-4). Key drivers of these inequities include Indigenous experiences of colonization, marginalization, family dislocation, racism, disconnection from land, loss of traditional lifestyle, and exclusion from the design, implementation, dissemination and governance of health research (1, 2). A key challenge in addressing Indigenous health inequities in Australia, Canada and New Zealand is the major data gaps in the coverage and quality of longitudinal Indigenous health assessment information.Well designed and implemented longitudinal studies provide sound evidence on the causes of health disparities, as well as an opportunity to monitor the incidence of key outcomes and provides the evidentiary foundation for implementation of public health approaches and interventions. The *International Indigenous Cohort Collaborative* works to address these gaps by bringing together Indigenous cohort study experts, community partners, knowledge-users and other stakeholders to assist with Indigenous cohort study development.This symposium will discuss ways in which our research can be conducted to ensure “wise-practices” for community engagement are followed throughout the duration of cohort studies. The term “wise-practice” is used in place of “best-practice” to ensure that Indigenous knowledge and practice is central and used to challenge the notion of robust and scientific “evidence” as something that only emerges from universities and/or non-Indigenous sources (5). The symposium will focus on a wise-practice framework and guidelines developed through shared learning and consensus building discussion circles.Panellists and participants will share information on ‘scaling-up’ studies, identifying robust community governance arrangements, potential research questions and priorities, inclusion of Indigenous specific methodologies and measures, use of suitable data platforms and catalysing new interdisciplinary collaborations. The results of these activities will support the development of longitudinal Indigenous cohort studies and in turn contribute towards developing valid and reliable health databases by, with and for Indigenous people around the world. **Proposed format of the session**1. Introduction and overview
2. Australia: Case study of the Mayi Kuwayu Study and potentially drawing on other cohort study experiences, such as the Longitudinal Study of Indigenous Children (LSIC)
3. Canada: Case study of Our Health Counts Study and potentially drawing on other cohort study experiences.
4. New Zealand: Case study of Te Ara Auahi Kore and potentially drawing on other cohort study experiences
5. Overview and panel session discussing Indigenous cohort study wise practices.

**Conference theme and/or subthemes addressed**1. Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.
2. Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights.
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| **Title of Presentation 1** An Overview: International Indigenous Cohort Collaborative |
| **General Objective**The symposium will focus on sharing and refining Indigenous cohort study wise-practices developed through shared learning and consensus building discussion circles. The results of these activities support the development of longitudinal Indigenous health cohort studies and in turn contribute towards developing valid and reliable population level health databases by, with and for Indigenous people around the world. **Proposed format of the session****Conference theme and/or subthemes addressed**Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights. |

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| **Title of Presentation 2** **Developing a National Indigenous Longitudinal Study (Mayi Kuwayu) in Australia Using Community Voices** |
| **General Objective**Culture is a key determinant of health and wellbeing for Aboriginal and Torres Strait Islander peoples in Australia, and for First Nations populations internationally. Cultural factors include (but are not limited to): identity; connection to country, family, and community; history; language; cultural knowledge and practice; and community engagement and empowerment. Aboriginal and Torres Strait Islander culture is increasingly recognised by communities, organisations and policymakers as a critical, yet under-researched, determinant of health. Despite this, there are currently virtually no data to establish the relationship between culture and wellbeing in the Aboriginal and Torres Strait Islander context, or to identify the mechanisms by which culture impacts on wellbeing. There is a clear need for research that identifies how Aboriginal and Torres Strait Islander peoples navigate the differing cultures in which their lives exist, and how this impacts their health and wellbeing.The Mayi Kuwayu Study is designed to address this lack of knowledge on a national scale, generating evidence about culture and its relationship to health and wellbeing through a large-scale cohort study of Aboriginal and Torres Strait Islander adults (estimated 16,000-40,000 participants). The Mayi Kuwayu Study will establish an ethical, community-focused and Aboriginal-controlled resource that will contribute to a holistic and contemporary understanding of Aboriginal and Torres Strait Islander culture, health and wellbeing. The overarching aim of the Mayi Kuwayu Study is to produce robust evidence on drivers of health and wellbeing, with a particular focus on integrating culture with standard risk factors. Specifically, the project will provide: (1) reliable national- and individual-level indicators of Aboriginal and Torres Strait Islander culture; (2) large-scale data on culture and cultural experiences, wellbeing, health behaviours, person-centred outcomes, sociodemographic and other factors, and their inter-relationships, both cross-sectionally and over time; and, (3) a state-of-the-art data resource for investigating Aboriginal and Torres Strait Islander wellbeing, which can also serve as a framework for policy and program planning.This panel discussion will cover: the genesis of the Mayi Kuwayu Study; the processes of developing the survey; findings from pilot tests of the survey; and, the next steps in study implementation.**Proposed format of the session****Conference theme and/or subthemes addressed**Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights. |

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| **Title of Presentation 3** Our Health Counts Ontario |
| **General Objective**In Canada, the majority of Indigenous people now live in cities (6) and there is good evidence that Indigenous health inequities do not improve with urban residence, and in some cases actually get worse (7-10). The virtual absence of population-based health status and healthcare utilization data for urban Indigenous peoples in Canada is a critical and alarming gap (11, 12). Urban Indigenous populations are not well captured through existing data collection mechanisms, and have essentially been left out of Canadian population health assessment and surveillance systems (3). The Well Living House applied Indigenous Health Research Action Centre along with their community partners, have worked to address this gap in population health data by undertaking the largest urban Indigenous health studies in Canada in 6 urban centres across Ontario. The OHC studies have provided evidence of the magnitude of census undercounts of ‘hard-to-reach’ subpopulations and have worked to improve estimation of the size of the urban indigenous population in urban centres in Canada, using respondent-driven sampling (RDS). The Toronto study for example showed that the most recent Canadian census underestimated the size of the Indigenous population in Toronto by a factor of 2 to 4. OHC also collected baseline data on demographic characteristics, including Indigenous identity, age, gender, income, household type and household size. The implications of collecting census completion information and population health statistics will have broad impacts across governmental and health policy, potentially improving healthcare access for urban communities. This presentation will discuss and provide examples of community based research agreements, Ownership, Control, Access and Possession (OCAP®) principles and knowledge translation and dissemination. This case study will also highlight Indigenous enumeration methods, including RDS which uses a kin-ship based recruiting method, and further wise practices for community engagement executed throughout the duration of the Our Health Counts studies.**Proposed format of the session****Conference theme and/or subthemes addressed**Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights. |

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| **Title of Presentation 4**The Te Ara Auahi Kore (TAKe) research project  |
| **General Objective**Te Rōpū Rangahau Hauora a Eru Pōmare (University of Otago, Wellington) and Whakauae Research Services (Whanganui) have been funded by the Health Research Council NZ to carry out the **T**e Ara **A**uahi **K**or**e** (TAKe) research project. The project started in November 2016 and will run for three years. It aims to:1. Evaluate the impact of tobacco control policies and interventions on smoking within a Māori cohort (group).
2. Evaluate the potential of different policy options for reducing smoking disparities and achieving a Tupeka Kore Aotearoa 2025 for Māori.
3. Understand how whānau experience tobacco control activities (e.g. tax, denormalisation of smoking etc.) and how this impacts on smoking behaviours among members.
4. Use findings to stimulate evidence informed action within Māori health providers and communities.

The project involves three research studies that will be conducted at intervals over three years. * The first study will be the Policy and Intervention (PAI) Survey. This is a survey of organisations engaged in tobacco control activities in your area and will be sent out to various organizations at the end of May 2017 and again in 2018. It will provide background information for the cohort study.
* The second and most resource intensive TAKe study will be a baseline and follow-up survey of a cohort of Māori smokers enrolled with each of the participating providers. This study started in late 2017.
* The third study will interview whānau to explore the impacts of tobacco control activities and identify opportunities for building whānau support for a Tupeka Kore (Tobacco Free) 2025. Resource limitations mean this study will only be conducted in the Wellington and East Coast locations.

Te Rōpū Rangahau Hauora a Eru Pōmare (University of Otago, Wellington) and Whakauae Research Services (Whanganui) are working in partnership with Te Tai Tokerau PHO, National Hauora Coalition, Ngā Mataapuna Oranga, Ngāti Porou Hauora, Ora Toa PHO, and Kokiri Marae Keriana Olsen Trust. We hope the knowledge gained from the research will help to inform Māori tobacco control activities in the regions where the study is taking place. To this end we have formed a Rōpū Kaitiaki (advisory group) that includes representatives from participating health providers, we will visit providers over the course of the study, and work with our partner organizations to employ Māori research assistants to conduct the fieldwork for the study. **Conference theme and/or subthemes addressed**Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights. |

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| **Title of Presentation 5** Overview and panel session discussing Indigenous cohort study wise practices. |
| **General Objective**A guiding intention of fostering the International Indigenous Cohort Collaborative is to support the development of “wise” practice guidelines for Indigenous cohort studies. The International Indigenous Cohort Collaborative constructed a framework of wise practice guidelines including governance, the development of research aims and objectives, methods and methodology, construction of instruments, analysis and knowledge translation and dissemination. This final presentation and panel session will draw on the three presented case studies to highlight the similarities and differences between the three contexts, and provide an analysis of emerging themes and opportunities for learning from the studies for current and future studies. This portion of the symposium will include interactive examples and allow for audience participation, including discussion and question and answer with panel members. **Proposed format of the session****Conference theme and/or subthemes addressed**Ensure health equity throughout the life course, within and among countries, making each member of the global society an empowered lifelong learner.Build effective, accountable and inclusive governance at all levels that promotes, peace, justice and respect of human rights. |

**References**

1. Foliaki S, Pearce N. Changing pattern of ill health for indigenous people. British Medical Journal. 2003;327(7412):406-7.

2. Cunningham C, Stanley F. Indigenous by definition, experience, or world view. British Medical Journal. 2003;327(7412):403-4.

3. Smylie J, Firestone M, Cochran L, Prince C, Maracle S, Morley M, et al. Our Health Counts Urban Aboriginal Health Database Research Project: Community Report. 2011. 2014.

4. Statistics Canada. Aboriginal Peoples Survey 2006: Adults, Children and Youth. In: Statistics Canada, editor. Ottawa, Canada2006.

5. Well Living House. Emergent principles and protocols for Indigenous Health Service evaluation: summary report of a provincial “three ribbon” expert consensus panel. Toronto: Well Living House, Centre for Urban Health Solutions, St. Michael's Hospital; 2017.

6. Vos T, Barker B, Stanley L, Lopez A. The burden of disease and injury in Aboriginal and Torres Strait Islander peoples 2003. Brisbane: The University of Queensland: School of Population Health; 2007.

7. Australian Bureau of Statistics. 2012–13 National Aboriginal and Torres Strait Islander Health Survey. Canberra: Australian Bureau of Statistics,; 2013.

8. Statistics Canada. Canadian Community Health Survey 2013. Ottawa.; 2012.

9. Carson KV. Smoking cessation and tobacco abuse prevention in Indigenous populations. Evidence Base. 2015.

10. Carson K, Brinn M, Peters M, Veale A, Esterman A, Smith B. Interventions for smoking cessation in Indigenous populations. Cochrane Database of Systematic Reviews. 2012.

11. Smylie J, Anderson M. Understanding the health of Indigenous peoples in Canada: key methodological and conceptual challenges. Canadian Medical Association Journal. 2006;175(6):602-.

12. Shah CP, Farkas CS. The health of Indians in Canadian cities: a challenge to the health care system. Canadian Medical Association Journal. 1985;133(9):859.