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Walking the path together: working in partnership to incorporate Indigenous knowledge in diabetes research

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Impacts of colonisation and the social determinants of health are significant contributors to the epidemic of type 2 diabetes in Indigenous peoples globally[1]. Indigenous (defined here as First Nations peoples in Canada and Aboriginal and Torres Strait Islander peoples in Australia) populations share unique strengths in their connection to land, language and culture. The impact of colonisation shared by Canadian and Australian Indigenous peoples, has resulted in significant discrimination and marginalisation leading to poverty, loss of lands, languages and cultures. Government policies in both countries forcibly removed Indigenous children from families and communities and placed children into residential schools, missions and/or government-run institutions, contributing to significant intergenerational trauma and loss of language and cultural connection.

Indigenous peoples in Australia and Canada experience disproportionately higher prevalence and earlier age of onset of type 2 diabetes and related chronic conditions than non-Indigenous populations[2,3]. In both countries, the intergenerational impact of type 2 diabetes among Indigenous peoples has been described, with in-utero exposure to maternal diabetes as a strong contributor to youth-onset type 2 diabetes risk [4,5]. The incidence of youth-onset type 2 diabetes and subsequently, diabetes in pregnancy, continues to rise in Australian and Canadian Indigenous peoples over the past three decades, resulting in an epidemic of intergenerational type 2 diabetes.

Barriers to chronic disease self-management include intergenerational trauma, loss of language, culture and geographic challenges, which have not routinely been addressed in prevention or treatment efforts. Despite intensive pharmacologic and lifestyle management, recent evidence from the USA (likely generalizable to other settings) has shown that medical management will fail in over 50% of youth with type 2 diabetes over a three-year period[6]. Indigenous youth face unique barriers to health including a lack of culturally-informed and safe care which incorporates traditional ways of knowing and being. In addition, Indigenous youth face significant poverty, food insecurity and stigma which significantly impacts glucose levels[7]. The inclusion of youth with type 2 diabetes, their caregivers and the community are paramount to developing relevant strategies for diabetes prevention and treatment. Development of a socio-ecological approach[8], requires equal partnership between non-Indigenous and Indigenous scholars and youth with lived experience. This "two eyed" way of seeing allows for a bidirectional discourse in priority setting, design and implementation of prevention/treatment efforts and appropriate interpretation of research results.

This paper discusses two initiatives, one Canadian and one Australian, that we have developed in partnership with Indigenous people and communities, to address the challenges of type 2 diabetes in Indigenous youth. Both initiatives developed formal Indigenous advisory groups with clear roles within the research's governance structures. These initiatives have strengthened the existing partnerships between researchers and Indigenous communities; Indigenous peoples' roles and contributions have been respected and recognized, including governance relating to Indigenous knowledges in Indigenous health research.

In 2010, an Indigenous stakeholder advisory group was formed to work in partnership with the DREAM (diabetes research envisioned and accomplished in Manitoba) research group in Canada. The goal was to expand upon western medical knowledge and include the knowledge of Indigenous scholars (elders, caregivers and individuals with lived experience) to elevate prevention and care efforts of Indigenous youth with/at-risk for type 2 diabetes. Indigenous and non-Indigenous researchers, community members and stakeholders meet quarterly to share ideas, successes and struggles. This partnership has been instrumental in prioritising patient and community-reported outcomes, building components of community-based interventions, and engaging Indigenous trainees in science and clinical research. Together, we have prioritised mental health support for youth, community-based diabetes screening, and resiliency-based interventions including culturally-based ceremonies. Youth and family research advisors have produced knowledge translation materials including a video on the stigma associated with type 2 diabetes.

The DIABETES across the LIFECOURSE: Northern Australia Partnership commenced in the Northern Territory (NT), Australia in 2011. This partnership of researchers, policy makers and health service providers, aims to improve systems of care and health outcomes for people with type 2 diabetes in remote northern Australia[9]. In 2017, an Indigenous Reference Group (IRG) was established, in response to an identified need by key partners for Indigenous leadership and guidance. The IRG advises investigators to ensure that research is conducted in culturally appropriate ways. As Aboriginal researchers, it is important to acknowledge that knowledge is power and should be used for the benefit of Indigenous people and their communities. It is essential to understand and acknowledge the many negative impacts that research has had historically for Indigenous people. As Aboriginal researchers and Aboriginal members we are accountable to our institutions, our people and our communities.

Incorporating Indigenous knowledge into research is paramount to ensure an independent Indigenous perspective on the management and conduct of a research project, so that research is conducted appropriately and respectfully with Indigenous people[10]. It is critical that research is respectful of local communities and that research priorities are aligned to those of local communities. Similar impacts of colonisation and systemic racism on Indigenous peoples in Canada and Australia have contributed to the highest rates of type 2 diabetes amongst any population worldwide. Yet in the face of adversity, Indigenous peoples in both countries continue to thrive and show exceptional resiliency. Although much progress has been made to identify the missing socio-ecological and cultural context of youth-onset diabetes (by the Canadian and Australian groups), more work remains. We will only begin to affect change in the type 2 diabetes landscape in Indigenous people if we work together, in partnership to build upon these strengths.

Declaration of interests

The authors declare no conflicts of interest.

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