SALURBAL
Salud Urbana en América Latina

LAC-URBAN HEALTH
Urban Health Network for Latin America and the Caribbean

PAN-DIASPORA project

DREXEL UNIVERSITY
Ubuntu Center
on Racism, Global Movements
and Population Health Equity
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Making the Invisible, Visible: Race, Racism and Health Data.
Lessons from Latin American countries

To advance research and action on racial/ethnic health inequities in Latin American countries, local, state, and national decision-makers must improve the collection of high-quality data on race and ethnicity and make it available to researchers and all society.

Key points:

- Afro-descendants and Indigenous people make up more than 1/3 of the population of Latin American region. Data on the health of these populations remains limited.

- The absence and poor quality of data on race and ethnicity in many Latin American countries makes Afro-descendent and Indigenous populations invisible in national health surveys and vital statistics registries.

- This lack of data prevents documentation of and action to address racial health inequities.

- Black and Indigenous movements in Latin America have led mobilization efforts to encourage governments to gather data on race and ethnicity and in recent years, more governments in the region have begun collecting this data.

- Institutional racism continues to generate and maintain barriers to gathering, disseminating, and using this data.

Racism and Racialization in Latin America

Present-day Latin America has been shaped by the region's legacy of colonization and slavery. Millions of West and Central Africans were kidnapped from the African continent and sent to Latin American countries through transatlantic trafficking and forced into generations of free labor as a part of the colonization of the region. The process of colonization also led to the genocide, forced labor, and expulsion of Indigenous people, the Native people of the Americas, from their lands. While each country in the region has a unique history, colonization has left a legacy of racial hierarchies rooted in racism, which defines people based on race, and has been used by European colonizers and their descendants to deny Afro-descendants and Indigenous people access to full citizenship and human rights.

Centuries later, these groups continue to face extreme marginalization and inequitable access to power and resources across the region in the aftermath of these historical and ongoing processes.

Latin American cities are home to more than

175 million
Afro-descendants

50 million
Indigenous people

who make up more than 30% of the region's urban population

33% of the population of the region is Afro-descendant

8% is Indigenous, together making up more than 1/3 of the population of the region

Source: United Nation. Race and Poverty in Latin America: Addressing the Development Needs of African Descendants. United Nations. 2020.

In the 20th and 21st centuries, structural and institutional racism against Afro-descendant and Indigenous people has been reinforced and supported, in part, by the cultural denial of racial diversity. This has also discouraged an acknowledgement of the fundamental role of racism in shaping social and health inequities. This has led to the widespread belief that economic inequality is the defining challenge of the region without proper acknowledgment of intersecting barriers that exist due to racism.

The importance of data

The demand for information about Afro-descendant and Indigenous populations and their living conditions– driven in large part by social movements– has been a growing and recurring issue in the region. These demands are leveraged as both a technical and political tool to promote access to services, expand citizenship, and guarantee human rights for Afro-descendants and Indigenous peoples. Though the region still has limitations in the availability of reliable data, important efforts have taken place to advance this agenda [3]. One of the most visible results has been the inclusion of racial or ethnic self-identification in most censuses in countries of the region [3].

Despite advances with census data, the absence and poor quality of race and ethnicity data in health surveys and vital statistics information (birth and death certificates) as well as the public inaccessibility of these data is still a problem in many Latin American countries, including those within the SALURBAL network. This expression of structural and institutional racism prevents the documentation of racial and ethnic health inequities among **Afro-descendent and Indigenous** populations across the region.

This regional challenge was acknowledged in a 2021 report from the Pan American Health Organization, which noted limitations in the availability of data on race and ethnicity in national health datasets [2]. While these issues are not new, the disproportionate toll of the pandemic on marginalized racial and ethnic groups and global uprisings against racism have forced a renewed sense of urgency about the need to be transparent about the ideological, political, institutional, and structural barriers to the collection and availability of race and ethnicity data in national health surveys and vital statistic information.

Defining Race and Ethnicity in Latin America

"Race" and "ethnicity" are complex terms, often used interchangeably. Race is a social construct used to create hierarchies among humans typically based on ancestry and distinctive physical features, such as skin color, hair texture, and body morphology, instituted historically through oppression, slavery, and colonialism. The concept of race is based on historical and contemporary ideologies of inferiority that are present in the power structures of today [3,4].

Ethnicity is typically related to a common ancestry, history, and cultural practices that are often self-defined by groups of people. It can also be based on shared beliefs, traditions, cultural norms, experiences, or religion. It refers to cultural practices, language, history, or ancestry transmitted through learning that begins in childhood. Members of a particular ethnic group view themselves as culturally different from other social groups, and they, in turn, are likewise viewed by others [2,5].

In this brief we use both terms, but we recognize that their use varies across countries in Latin American.

Gaps in race and ethnicity data

A review of census, health survey questionnaires, and vital statistics databases compiled by SALURBAL for the period between 2000 and 2018 was conducted to identify questions that pertain to race and ethnicity. This included questions that ask explicitly about race and ethnicity as well as questions on language and culture which serve as proxies for race and ethnicity. The SALURBAL Project includes 11 Latin American countries: Argentina, Brazil, Chile, Colombia, Costa Rica, El Salvador, Guatemala, Mexico, Nicaragua, Panama, and Peru.

Questions included in last census data collection across Latin American countries from 2000 to 2018.

Country (year*)	Census questions and answers**
Argentina (2010)	Is anyone in this household an indigenous person or a descendant of indigenous peoples (native or aboriginal)? - Yes (indicate the number, and which people)/ No or Ignored. Is any person in this household of African descent or has ancestors of African descent or African origin (father, mother, grandparents, great-grandparents)? - Yes/ No/ Ignored.
Brazil (2010)	Your color or race: - White, Black, Yellow, Mixed/ Brown, or Indigenous. Do you consider yourself indigenous? - Yes/No/Ignored. What is the ethnic group or people to which you belong?List the ethnic group Do you speak an indigenous language at home? Which one(s)? - Yes/No/Ignored. Specify the indigenous language(s) (up to two entries). Do you speak Portuguese at home? - Yes/No.
Chile (2017)	Do you consider yourself a member of any indigenous or aboriginal people? - Yes/No. Which one? - Mapuche, Aymara, Rapa Nui, Lican Antai, Quechua, Colla, Diaguita, Kawésqar, Yagán or Yámana, other (please specify).
Colombia (2018)	According to your culture, people, or physical traits... you are or recognize yourself as: - Indigenous (to which indigenous people do you belong? Which clan do you belong to?). - Gitano(a) or Roma? (To which group do you belong? To which kumpania do you belong?). - Raizal from the Archipelago of San Andres, Providencia, and Santa Catalina. - Palenquero(a) from San Basilio. - Black, Mulatto, afro-descendant, Afro-Colombian. - No ethnic group.
Costa Rica (2011)	Do you consider yourself indigenous? - Yes/No. Which indigenous people do you belong to? - Bribri, Brunca or Boruca, Cabécar, Chorotega, Huetar, Maleka or Guatuso, Ngöbe or Guaymí, Teribe or Térraba, From another country, or No people. Do you speak any indigenous language? - Yes/No. Do you consider yourself? - Black or Afro-descendant, Mulatto, Chinese, White or Mestizo, other, none.
El Salvador (2007)	Are you? - White, Mestizo (mixed white/indigenous), Indigenous, Black (mixed race), other. If you are indigenous, to which group do you belong - Lenca, Kakawira (Cacaopera), Nahua-Pipil, other (please specify).

Country (year*)	Census questions and answers**
Guatemala (2018)	According to your origin or history, how do you consider yourself or self-identify? - Mayan, Garifuna, Xinka, Afro-descendant/creole/Afromestizo? Ladino? Foreigner. What linguistic community do you belong to? - Maya linguistic community codes? Do you regularly wear Mayan, Garifuna, Afro-descendant or Xinka clothing or costume? - Yes/No. What language did you learn to speak?
Mexico (2010)	Do you speak any dialect or indigenous language? - Yes/No. What dialect or indigenous language do you speak? List dialect or indigenous language. Do you also speak Spanish? - Yes/No.
Nicaragua (2005)	Do you consider yourself to belong to an indigenous people or ethnic group? - Yes/No. To which of the following indigenous peoples or ethnic groups do you belong? - Rama, Garifuna, Mayangna-Sumu, Miskitu, Ulwa, Creole (Kriol), Caribbean Coast Mestizo, Xiu-Sutiava, Nahoa-Nicarao, Chorotega-Nahua-Mange, Cacaopera-Matagalpa, Other, Don't Know. Do you speak the language of the indigenous people or ethnic group to which you belong? - Yes/No.
Panama (2010)	Do any indigenous people live here? - Yes/No. Does anyone in this household consider him/herself black or afro descendant? To which indigenous group does he/she belong? - Kuna, Ngäbe, Buglé, Naso/Teribe, Bokota, Emberá, Wounaan, Bri Bri, Other (specify), None. Do you consider yourself? - Colonial Black, Black West Indian, Black, Other (specifies), None.
Peru (2017)	What is the language or mother tongue you learned to speak as a child? - Quechua, Aimara, Ashininka, Awajún/Aguaruna, Shipibo-Konibo, Shawi/Chayahuita, Matsigenka/Machiguenga, Achuar, Other native or indigenous language (fill in), Spanish, Portuguese, Other foreign language, Peruvian sign language, do not listen/not speak. Because of your customs and your ancestors, do you feel or consider yourself to be: - Quechua, Aimara, Amazonian native or indigenous (specify), belonging to or part of another indigenous or native people (specify), black/moreno/zambo/mulatto/Afro-Peruvian people or Afro-descendant, white, mestizo, other (specify).

*Data collected only in the period between 2002 to 2018. **Free translation of the question and answers available in Spanish and Portuguese in the last official census questionnaires available during the period.

While most countries collect race or ethnicity data on census, only a few routinely collect this data in their health surveys and even less do so in vital statistics registries.

It is important to highlight that for some Latin American countries, race and ethnicity data in the census and health surveys could have been added after 2019, highlighting the need to follow-up and monitor data collection on race and ethnicity in the region.

LEGEND

- 🟢 Census Data
- 🔴 Health Survey Data
- 🟤 Vital Statistics

Mexico 🔴

Guatemala 🔴🟢🟤
El Salvador 🟢
Nicaragua 🔴🟢
Costa Rica 🟢
Panama 🟢

Colombia 🔴🟢🟤

Brazil 🔴🟢🟤

Peru 🔴🟢

Chile 🔴🟢

Argentina 🟢

Census Data (2002-2018)
Nine out of eleven countries' census capture data on Afro-descendant people (Argentina, Brazil, Colombia, Costa Rica, El Salvador, Guatemala, Nicaragua, Panama, Peru) and ten capture data on Indigenous people (Argentina, Brazil, Chile, Colombia, Costa Rica, El Salvador, Guatemala, Nicaragua, Panama, Peru). Mexico is the only country that did not ask a direct question about race and ethnicity during this period.

Health Survey Data (2000-2019)
Only five countries' health surveys capture data on Afro-descendant people (Brazil, Colombia, Guatemala, Nicaragua, Peru); and seven capture data on Indigenous people (Brazil, Chile, Colombia, Guatemala, Mexico, Nicaragua, and Peru).

Vital Statistics (2000-2017)
Three countries (Brazil, Colombia, and Guatemala) include race data on birth certificates (race of newborn or mother). Only Brazil collects race data on death certificates.

Falling through the cracks in the data cycle

Even when race and ethnicity questions are included in census surveys, health surveys, and registries for vital statistics, there are many points during the data cycle where this data can be lost.

Falling through the cracks in the data cycle

- Conceptualizing and defining race and ethnicity
- Creating data collection instruments
- Data collection and registration
- Data Processing
- Data access and integration
- Data Analysis
- Interpreting and disseminating of research findings

Below are examples of barriers to data collection on race and ethnicity in Latin American countries, implications for data availability and quality, and recommended solutions/approaches that have been implemented in various country settings. Note, that there is considerable variation across Latin American countries with regard to data collection and availability on race and ethnicity – countries like Brazil, for example, have made incredible progress in this area. Thus, the examples below may not apply in all settings. However, they do provide important insights on salient barriers and guidance on how to evaluate their implications, and tangible ways to advance efforts to improve race and ethnicity data collection, availability and quality.

	Barriers	Implications
Conceptualizing and defining race and	*The importance of race and ethnicity are ignored and/or equated with biological, genetic, or ancestral differences. *Racial differences are minimized and conflated with differences in economic status, ignoring the role of structural and institutional racism. *Race and ethnicity can be fluid for individuals and populations across time, geography, region, political contexts, and situations.	*Improper framing of research questions on race and ethnicity. *Information on race and ethnicity is not considered important and therefore omitted from data collection instruments. *Limited ability to document racial and ethnic health inequities and propose policy action.
Creating data collection instruments	*Disagreements or inconsistencies between categories for race and ethnicity that appropriately depicts the full, representative spectrum among Afro-descendants and Indigenous groups. *Limited or absence of standardization of race/ethnicity categories collected across census, health surveys, and vital statistics registries.	*Categories of race and ethnicity may be incomplete or poorly operationalized resulting in catch-all categories like "other" or "not informed" which leads to lost information and/or misclassification. *Data collection on race and ethnicity may be inconsistent across data systems.

	Barriers	Implications
Data collection and registration	*Incomplete race and ethnicity categories on data collection instruments. *Policies (e.g., quotas, reparations) that offer a social benefit may influence how individuals self-identify. *Registration of race and ethnicity information by the respondent (self-reported) versus the interviewer (interviewer's reporting race/ethnicity without directly asking the respondent).	*Social stigma of non-white identities caused by racism can make respondents ignore questions or feel uncomfortable answering, leading to missing data. *Social stigma may discourage respondents from addressing the race and ethnicity question accurately or at all, leading to missing data or misclassification. *Interviewer-reported versus respondent-reported race and ethnicity may lead to misclassification of categories and lack of accuracy in the information collected. *Data collectors are often not trained or are uncomfortable asking about race or ethnicity and may misclassify individuals.
Data Processing	*Data on race and ethnicity categories with small populations are combined into an "other" category. *Large amounts of missing data or unclear categories discourages data use or involves complex imputation techniques that may not be robust for accurately estimating missing data.	*"Other" category hides differences between racial groups, leaving some racial and ethnic groups "invisible". *Large amounts of missing data make it challenging to process data for analysis. *Statistical strategies to address missing data are sometimes biased based on limited pre-existing knowledge of socio-demographic characteristics.

	Barriers	Implications
Data access and integration	*Available race and ethnicity data cannot be integrated with socio-demographic and health data due to restrictions, preventing health-related analyses. *Governments and other data holders rarely make race and ethnicity data publicly available for use by researchers, activists, or other groups.	*Reduced ability or inability to conduct research on the health of marginalized racial groups.
Data Analysis	*Lack of good quality data about marginalized racial and ethnic groups. *The use of racial categories as proxies for biological differences instead of proxies for experiences of racism.	*Limited understanding of racial and ethnic health inequities of unrepresented groups. *Improper implementation and interpretation of race in statistical analyses. *Analyses on racial inequities are biased, or results are inaccurate or inconclusive.

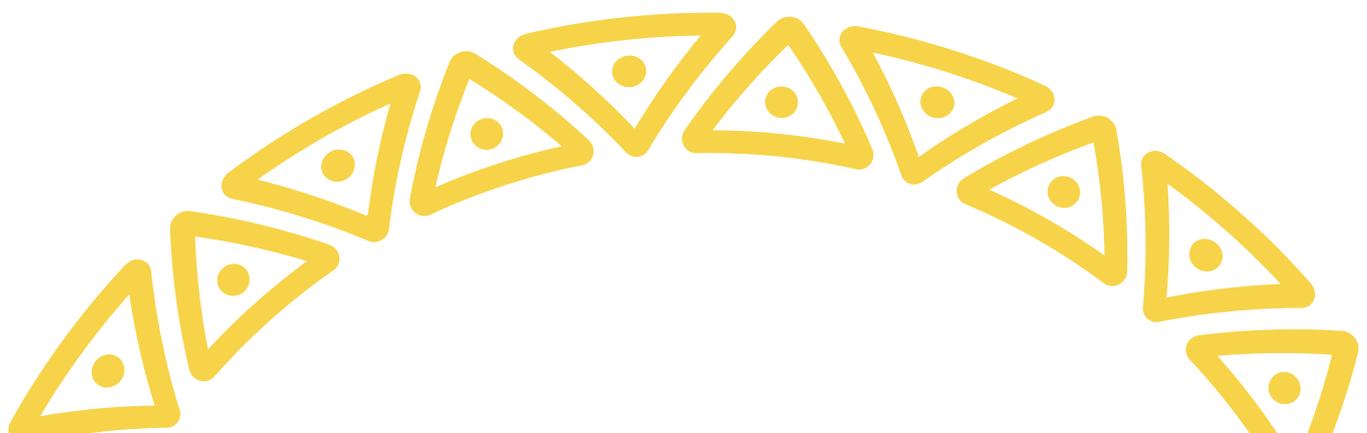|	Barriers	Implications
Interpreting and disseminating of research findings	*Racism is a barrier to unbiased interpretation and dissemination of research findings. *Limited use of existing theoretical and conceptual models leads to improper interpretation of research findings. *Barriers to publishing research on race and racism and health inequities in major health journals. *Multi-pronged dissemination strategies not utilized.	*Limited published data on race and ethnicity. Knowledge about social and health inequities affecting marginalized racial groups is limited or systematically excluded. *Limited, poor-quality data on racial and ethnic inequities cannot adequately or appropriately inform policies and strategies that could address racial and ethnic health inequities. *Reduced ability to advance research studying the effect of racism as a fundamental structural determinant of health and well-being.

The compounded impact of these societal, structural, and technical barriers limits the ability of researchers and movements to document racial and ethnic health inequities in Latin American countries, examine the pervasive effect of racism and discrimination on shaping health and racial and ethnic health inequities, and advance solutions that will improve the health and well-being of Afro-descendant and Indigenous populations in the region.

Case Studies

To illustrate some of the barriers, implications, and possible ways to advance efforts to improve race and ethnicity data collection, availability, and quality, we present two case studies focusing on the Brazilian and Colombian contexts, considering they are the Latin American countries with the highest concentration of Afro-descendants in the region.

Brazil

With the largest Black population in the Americas, and the second largest in the world [6], Brazil is home to over 97 million Black individuals, nearly 56% of the country's population [7]. The country has a longstanding tradition of collecting data on race in census, health information systems and health surveys. The inclusion of race information in the census began in 1872. During those times only free people could self-declare their race/color, while enslaved people had their declaration defined by enslavers. The purpose of collecting race data in the census was not only to classify the population but also, and primarily to create a racial hierarchy among White, Black, Mixed/Brown (Pardos), and Caboclo. It is noteworthy that the Mixed/Brown category was considered residual, as it included Indigenous people and those who declared themselves Caboclo/Mulatto. **Only on the census of 1991, the first one after the Citizen Constitution (1988), the indigenous category was officially inserted among the categories of race/color collected.** To this point, and until the present day, the Brazilian census collected race and ethnicity data, considering five self-declared categories (White, Black, Mixed/Brown, Indigenous and Yellow (Asian descendant) [8]. The same approach is used in health information systems and in vital statistics registrations to collect information on race.

The work done by Brazilian Black Movements has been fundamental in maintaining and improving race information in the census, and in increasing the

inclusion of race data in health information system and health surveys.

During the 2000 census, there was strong mobilization through awareness campaigns for Brazilian citizens to completion of the race/color declaration that was part of the census ("Don't let your color go blank"/Não deixe sua cor passar em branco) [9]. Around the time of the 2010 Brazilian census, the Brazilian Black Movement extended their mobilization efforts to other Latin American countries with the campaign "Race in the Americas".

In Brazil, race data was first included in mortality and live birth registries, and disease surveillance systems in 1996, and was added to hospitalization data systems in 2008. However, the completion of the race/color field became mandatory across all types of health data collection only in 2017 [10]. Even with legislation requiring the fulfillment of race information in all health information systems, race data was missing for approximately 34% of hospitalizations due to acute respiratory syndrome (including COVID-19) during the first months of the pandemic. **This created clear barriers to documenting racial inequities in COVID-19 cases and deaths that were noted by academics and activists [11] leading to changes in the disease surveillance system that guaranteed the collection and public availability of race/color information from August 2020 onwards.**

Colombia has the fourth largest Afro-descendent population in the Americas [2,12]. The 2018 census indicated that there are over 4.6 million Afro-descendants in the country, representing over 9% of the total population [13–15]. Despite centuries of presence in Colombia, African ancestry was not formally recognized by the government until 1991 [16]. The government did not include race or ethnicity in the census until 2005, when Colombia added a module for "ethnic self-recognition" [14,17] . This ethnic self-recognition module has six possible ethnic groups, including three categories for Black individuals [16,18–20].

In Colombia, directives to collect race or ethnicity data across health information systems is inconsistent, so, assessment of racial/ethnic inequalities is possible but challenging. For example, ethnic identification is included on birth certificates but not on all versions of death certificates and is not mandatory for all public health conditions of compulsory notification [21]. Even when available, validity and comparability of data could be affected by whether the information is self-reported or determined by surveyors or healthcare practitioners [22–24].

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[1]The ethnic self-recognition module included: 1-Indigenous; 2- member of the ROMA community (gypsi but the term in English is derogatory); 3- Afro descendant Palenquero; 4- Afro descendant Raizal /Islander; 5- Afro-descendant Inland (Including Negro, "mulato", "zambo") not palenquero or raizal; 6- Other.

Although ethnicity data collection has improved in Colombia over time, the use of this information to assess of potential inequalities is often overlooked. For instance, ethnicity data was collected in the national surveillance system from the beginning of the COVID-19 pandemic, but early official reports did not present differences in COVID-19 cases or deaths by ethnicity. The information was only used when the international community highlighted differences among Black/African descendants and Latinos in the global North [21,25–27].

Another example of challenges in understanding racial/ethnic health inequities in Colombia [23,28–30] is the case of dengue severity. Although according to the scientific literature, severe dengue is less likely to occur in people with African ancestry [31,32], surveillance reports indicate higher severity and mortality among Afro-Colombians [33,34]. Researchers have found that inequities in access to healthcare and lower likelihood or delayed healthcare seeking behavior (resulting from the differential intersecting effects of race/ethnicity, socioeconomic situation and therefore access to health care or insurance policies) among Afro-Colombians, were the drivers of differential notification which led to an overestimation of severity risk among Afro-Colombians. (i.e., the spurious racial inequality observed on severity was actually, due to the presence of inequality on access to healthcare and differential notification of cases among Afro-Colombians) [35].

The advances of race and ethnicity data collection, availability, and quality in Latin American is important since it could allow us to make visible those who historically have been invizibilized. Therefore, to continue the advancement in the region it is necessary to take actions at different levels.

Recommendations for researchers and policy makers

1 Decision makers and social stakeholders

*Conduct dialogues with Afro-descendant and Indigenous populations and social movements to broaden the understanding and importance of race and ethnicity information and the nuances around racial and ethnic identification.

*Include Afro-descendant and Indigenous people and movements in spaces of decision-making power to promote the inclusion of quality information on race and ethnicity in health surveys and vital statistics.

*Develop formal agreements across different governmental offices collecting data at the population level on the kind and number of racial and ethnic categories.

*Engage communities and key stakeholders in the creation of laws and mechanisms that ensure access to race and ethnicity data.

*Continue and expand mobilization efforts among Black and Indigenous groups across the region revealing existing gaps and demanding change.

*Improve capacity for and encourage the integration of different data sources.

*Train data collectors and respondents on issues related to race and ethnicity.

*Create data sources that can be made publicly available and accessible for communities and activist organizations.

2 Technical offices and academic institutions

*Institute structural changes in the training of health professionals including mandatory curriculum on race, racism, and health.

*Build critical consciousness and awareness about the origins of race and racism in Latin America among health professionals and researchers through transdisciplinary workshops and curricula.

*Review and expand categories of race and ethnicity in consultation with Afro-descendants and Indigenous populations.

*Propose actions to harmonize race and ethnicity data considering differences and similarities across categories and data sources.

*Revise survey questions to reduce the likelihood of misclassification/incompleteness.

*Increase data completeness by improving data collection.

3 Data users

*Integrate theoretical and conceptual models (e.g., Intersectionality) that guide proper statistical analysis.

*Utilize descriptive approaches even when data is limited and avoid extrapolation of results.

*Compare the sociodemographic and health characteristic of individuals with missing data on race and ethnicity to those with complete data on race and ethnicity in order to understand the possible implications of excluding individuals with missing race and ethnicity data from analyses.

*Incorporate direct measures of discrimination and racism (e.g., residential segregation) into analysis.

*Use qualitative approaches to improve interpretation of data and statistical analyses.

*Ground findings within rigorous theoretical and conceptual frameworks and historical perspectives.

Citation

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Salud Urbana en América Latina (SALURBAL), Urban Health in Latin America, is a project that studies how urban environments and urban policies impact the health of city residents throughout Latin America. SALURBAL's findings inform policies and interventions to create healthier, more equitable, and more sustainable cities worldwide. SALURBAL is funded by the Wellcome Trust.

The Ubuntu Center on Racism, Global Movements & Population Health Equity is a research center at the Drexel University Dornsife School of Public Health in Philadelphia, PA established to bring together a vibrant mix of activists, environmentalists, researchers, and community residents whose range of perspectives, expertise, and experience will mobilize our strengths and capacities. Our aim in this regard is to provide the platform and organizational infrastructure to advance collective anti-racism scholarship, training, and action.

The **PAN-DIASPORA Project** is a collaborative research initiative designed to examine the availability, quality and scope of data collected and used on racial/ethnic inequities in urban areas in the Pan-American region, including Brazil, Colombia, Canada, and the United States.

The **Urban Health Network for Latin America and the Caribbean (LAC-Urban Health)** seeks to promote regional and multisectoral collaboration in order to generate evidence on the drivers of urban health and health equity and translate this evidence into policies to improve health across cities in Latin America and the Caribbean.