



Engaging black and minority ethnic groups in health research: 'hard to reach'? Demystifying the misconceptions

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Health disparities, upheld by racial hierarchies, continue to worsen in populations based on interacting and multilevel social, economic, and geographic factors. These disparities, long-standing concerns of health equity researchers, have recently received additional attention in the context of the COVID-19 pandemic, and in the United States (US) due to police killings of Black Americans [1, 2]. *Engaging Black and Minority Ethnic Groups in Health Research: 'Hard to Reach'? Demystifying the Misconceptions* by Natalie Darko, Associate Professor at the Stephen Lawrence Research Centre at De Montfort University is a timely book with potential to contribute to a research paradigm that achieves more equitable outcomes. One driver of health disparities in science is the historical and ongoing exclusion of minoritized racial and ethnic participants in health research. When investigators fail to recruit and retain participants of diverse backgrounds, stakeholders (e.g., policymakers, funders, researchers, and other end-users of research findings) inevitably base their funding, programming, and policy decisions on evidence that does not reflect distinct populations, which may ultimately undermine the validity of the evidence base and further drive inequities.

Set in the United Kingdom (UK), Darko's book elucidates the harms of labeling populations as "hard to reach" in health research and uses primary findings from several intersectional case studies to challenge the false narrative that the groups that are systematically excluded from research are truly hard to reach. The book explains mistakes researchers, clinicians, and policymakers commonly make when considering diverse racial and ethnic identities (Chapter 1), defines structural racism, and describes racial and ethnic health disparities affecting groups in the UK (Chapter 2).

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Darko then discusses problems that arise when researchers reduce complex identities to simplified categories that fail to recognize their dynamic nuances. Race, ethnicity, culture, and geographic origins, all distinct aspects of identity, are commonly conflated to label groups. In the UK, for example, Gypsy, Roma, and Travellers are “subsumed into one ethnic group category” (p. 41), despite major differences in language, history, and health practices (Chapter 3). Next, she introduces Intersectionality Theory and its application to research (Chapter 4) with findings from case studies in communities of marginalized subpopulations in the UK (Chapters 5–7).

A notable strength is that Darko engages readers in a lesson on the term “hard to reach” when referring to certain groups systematically disenfranchised in healthcare and health research. Per Darko, this terminology “shifts attention away from the barriers that ethnic minorities face in accessing services and research and the inequalities that may be influential to this” (p. 15). When decision-makers continue to use antiquated and harmful language, it represents “utilization by dominant and majority groups to legitimize hierarchies and to maintain segregation, marginalization, and discrimination towards minorities (p. 17).” ‘Hard to reach’ and similar terms wrongfully imply homogeneity within distinct groups. Darko makes a poignant case by naming the structural influences through which racism harms the health of marginalized Black, Asian, and new immigrant communities in the UK, rather than blaming the individuals who experience chronic discrimination and the greatest barriers to health.

Darko makes a compelling argument for researchers, practitioners, and policymakers to improve the specificity, transparency, and cultural competency of racial and ethnic data collection and reporting. The book examines glaring limitations about race and ethnicity data collection methods clarified in the wake of the COVID-19 pandemic. In doing so, Darko began to shed light on the potentially devastating consequences when governments and researchers collect and report racial and ethnic health data without congruence. Unfortunately, Darko provides minimal background of how the UK government and agencies define these racial and ethnic categories, beyond Black Minority Ethnic (BME) and Black Asian Minority Ethnic (BAME) groups. Darko did explain that people of minority ethnic backgrounds are defined in her book as “any ethnic groups apart from majority white British” (p. 13) and that the UK National Health Service (NHS) uses 20 ethnic categories (p. 10) in their health monitoring records, but she does not provide a comprehensive list of the groups. In both the UK and the US, the survey items, categorical response options, shared language to identify unique racial and ethnic groups, and data aggregation methods of race and ethnicity vastly differ by stakeholder group and within them. Use of data methodologies that lack a coordinated and well-integrated approach skews the documented prevalence of racial and ethnic health disparities and produces incorrect comparisons and false conclusions, leading to policies lacking sufficient external validity.

The adoption and application of additional theory-based methodologies would have strengthened the book. Darko defines epistemology loosely as “the study of knowledge (the forms of knowledge) and how we reach it” (p. 113) when justifying her choice to use the Life Story method to collect qualitative data. However, the case studies presented in the book (Chapters 5–7) all used and described aspects



of community-based participatory research (CBPR) but did not sufficiently recognize its epistemology. CBPR is widely published and has been shown to increase the diversity of recruitment relative to traditional techniques [3]. Similarly, Darko applies constructs of Intersectionality Theory but could have incorporated others that specifically examine the impacts of structural racism because this was a significant focus of the book. For example, Critical Race Theory (CRT) identifies and aims to dismantle the root causes of racism and racial hierarchies [4]. Research through a CRT lens requires a community-based participatory approach, among other empirically tested equity-driven analytic techniques. Public Health Critical Race Praxis (PHCRP) applies CRT to health equity research and addresses universal shortcomings in public health, some of which appear in the book, such as the need for a shared language to generate new knowledge surrounding complex problems across disciplines [5, 6].

The case studies that Darko implemented and introduced in the book highlight the individual experiences of participants from certain marginalized backgrounds in health research. Overall, the case studies were descriptive but study-level decisions and research methodologies, such as recruitment techniques, were not provided and therefore would not be actionable or replicable for other researchers. This timely book provides high-level guidance to investigators and practitioners but may lack innovation for readers with more experience in these domains. In future editions, Darko may move beyond describing the status of health disparities by detailing the necessary steps for the long-term engagement of historically marginalized communities in health research. Those who are new to the health equity field and wish to gain a foundational understanding are sure to benefit from reading this book.

Our long-standing research interests include advancing health equity through novel evidence synthesis methods focusing on community-based interventions and implementation, chronic disease prevention, and data sciences. This work not only requires rigorous investigative and analytic skills but an intentional paradigm shift, guided by ethics and empathy, to reduce harm in the communities that own these data. This timely book distinguishes itself from traditional textbooks by naming the historical and present-day structures driving racial and ethnic health disparities through exclusion from U.K.-based health research. It holds promise as a foundational text for future generations of early career scholars.

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