

Racism, xenophobia, discrimination and data disaggregation: a complex but critical step to improving child health

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Racism, xenophobia and discrimination are major determinants of child health, leading to poorer health among affected children at every stage of their life and with potential intergenerational implications.^{1 2} Poor health outcomes for children may arise directly from interpersonal forms of violence and abuse but also structurally through restricted access to healthcare and other services. Health impacts can include psychological distress, depression, malnutrition, asthma, higher health risks in later life and, in some cases, lead to increased mortality in affected populations.³ Disaggregation of data makes health inequities visible that would otherwise be masked, allowing for an intersectional approach to designing policies and programs. Regular tracking of disaggregated data can also help hold decision makers to account for progress towards greater equality and inclusivity. But child health data is infrequently disaggregated in ways that can spotlight inequalities by children who face racism and discrimination insufficient action on this critical health issue.

Health indicators, when presented as an average, can hide disparities between groups. If child health indicators could be disaggregated by categories of minoritisation (such as caste, ethnicity, Indigeneity, migratory status, race, religion and skin colour¹), we would be better able to quantify disparities between groups of children and understand the impact of racism on child health, encompassing both individual acts of interpersonal racism and upstream structural racism. This information can in turn, spur research, such as longitudinal studies which can provide valuable insight into causality and how these disparities develop and persist over time, and help us understand the complex interplay between individual experiences of racism, structural racism, and health outcomes. The Sustainable Development Goals have been criticised for their lack of focus on racial justice, but calls for disaggregation exist, for example the 2014 General Assembly resolution (68/261) proposed a 'minimum disaggregation matrix' for which SDG indicators should be "be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics". The

WHO health equity monitor is an example of how this might work, showing inequalities between countries of different income levels, but also within countries by wealth quintile, education level, and other dimensions.

Measures of racism and other forms of discrimination experiences and incidence are usually limited to research studies not designed to monitor trends over time and place at the aggregate or societal level. Repeated household surveys, in particular the Demographic and Health Surveys (DHS) and Multiple Indicator Cluster surveys (MICS), have been used to examine ethnic differences in under five mortality⁷ from 36 countries and immunisation⁸ from 64 countries, with ethnicity defined in variable ways in each country. But the DHS and MICS are not conducted in every country and have not systematically used these categories. Even though routine health information data systems collect data regularly, these cannot easily be broken down into population sub-groups who experience processes of discrimination and minoritisation.

There are many challenges to adopting widespread disaggregation across discrimination categories. Uniformity of categories across contexts is often not possible because the hierarchies that divide societies and which group is in ascendance differ by country and region. Each country must decide which categories are correct: while migratory status may be relevant to all countries, for example, caste would only be for some. These categories may also overlap and change over time, and there can be sensitivities around the groupings, especially those imposed by others. Categorisation of populations was historically used by colonial powers to subdivide the people. Divisions were created and fostered that persist. Homogenising categories creates its own risks of erasure, and yet categories cannot be infinitely divisible, otherwise analysis and interpretation become impossible. Given these sensitivities, there may be well founded concerns around disaggregating data by population characteristics and how this information could be used. Some countries, such as France, choose not to collect ethnicity and race data based on historical and philosophical beliefs about the universality of political

citizenship. But a universalist 'color blind' policy such as this can also hide health disparities amongst groups.¹⁰

To respond to these concerns, a Human Rights-Based approach to data is required.¹¹ Within national health information systems and repeated household surveys, data on categories of race, ethnicity, and so on should be collected respectfully, with consent, and reported anonymously, emphasising self-identification with the incorporation of safeguarding frameworks and transparency around data collection. An inclusive approach, working with children and young people and caregivers is required to ensure the data collected is acceptable to them. In addition to the sources described above, different forms of data may be needed, including qualitative data, to flesh out and analyse this complex issue.

Systematic and robust routine data collection on interpersonal, institutional and structural dimensions of racism, xenophobia, and discrimination may be considered too controversial or difficult to implement by many national governments, but we can take inspiration from the women's movement, where issues such as violence against women have been successfully integrated into the SDGs.

As an initial step, we propose reporting on whatever disaggregated child and adolescent health data is available, which could be linked to the WHO-UNICEF Child Health and Wellbeing Dashboard [Please add link: <https://cap-2030.org/dashboard/>], which is based on the Convention of the Rights of the Child (add URL here). However piecemeal and incomplete this is, it is a vital first step in acknowledging the existence of this critical threat to global health – and visible data gaps have been known to motivate improved data collection. The next step is to improve collection mechanisms/tools by building capacities within countries to collect and analyse and to assess the quality of these data and then expand the range of disaggregation variables available for use in these collection tools. International institutions, such as the WHO and UNICEF Technical Advisory Groups, in collaboration with civil society organisations,

should provide robust guidance on how countries should collect and report this data, although this is likely to be a politically difficult topic. Considerable delicacy will be needed to raise the topic in international forums, although the constituencies for change do exist. The funding to properly resource the data collection to enable disaggregation must follow, to support countries to improve data collection tools, global guidance and further research.

To improve children's health, deliver their rights and attain the vision of the Convention on the Rights of the Child for all children to have access to health services and to live a life free from discrimination, we must measure and monitor progress across and between different groups of children. The difficulty of the task can be met by our aspirations about how our societies can be organised in a fairer and more just manner.

Conflicts of interest

DD is founder and director of the Race & Health group in UCL.

Author contributions

DD wrote the first draft. All authors edited and critically revised the text.

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References

- 1 Devakumar D, Selvarajah S, Abubakar I, *et al.* Racism, xenophobia, discrimination, and the determination of health. *Lancet* 2022; **400**: 2097–108.
- 2 United Nations Children’s Fund. Rights denied: The impact of discrimination on children. UNICEF, New York, 2022 <https://www.unicef.org/reports/rights-denied-discrimination-children> (accessed Feb 17, 2023).
- 3 Selvarajah S, Maioli SC, Deivanayagam TA, *et al.* Racism, xenophobia, and discrimination: mapping pathways to health outcomes. *Lancet* 2022; **400**: 2109–24.
- 4 François-Xavier Bagnoud Center for Health and Human Rights at Harvard University. Frontier dialogue consultations on addressing structural racial and ethnicity-based discrimination. UNSDG Task Team on Leaving No One Behind, Human Rights and the Normative Agenda https://cdn.who.int/media/docs/default-source/documents/gender/frontier-dialogue-unsdg-9-sept.2021.pdf?sfvrsn=bbb8a9e9_15&download=true (accessed Feb 3, 2023).
- 5 Nielsen RC. UN Data Revolution. UN Data Revolution. 2014; published online Sept 15. <https://www.undatarevolution.org/> (accessed Feb 2, 2023).
- 6 Diaz T, Strong KL, Cao B, *et al.* A call for standardised age-disaggregated health data. *The lancet Healthy longevity* 2021; **2**. DOI:10.1016/S2666-7568(21)00115-X.
- 7 Victora CG, Barros AJD, Blumenberg C, *et al.* Association between ethnicity and under-5 mortality: analysis of data from demographic surveys from 36 low-income and middle-income countries. *The Lancet Global health* 2020; **8**. DOI:10.1016/S2214-109X(20)30025-5.
- 8 Cata-Preta BO, Santos TM, Wendt A, *et al.* Ethnic disparities in immunisation: analyses of zero-dose prevalence in 64 countries. *BMJ global health* 2022; **7**. DOI:10.1136/bmjgh-

2022-008833.

- 9 Practical Guidebook on Data Disaggregation for the Sustainable Development Goals. In: Asian Development Bank. 2021.
- 10 LaBreck A. Color-Blind: Examining France's Approach to Race Policy. Harvard International Review. 2021; published online Feb 1. <https://hir.harvard.edu/color-blind-frances-approach-to-race/> (accessed Feb 2, 2023).
- 11 United Nations. A human rights-based approach to data. 2018. <https://www.ohchr.org/sites/default/files/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf> (accessed Feb 3, 2023).