What works: Case studies in ethnicity data use

Exploring Ethnicity Data Use and Gaps in Health Care

December 2025

Case Study Pack

This case study pack presents three applied examples from the 2025 Ethnicity Data Gaps Insight Infrastructure Programme report, offering grounded insights for policymakers, researchers and practitioners working to strengthen the use of ethnicity data across health and care.

Across the case studies, contributors challenge long-standing assumptions and expose fault lines in the current data landscape. The cases highlight the importance of community-led data collection, systems that work effectively together, and analytical approaches rooted in anti-racist principles.

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Case Study 1: Centring Racism in Ethnicity Data Collection and Analysis

Contributor: Professor Laia Bécares, King’s College London

Professor Laia Bécares used her contribution to the Insight Infrastructure Programme to challenge an entrenched assumption in health data analysis, that ethnicity is an individual risk factor. Instead, she argued for a racially just approach, one that sees racism, not ethnicity, as the fundamental and changeable cause of health inequalities. Drawing on her research using longitudinal data from Understanding Society, Bécares demonstrated how racism harms health directly and indirectly. The research found that experiences of racial discrimination have immediate and damaging effects on mental and physical health. Racism was also shown to undermine household income over time, poorer health. These findings centre the tole of racism in leading to poor health of minortised ethnic groups both directly, and indirectly by leading to lower socioeconomic positions and illustrated that addressing health inequalities through socioeconomic levers alone will not be effective unless the role of racism itself is confronted.

Using this research, Bécares criticised the common analytical approaches that treat ethnicity as a fixed, behavioural, or cultural variable, devoid of context. This framing, she argued, essentialises ethnic identity and obscures the structural processes that produce inequality. A racially just framework instead views ethnicity as a social construct shaped by racialisation and differential access to power and opportunity. It demands that researchers go beyond description to ask what produces inequality and who is responsible for it.

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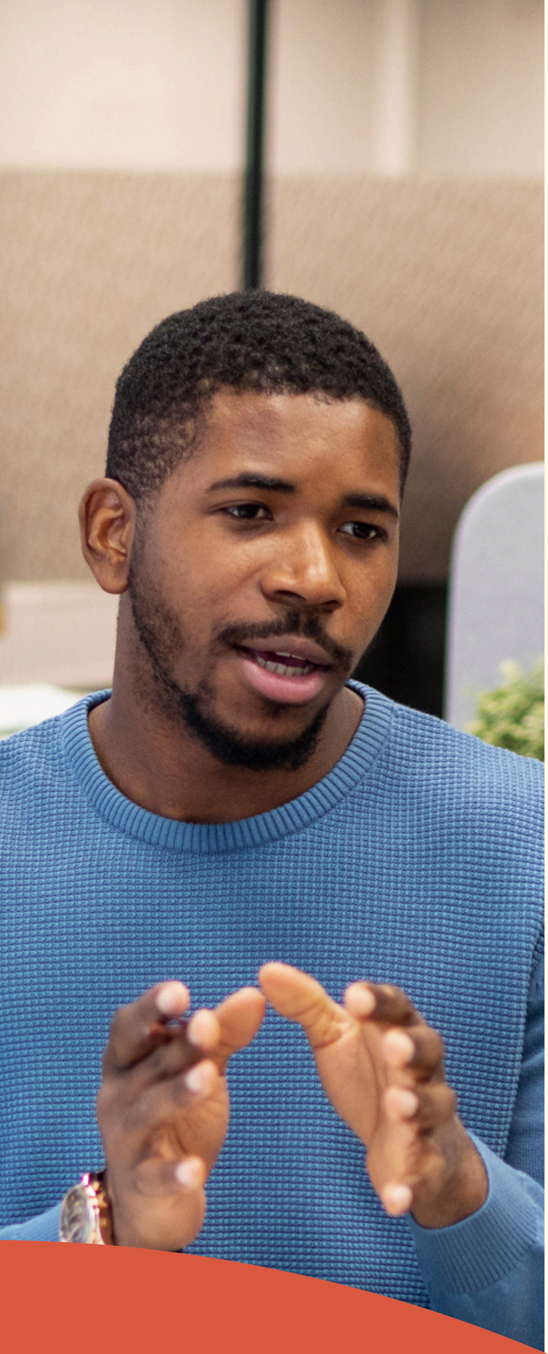

The implications for data collection in taking forward a racially just framework are also profound. Bécares noted the lack of recent survey data with sufficiently large samples of minoritised groups, citing that the last boosted sample in the Health Survey for England was more than a decade ago. She called for better-funded, inclusive surveys designed in collaboration with communities, and for the routine inclusion of detailed life-course measures of racial discrimination. An example of such measure is that included in the Evidence for Equality National Survey (EVENs), which Bécares developed with colleagues from UK, the US and New Zealand.

At its core, Bécares's case is not just methodological, but ethical. Without frameworks that name and measure racism, data risks reinforcing the very inequalities it seeks to document. A shift toward racially just approaches in health research and policy are therefore not optional, but foundational to meaningful change.

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Case Study 2:

Under-recorded and Overlooked – Gypsy, Roma and Traveller Communities in Health Data

Contributor: Sarah Mann, Friends, Families and Travellers

Sarah Mann, CEO of Friends, Families and Travellers offered a reminder of what happens when ethnicity data fails to reflect the diversity of communities it is meant to serve. Drawing on FFT’s frontline and policy work, Mann highlighted the chronic invisibility of Gypsy, Roma and Traveller communities in national datasets, even in cases where the impacts of inequality are both visible and severe.

Despite being among the most disadvantaged ethnic groups in the UK, Gypsy, Roma and Traveller populations are frequently absent from key data collections. Mann noted that while Gypsy, Roma and Traveller ethnicities are recorded in some systems, such as school-level education data, it is missing from others, including many NHS datasets and major labour market surveys. This inconsistent categorisation undermines efforts to monitor inequalities, compare outcomes, or tailor services to community needs.

Mann called for decisive action: the 2021 Census included improved ethnicity categories that allow respondents to self-identify as Romany Gypsy/Irish Traveller, or Roma. Disaggregation would be preferable, but these categories are ready to be adopted, and delaying their implementation will only deepen exclusion. Harmonisation alone, however, is not enough. Mann stressed the need for systems to apply these categories meaningfully, with sufficient granularity, visibility, and engagement with the communities they describe.

As one local authority official put it during a parliamentary hearing: “You cannot commission for what you do not know.” Without full inclusion in ethnicity data, the systemic inequalities faced by Gypsy, Roma and Traveller communities remain hidden and so do the opportunities to address them.

Case Study 3: Methodological Imagination in Ethnicity Data Analysis

Contributor: Dr Brenda Hayanga, City St George's, University of London

Dr Brenda Hayanga made the case for what she termed "methodological imagination": the ability to work creatively and rigorously with imperfect data to uncover ethnic inequalities in health. Her reflections, grounded in personal research experience, offered an illustrative example of how limitations in ethnicity data need not prevent meaningful analysis, but rather demand a more resourceful and critical approach.

Hayanga acknowledged, while ethnicity data recording in the UK had improved over the years, data challenges faced by many researchers still persist such as routine health and care datasets riddled with inconsistencies, particularly in the recording of ethnicity. These gaps, like the overuse of 'Other' categories or inconsistent coding practices, disproportionately affect minoritised ethnic groups and risk obscuring patterns of inequality . The absence of detailed or reliable ethnicity data in sectors like social care further narrows the field of inquiry .

Yet rather than waiting for the perfect dataset, Hayanga described how researchers can draw on multiple data sources, combining quantitative analysis with qualitative follow-up or cross-validating survey and administrative data. In her own study on social isolation and loneliness among older people from minoritised ethnic backgrounds, she revised her methodology to incorporate both survey data and a mixed-methods synthesis. Despite the challenges she was able to identify significant disparities in social connectedness between white and minoritised ethnic older adults. Her work, therefore, reinforces a central message of the Insight programme: data use must be guided not just by technical capacity, but by purpose, ethics, and imagination.

However, Hayanga also cautioned that this kind of methodological adaptability comes at a cost. It demands time, funding, and interdisciplinary expertise, and may delay the translation of research into policy and practice.

Read Exploring Ethnicity Data Use and Gaps in Health

Together, these cases provide insights for policymakers and practitioners seeking to develop a more equitable and accountable approach to ethnicity data.

Read the report for key findings and recommendations for action.

Or access it via our website:
raceequalityfoundation.org.uk/understanding-ethnicity-data-gaps