The Global Alliance for Chronic Diseases researchers' statement on non-communicable disease research with Indigenous peoples

The Global Alliance for Chronic Diseases (GACD) is an international alliance of public funders of health research in over 70 countries. GACD supports non-communicable disease (NCD) implementation science research in low-income to middle-income countries (LMICs) and priority populations in high-income countries, such as Indigenous peoples.[1] GACD's Indigenous Population Working Group (IPWG), led by Indigenous researchers, was established to ensure Indigenous guidance, and address gaps in implementation science with Indigenous peoples.

Indigenous peoples represent a diversity of cultures, contexts, and lived experiences. They inhabit over 90 countries, constitute 6% of the global population (~370 million people), and speak 7000 languages.[2] According to the UN, Indigenous peoples represent approximately 15% of the world's extremely poor, with a life expectancy of up to 20 years less than non-Indigenous peoples.[3] This health inequity is primarily attributable to high rates of non-communicable, chronic diseases.

Chronic diseases have a greater debilitating effect on the health and mortality of Indigenous populations because of colonisation, which impacts mental, emotional, spiritual, and physical health. Colonisation undermines the health of Indigenous peoples in many ways, including the commodification, pollution, and extraction of elements of life (eg, water, animals, and land),[4] which maintains socioeconomic disadvantages and lifestyle risk factors such as poor nutrition, physical inactivity, smoking, and obesity.

A key criticism of Indigenous health research is the preponderance of descriptive studies and studies that highlight deficit narratives, with little research focused on the social–cultural determinants, protective factors, and health-promoting aspects of Indigenous cultures.[5] There are also less Indigenous people with advanced university degrees and research training than non-Indigenous people. A paucity of Indigenous researchers can lead to an imbalance in collaborative research practice, where non-Indigenous researchers appear to know better how to proceed but might not have acquired sufficient knowledge about the culture, history, and context of the people they intend to study.

The complex and ongoing influence of colonisation must be explored and addressed to overcome the disproportionately harmful effect of chronic diseases in Indigenous populations. Understanding the local needs and aspirations and the reasons for the rise in NCDs will help to fill gaps in implementation research. Enhancing the Indigenous research workforce requires supporting early-mid-career researchers and developing Indigenous principal investigators.[6] Research must provide immediate tangible benefits to the communities being studied.

Decolonising and Indigenising research methods and practices has been helpful in enabling Indigenous peoples to improve their lives, by overcoming the failures of inherently colonial structures, policies, and practices.[7] Strategies include discourses acknowledging the strengths of Indigenous communities, privileging Indigenous knowledges, and respecting Indigenous research frameworks. Community-based participatory research methods and approaches are needed to overcome many of the shortcomings of extractive Eurocentric research,[8] such as integrating the principles of co-design within Indigenous worldviews. Research should be conducted with and by Indigenous peoples, not for or on Indigenous peoples. Co-design involves a partnership with the Indigenous communities who will be the end-users of the research and should take place throughout the entire research process, from generating the research question through to design, implementation, evaluation, and the dissemination of the findings.

High-quality evidence is essential to address inequities and close gaps in Indigenous peoples' health outcomes. Understanding context is crucial to improving population-health outcomes. For effective implementation and sustained programmes, locally designed and contextually adapted programmes and services must be supported with strategies rooted in Indigenous cultures and must continuously encourage

local leadership and decision making.[9,10] Collaboration involves privileging Indigenous knowledges, creating safe spaces for knowledge exchange, respecting people's self-determination, and building skills and research capacity. At the outset, attention must be paid to community concerns, cultural protocols, data sovereignty, Indigenous collaboration in the interpretation of findings, and ethical considerations congruent with cultural values. Cross-cultural rigor is crucial to building trust and avoiding harmful colonial practices.

Non-Indigenous researchers and Indigenous peoples need to develop a trusting relationship to recognise and appreciate the value of what can be learned from each other. Shared confidence depends on non-Indigenous researchers developing knowledge of Indigenous cultures, histories, and contexts and compassion for the challenges Indigenous people face. Indigenous research partners might need to increase their understanding of research, its methodologies, inherent limitations, and ethical challenges.

Ideally, decolonising research practices will involve decolonising the funding by ascertaining which institutions are eligible for funding and mapping how funding is disbursed by funders. Currently, most public funders provide a grant award to a single administering research institution (the employer of the principal investigator) with money then flowing to other participating investigators and institutions. This financial control model is tolerated among academic researchers; however, it can foster a power imbalance between the researchers and the community. Co-design, including a choice of research topic, can help investigators and methodologies ameliorate this power imbalance, but cannot fully overcome it. Research governance must include co-leadership, data ownership, sharing, intellectual property rights, and ethical considerations congruent with cultural values. Budgetary allocations among the research institutions and Indigenous communities must be clearly articulated in research proposals to promote maximum self-determination. Appropriate and equitable governance should be an important consideration in funders' decisions to support a proposal. Funding organisations must be active participants in the decolonisation of the research process.

We advocate that implementation science research with Indigenous communities apply co-design principles to seek Indigenous perspectives and understand conflicts with colonist worldviews. Successful collaboration requires non-Indigenous researchers to develop their knowledge and understanding of Indigenous Peoples' sociocultural perspectives, to be open to alternative approaches and conceptualisations of research goals and methodologies, and to build the research capacity of Indigenous peoples. Cross-cultural sensibility and rigor will improve research quality and true partnerships for the benefit of Indigenous communities. This statement advocates using decolonisation methodological frameworks that privilege Indigenous voices and ways of knowing, being, and doing. The statement also supports building Indigenous researcher capabilities to lead future GACD-funded research. The principles outlined are intentionally broad to reflect the heterogeneity of Indigenous peoples and to ensure their different sociocultural and health contexts are recognised and respected.

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