Pan-American data initiative for the analysis of population racial/ethnic health inequities: the Pan-DIASPORA project

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The Americas region includes Anglophone North America, Latin America (including Spanish, French and Portuguese-speaking countries and territories in North, Central, and South America), and the Caribbean (including Anglophone, Spanish-speaking, and Franco-phone countries and territories).[1] Within this multi-racial and ethnic region, nearly 200 million individuals self-identify as Afro-descendants (i.e., individuals tracing their lineage back to Africa) and 58 million individuals self-identify as Indigenous people.[2–4] Across the Americas, these communities are faced with systemic discrimination, exclusion, and inequity rooted in the legacy of colonization and enslavement, notably evident in health inequities.[5–7] Despite being a third of the population in the region, the scarcity of accurate disaggregated data on race and ethnicity in sources studying social and structural determinants perpetuates a statistical invisibility, obstructing a comprehensive understanding of health inequities rooted in a history of slavery, racism, discrimination, and stigma.[3,7,8]

Historical and ongoing social movements across the Americas have led mobilization efforts to gather better quality data related to race and ethnicity, particularly related to health outcomes and living conditions. The urgency, highlighted by the COVID-19 pandemic,[6] emphasized the importance of improving the visualization of these populations and identifying the main pressing issues for informed policymaking. Governments and institutions are compelled to work towards equitable data governance alongside historically marginalized communities.[3] The Pan American Health Organization (PAHO) advocates for comprehensive data collection, management, and analysis emphasizing Afro-descendants and Indigenous peoples; while recognizing that collecting data is not enough, and it must be used to improve social and health outcomes with the purpose of achieving health equity.[2,5]

Hence, the Pan-American Data Initiative for the Analysis of Population Racial/Ethnic Health Inequities (Pan-DIASPORA) project, an initiative led by Afro-descendant and Latinx scholars, aims to fill the current gap in knowledge by examining the availability, quality, and scope of data collected and used on racial and ethnic inequities in the Americas. Our program is designed to mobilize actions aimed at:

1) **Examining the current data collection practices** on race and ethnicity in the Americas using country-specific existent routinely collected data;
2) **Evaluating the use and scope of population-based race and ethnicity data** from 2000 to 2023 in the context of major health outcomes inequities in the region (e.g., maternal and child health, cardiovascular health, and vector-borne diseases),[2,3] examining their use and implications on the understanding of health inequities present in the region;
3) **Generating practical and technical guidelines** for the collection, utilization, analysis, and interpretation of race and ethnic data in the Americas to strengthen and integrate information systems, contributing to inform decision-making and academia on identifying strategies to mitigate and eliminate racial and ethnic health inequities in the Americas.

The Pan-DIASPORA project extends beyond data curation and synthesis. We will analyse the explicit and implicit use of theoretical and conceptual frameworks describing ethnic and racial inequities,[5,7,9] including references to racism, discrimination, and intersectionality in Latin America and the Caribbean region (LAC), where data is scarce. While often used interchangeably, our approach broadens the scope to encompass both ethnicity and racial outcomes, recognizing their distinctiveness.[8,9] Our research also integrates the assessment of health and social inequities across various contexts in the region, focusing on the Afro-descendant population. Our expected findings will highlight research gaps, challenges, and successful practices over the last 20 years, for which we are creating country and outcome-specific timelines of racial and ethnic health disparities with identified opportunities for improvement.

The Pan-DIASPORA project lays the foundation for in-depth work on racial and ethnic health inequities in the region. To get our research into policy and practice, we establish a dynamic data repository on race and ethnic inequities in the Americas, available to knowledge users, including social movements, and academic and governmental institutions. Overall, the expected results will be useful for different stakeholders and in support of social movements for racial and ethnic equity in health across the region. We aspire to cultivate a multidisciplinary network of scholars across the region, committed to combating racial and ethnic inequities across health outcomes, considering the shared and unique roles of colonization, enslavement, and racialization process[3,7] that continue to shape observed health inequities.

Contributors

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