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The Global Alliance for Chronic Diseases researchers' statement on

Non-communicable disease research with Indigenous peoples



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Meharg DP et al, on behalf of the
GACD Indigenous Populations
Working Group

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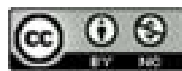
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RESEARCHERS' STATEMENT

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Background

The Global Alliance for Chronic Diseases (GACD) is an international alliance of public funders of health research (1). GACD represents more than 80 percent of all public research funding in the world, and over the last ten years has invested \$223 million in non-communicable disease (NCD) research in more than 70 countries (1). The GACD supports NCD implementation science research in low to middle-income countries (LMIC) and in priority populations in high-income countries, such as Indigenous Peoples (2). GACD has initiated six research funding calls in hypertension, diabetes, lung disease, mental health, scaling up interventions for hypertension and diabetes, and most recently cancer prevention and early diagnosis (1, 2). As of June 2022, GACD have funded 134 projects in total, 15 involving Indigenous Peoples from countries such as Australia, Canada, New Zealand, India, Tanzania, China and Mexico. The total research investment with Indigenous peoples to date is approximately US\$16 million, with funding periods ranging from 2–5 years.

To ensure effective Indigenous representation and guidance to develop GACD Indigenous research initiatives, the GACD's Indigenous Population Working Group (IPWG) was established in 2018. The GACD IPWG is led by Indigenous researchers. Membership consists of Indigenous and non-Indigenous researchers, clinicians, medical administrators, and policy makers from across the world. The GACD IPWG respects the principle of self-determination and is committed to building an integrated network of Indigenous and non-Indigenous researchers through reflective allyship, to transform how GACD funded Indigenous health research is approached. The GACD IPWG aims to address gaps in implementation science related to NCD research with Indigenous Peoples. Members of the GACD IPWG recognize Indigenous Peoples have different economic and socio-cultural contexts when compared to non-Indigenous people. Understanding these unique differences is essential to strengthening the viability, suitability, and sustainability of Indigenous research in implementation science. Through this statement the GACD IPWG intends to guide future research activities to:

- a) Promote the application of implementation science in Indigenous contexts;
- b) Co-design research with Indigenous Peoples that align with their goals, values and perspectives;
- c) Promote culturally safe research practices guided by Indigenous epistemologies, methodologies, and practices (i.e. Indigenous ways of knowing, being and doing);
- d) Promote research that responds to the knowledge needs expressed by Indigenous communities;
- e) Increase the research capability of Indigenous Peoples and Indigenous researchers to develop and lead research that addresses their concerns, and;
- f) Advocate for additional funding to support collaborative research with Indigenous communities.

Implementation science research

Implementation science is the scientific study of methods to support the systematic uptake of research findings into practice (3). In health research, implementation science aims to improve the quality and effectiveness of health services by promoting the uptake of research evidence in routine health care (4). Implementation science contributes to the 'know-do' gap in real world settings by considering the local context. It uses systematic research methods to evaluate and improve knowledge translation to inform policy (4, 5). Various frameworks are available to guide implementation science research practice, such as the Knowledge-to-Action Cycle. The Knowledge to Action Cycle prompts researchers to adapt interventions, using participatory action to fit local contexts of the community or organization (5, 6). Implementation science is also committed to understanding factors affecting successful implementation through outcome variables, such as acceptability, adoption, equity, appropriateness, feasibility, fidelity, cost, coverage, and sustainability (5).

Implementation science research within an Indigenous context

Within an Indigenous context, effective implementation science-based interventions respond to the local contexts and embed Indigenous voices, knowledges and cultures as central elements (7). Such research should be guided by shared decision-making through sustained community stakeholder engagement (7). It is essential to ensure health interventions are culturally appropriate, relevant and community owned and include elements of culture-centered approaches, community engagement, systems thinking and knowledge translation to support gains in health outcomes and equity (7). Further, implementation science theoretical frameworks and guidelines used for NCD health interventions with Indigenous communities should be continually reviewed from an Indigenous perspective. A case in point is the World Health Organization's (WHO), *'Implementation Research in Health: A Practical Guide'*: this guide informs the implementation of health public policy and programs and the scale up of health interventions (6), but does not offer any specific guidance for undertaking implementation science research with Indigenous Peoples. It would be invaluable to incorporate recent learnings on the importance of incorporating Indigenous knowledges, methodologies and culturally centered approaches to promote self-determination, community engagement and cultural adaptation (7-9). These are all essential elements when designing sustainable and effective interventions to address NCDs within Indigenous communities, with each element enhancing implementation to attain maximum impact.

Collaborative Indigenous funding

It is of fundamental importance to obtain funding to support collaborative seeding or scaling-up projects in implementation science with Indigenous peoples (10). Funding collaborative Indigenous research guided by Indigenous ways of working supports cross-cultural knowledge exchange between countries and Indigenous peoples (11), recognizing both commonalities and differences in Indigenous peoples from different cultures. The Tri-partite agreement between health research funding agencies in Australia, New Zealand and Canada provides a robust example of collaborative Indigenous research that respects the expertise, cultures, and values of the communities they represent. The agreement aims to improve the health and wellness of Indigenous Peoples and strengthen the Indigenous health research workforce in these similarly colonized countries (12). Building on lessons learned, the funders embarked on joint research calls in areas of significant health burden such as diabetes, suicide prevention and chronic lung disease. Three of the GACD alliance members, the National Health & Medical Research Council - Australia, Canadian Institutes of Health Research, and the Health Research Council of New Zealand, encourage research proposals that include co-funding between these organizations to conduct implementation science research with the Indigenous Peoples of these three countries. To date, however, GACD have not funded any proposals that have been jointly co-funded across these three organizations. Systemic barriers related to different submission criteria of the funding bodies across these countries have impacted GACD IPWG members successfully submitting co-funded proposals. Barriers such as these need to be addressed to ensure funds for collaborative Indigenous research are available and utilized as intended.

The Statement

The issue

Indigenous Peoples worldwide represent a remarkable diversity of cultures, contexts, and lived experiences. The United Nations estimates Indigenous Peoples make up 6 percent of the global population (approx. 370 million Indigenous people), across more than 90 low-, middle- and high-income countries and speaking 7,000 languages (13). Indigenous Peoples represent approximately 15 percent of the extreme poor, with a life expectancy that is up to 20 years less than non-Indigenous peoples worldwide (14). Even within high income countries Indigenous peoples experience sizable health disparities compared with non-Indigenous people living in the same country (15). Historically this was primarily attributable to infectious diseases but currently is also a consequence of high levels of non-communicable, chronic diseases and persisting health inequities across the lifespan.

For Indigenous Peoples, the high levels of chronic disease and associated morbidity and mortality are not mitigated by residing in high-income countries. While chronic diseases are prevalent within industrialized societies, these diseases appear to have a greater debilitating effect on the health and mortality of Indigenous populations (16). The common unifying factor in these disparities is not genetic or physiological – it is the shared experience of colonization which impacts mental, emotional, spiritual, and physical health (17). Colonization acts to undermine the health of Indigenous Peoples by a variety of means including the commodification and extraction of elements of life (e.g., water, animals, land) considered integral to Indigenous well-being (18). Persisting socio-economic disadvantages and lifestyle risk factors such as poor nutrition, physical inactivity, smoking, and obesity continue to be more prevalent among Indigenous populations, placing these communities at a greater risk of developing chronic diseases (19). Moreover, most of the Indigenous population have moved away from their traditional dietary habits due to modernization and industrialization.

A growing body of evidence links the effects of Indigenous Peoples' intergenerational trauma, adverse childhood experiences, and ongoing colonization with chronic diseases and adverse health outcomes (20, 21). At a physiological level these effects may be mediated by epigenetics (20, 22, 23) or what some Indigenous communities would term "blood memory." In addition, institutional practices, policies, and cultures are decidedly colonial and ethnically subversive in nature and have excluded Indigenous voices, and ways of knowing, being and doing, from important dialogues regarding health, research, education, and policy. This may explain the failure of health research involving Indigenous communities to reliably improve outcomes (24-26). Thus, there is an imperative to explore approaches to implementation science which translate to improved health outcomes for Indigenous communities (27).

High quality evidence is essential to address inequities and close gaps in Indigenous Peoples health outcomes (27). There are relatively few Indigenous people with advanced university degrees and training in developing and conducting research (28, 29). This is compounded by challenges related to the educational pipeline, contributing to the underrepresentation of Indigenous researchers as Principal Investigators (30). This can result in an imbalance in collaborative interactions, where non-Indigenous researchers, who have research expertise appear to know better how to proceed, but have not acquired sufficient knowledge about the culture, history and circumstances of the Indigenous people they intend to study. This may hinder the development of true partnerships and collaborations, or at the least require substantial investments of time and energy by the Indigenous community and the non-Indigenous researchers in acquiring this knowledge and developing a common ground for discussion and collaboration (31).

It is important for researchers and policy makers to recognize that effective implementation of a health program or service in an Indigenous community, incorporates Indigenous knowledges, values and cultures (32). For effective implementation, locally designed and contextually adapted programs or services need to be supported with strategies rooted in Indigenous culture and be continuously encouraging of local leadership and decision making (27). Involving and training the Indigenous population to sustain the

implemented changes should also be explored. Further, a limitation within the field of Indigenous health research is the preponderance of descriptive studies and paucity of interventional research (33, 34). There is not only the need for Indigenous health-related research, but additional attention should be given to the nature and style of the research (31). Key criticisms about Indigenous health research to date is its focus on risk factors and deficits, with limited research focused on the social-cultural determinants, protective factors and health-promoting aspects of Indigenous cultures (34). The increasing interest in implementation science and program evaluation within Indigenous contexts may begin to address some of these deficits (35-38).

The solution

In order to address the harmful effects of chronic diseases which disproportionately affect Indigenous communities, the complex and ongoing *influence of colonization* must be explored and addressed (39, 40). Colonization is embedded in many aspects of western research practices. Research with Indigenous Peoples must value respect, responsibility, relationships, and reciprocity if it is to be done 'in a good way' (41, 42). Learning the *local needs and aspirations*, and the reasons for the rise in NCD among Indigenous Peoples through research will help in understanding the Indigenous communities in more detailed manner and assist in filling the necessary gaps in implementation research. This research needs to be complemented by studies of the health-enhancing potential of Indigenous cultures, values and traditional practices. While testing the effectiveness of interventions in Indigenous communities, the *context* is critical to improving population health outcomes (43). There is a new era of Indigenous research with an imperative for a stronger alignment of research ethics, methods and approaches that are congruent with Indigenous values and worldviews, and research led by Indigenous peoples (44). Enhancing the future Indigenous research workforce requires advocating and supporting the progression of early-mid career Indigenous researchers and initiatives to develop Indigenous Principal Investigators (30, 45-47). Further, research findings must provide *immediate benefit back* to the study communities or organizations.

Decolonizing and Indigenizing methodologies and practices to research have been proposed to be more respectful and useful in improving the lives of Indigenous Peoples, by overcoming the failures of inherently colonial structures and practices (48-51). The methodological approach to research *with* Indigenous People is as important as the outcomes. Strategies include discourses acknowledging the strengths of Indigenous communities, privileging Indigenous knowledges, and utilizing Indigenous research paradigms (52-57). *Community-based participatory research* methodologies and approaches are needed to overcome many of the shortcomings of extractive Eurocentric research (36, 58-60). In participatory research, the *principles of co-design* fit with the philosophical paradigms of Indigenous Peoples, which focus on connectiveness and collective enquiry and decision making (61). Indigenous Peoples have a strong directive that research should be done *with, for and by them, not on them* (62). Co-design is 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 design, implementation, evaluation and dissemination of the findings (63).

A strong commitment to the principles of co-design to work collaboratively with Indigenous communities, privileging Indigenous knowledges, creating safe spaces for knowledge exchange, respecting Indigenous self-determination, and *building local skills and research capacity* is imperative for any research to be meaningful and impactful. At the outset of any research or implementation science endeavor, attention must be paid to community concerns, cultural protocols, data sovereignty, and ethical considerations that are congruent with cultural values. This is crucial to *building trust* and to avoid replicating harmful colonial practices. Ultimately, open dialogue and the development of meaningful relationships with Indigenous Peoples is needed to reduce the health inequities that are rooted in the historical and ongoing effects of colonization (64).

To develop the necessary foundation for collaborative research, there is a need for both non-Indigenous researchers and members of Indigenous communities to develop a trusting relationship in which they see and appreciate the value of what may be *learnt from each other*. This may involve non-Indigenous researchers developing knowledge of the culture, history and context of the Indigenous people, and

compassion for their struggles and challenges. Indigenous research partners may need to increase their understanding of research, its methodologies and ethical challenges, in order to better engage in dialogues and collaborations with non-Indigenous researchers. GACD is committed to incorporating opportunities for Indigenous people and non-Indigenous researchers to increase their knowledge, including opportunities to increase Indigenous capacity to develop, conduct and assess the quality of research and the implications of research findings for their communities.

Ideally decolonizing practices will involve *decolonizing the funding practices* themselves, ascertaining which institutions are eligible for funding and mapping out how the funding itself is directly disbursed by a funder. However, 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 / institutions. This model of financial *control* is tolerated amongst academic researchers; however, it can foster a real power imbalance between the researchers and the community. Apart from ensuring participatory research, co-design, in which there is a choice of research topic, investigators and methodologies can ameliorate this power imbalance, but it cannot fully overcome it. It is important that the governance of the research, including co-leadership, data ownership and sharing, intellectual property rights, ethical considerations that are congruent with cultural values and budgetary allocations amongst the research institutions and Indigenous communities are clearly articulated in every research proposal to allow for *self-determination*. Appropriate and equitable governance must be an important consideration in the decision to support a proposal by any funder. Funding organizations themselves must be active participants in decolonization of the research process. A summary of some key solutions is outlined in [Table 1](#).

Conclusion

This statement advocates for increased research integrity in NCD research that involves Indigenous Peoples. Through effective collaboration, Indigenous and non-Indigenous researchers will promote Indigenous research involvement, leadership, and governance in research endeavors with Indigenous communities. We advocate that research with Indigenous communities applies co-design principles to seek Indigenous perspectives and understand variations from the Western perspective. This requires non-Indigenous researchers to develop their knowledge and understanding of Indigenous Peoples' socio-cultural perspectives, to be open to alternative approaches and conceptualizations of research goals and methodologies, and to build the research capacity of Indigenous Peoples. This will improve not only the quality of research, but also the ability to better work together in true partnerships for the benefit of Indigenous communities. This statement advocates the use of decolonization methodological frameworks that privileges Indigenous voices and guided by ways of knowing, being and doing. It also supports building Indigenous researcher capabilities to lead future GACD funded research as Principal Investigators with their Indigenous communities. The principles outlined in the statement are intentionally broad to ensure the heterogeneity of Indigenous Peoples and their different socio-cultural, health and political contexts are recognized, respected and valued.

Table 1: Summary of key solutions

RESEARCH INITIATION

- Building trust, developing relationships and learning from each other.
- Understanding local needs and contexts.
- Researching 'with' not 'on' Indigenous Peoples.
- Aligning research with Indigenous worldviews.
- Aligning research with local priorities, values and needs.
- Obtaining ethics approval from Indigenous research ethics committee.

RESEARCH DESIGN

- Applying decolonizing and Indigenizing methodological frameworks.
- Using community-based participatory research and principles of co-design.
- Developing a partnership throughout the entire research process.
- Prioritising Indigenous knowledges, perspectives, and voices.

RESEARCH OUTCOMES

- Achieving measurable and timely outcomes with Indigenous Peoples.
- Ensuring community involvement in the interpretation and dissemination of findings.
- Fostering research with Indigenous ownership of the findings and end results.
- Developing plans for dissemination of findings with the communities involved.
- Enhancing the research workforce to enable Indigenous-led research.

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About the Global Alliance for Chronic Diseases

Who we are

The Global Alliance for Chronic Diseases (GACD) is the first collaboration of major research funding agencies to specifically address chronic, non-communicable diseases. Together, the members of the alliance represent 80% of global public funding for health research.

Our focus

Implementation science | Non-communicable diseases | Low- and middle-income countries and vulnerable populations in high-income countries

“Implementation science examines what works, for whom and under what circumstances, and how interventions can be adapted and scaled up in ways that are accessible and equitable.”

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To reduce the burden of chronic non communicable diseases (NCDs) in low-and middle-income countries, and in indigenous populations facing conditions of vulnerability in high-income countries, by building evidence to inform national and international NCD policies and contribute to the achievement of the Sustainable Development Goals.

Our strategic objectives

- Investing in impactful implementation science research.
- Building implementation science capacity and capability in relation to NCDs.
- Facilitating collaborations and partnerships to support GACD impact.

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