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The Racial Data Gap: Lack of Racial Data as a Barrier to Overcoming Structural Racism

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The Black Lives Matter movement marks a critical moment in the ebb and flow of racial progress. But as Camisha Russell (2022) points out, this moment might not last long. Prior high-water marks in racial progress arising from the Civil War and the Civil Rights Movement quickly receded to make way for segregation and mass incarceration. In providing this historical context, Russell conveys why racism is not only a bioethical issue but also an urgent public health crisis. If we are to have any hope of answering Russell's call to make this racial reckoning "our last," we must thoroughly study racial and ethnic public health disparities. To do this, we need better data. And better data, in turn, require not only attention to individual practices but also the development and implementation of antiracist policies.

BACKGROUND



We have found that public health data consistently and systematically omit or misrepresent the racial and ethnic identities of people who face the greatest structural health risks (COVID Tracking Project *n.d.*). Without reliable racial data, any attempt to meet "this Black Lives Matter moment" by studying and dismantling structural barriers in health will be hobbled. The omissions and misrepresentations we discuss here constitute a racial data gap, which is both a consequence and a cause of structurally racist assumptions, norms, and policies that have dire consequences for public health. Below, we draw on the CDC's publicly-

available mortality data to illustrate how the racist barriers described by Russell cannot be approached—let alone overcome—until we eliminate this racial data gap.

First, we discuss why it is imperative to redress the racial data gap. We then describe how the racial data gap widens at the intersection of race and ethnicity, and discuss both scientific and ethical issues concerning this intersectional data gap. Finally, we describe the kinds of antiracist policies needed for clinicians, bioethicists, researchers, and policy-makers to harness the momentum of the Black Lives Matter movement.

THE RACIAL DATA GAP

Existing racial misclassifications in public health data are ubiquitous. Yet it is impossible to fully understand the health implications of racism—or any other difference in the way people are treated—when the populations most at risk have been grossly miscategorized across risk categories. By way of analogy, the relative risks of two pharmaceutical treatments cannot be determined if nearly half of participants receiving [only] treatment A are miscategorized as receiving [only] treatment B. For the same reason, the mortality risks faced by Indigenous populations of the continental U.S. and Alaska cannot really be known if, as the CDC believes, nearly half of their death certificates misidentify their race as white (Arias, Heron, and Hakes 2016).

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There are two additional factors that make the racial data gap especially ethically fraught. First, the racial data gap disproportionately and unjustly harms members of those groups that are already most harmed by structural racism. And second, the racial data gap can cause health disparities to appear smaller than—or even the opposite of—what they truly are. Furthermore, this second problem may exacerbate the first.

For example, anyone can access the CDC WONDER website and view data showing that from 1999 to 2011, there were 54.0% fewer deaths per capita among American Indians and Alaska Natives (AIAN) than among white people (CDC, National Center for Health Statistics n.d.). This might be misinterpreted as a sign that mostly-Indigenous communities need fewer health resources than mostly-white communities. However, 48.6% of AIAN deaths from 1999 to 2011 were misattributed to different racial groups (Arias, Heron, and Hakes 2016), so this apparent mortality advantage may be entirely due to the confounding effects of the racial data gap.

How did some of our most comprehensive public racial and ethnic health data become so impoverished? The answer lies, at least partly, in the way such data are collected. The CDC retrieves their mortality data from the states, which collect their data from a variety of county- and local-level sources, which in turn get their data from death certificates. Cause-of-death information on death certificates is typically provided by medical professionals but the race and ethnicity of decedents is (per current policy) recorded by funeral directors.¹

If anywhere in this sequence there is a loss of resolution about race, ethnicity, or cause of death, the data needed to study public health disparities will become distorted. In other words, race-conscious practices can only redress the racial data gap if they are undertaken at every step in the process. For this reason, individual commitments against structural racism are not enough to eliminate the racial data gap. Antiracist policies are necessary to eliminate weak links in racial and ethnic public health data collection and reporting.

THE INTERSECTIONAL DATA GAP

We lack robust data regarding public health disparities not only across racial categories, but also within racial categories. Consider the intersection of race and

¹Funeral directors are supposed to ascertain that information from family members or other informants, though the CDC has worried for over 50 years that these protocols “might not have been strictly adhered to for a variety of reasons, including local attitudes” (Hambright 1969).

Table 1. Selective erasure in CDC mortality data, 1999–2011.

	Black	Hispanic or Latino	Black, Hispanic, or Latino
Census records	22,542	13,487	455
Death certificates	22,384	12,894	312
Ceiling sensitivity	99.30%	95.60%	68.57%
Exact sensitivity	97.2%	88.4%	Unknown

Ceiling sensitivity represents total death certificates as a percentage of total census records in the matched sample (i.e., maximum possible accuracy assuming 100% specificity). Exact sensitivity expresses percent of decedents whose death certificates match their own census records for race/ethnicity (i.e., measured actual accuracy).

ethnicity. In 2016, the CDC audited their mortality data by comparing the race and ethnicity recorded on nearly a quarter-million death certificates to the census records of those same decedents (Arias, Heron, and Hakes 2016). There and elsewhere (Rosenberg et al. 1999; Arias et al. 2008; Arias et al. 2010), the CDC presented the percent of death certificates on which race matched self-reported race on census records, and on which ethnicity matched self-reported ethnicity. None of these reports assessed the accuracy (*exact sensitivity*) of death certificates at the intersection of race and ethnicity, but the maximum possible percentage of death certificates that match decedents self-reported race and ethnicity (*ceiling sensitivity*) can be estimated by comparing race-by-ethnicity subtotals (Table 1).²

Here, a lack of “commitment to the value of Black lives” (Russell 2022) manifests as a 30% discounting of Black deaths among Hispanic and Latino populations.³ Public health data that are so inaccurate due to structurally racist practices can lead to distorted or even reversed impressions of racial and ethnic disparities in mortality. These mistaken impressions, in turn, may cause even well-meaning, evidence-based policies to exacerbate racial and ethnic inequities.

ANTIRACIST POLICIES

Based on the racial and intersectional data gaps described above, we make the following recommendations.

Collection

Race and ethnicity data should be collected by medical professionals, rather than those providing death care

²Data retrieved from Arias, Heron, and Hakes (2016). This and other CDC reports provide only (a) race totals and (b) race subtotals labeled as “Non-Hispanic” [sic]. Our subtotals were calculated as the difference of the two, and do not account for the 1.5% of census-takers who do not respond to the census’s Hispanic origin item (Ramirez and Ennis 2010).

³In this commentary, we use OMB/CDC conventions for racial and ethnic categories to report data from primary sources, and do not take a stance on those conventions here.

services. Medical professionals should collect these data by consulting patients or their kin whenever possible, rather than presuming race or ethnicity, and should indicate the source of the information. Agencies responsible for reporting racial and public health data should also be encouraged to collect supplemental data beyond those in the enforced standards, and the ethics board should commission studies of both standard and supplemental data to understand and eliminate inalcitrant weaknesses and missingness in racial and ethnic public health data.

Intersectionality

Racial public health data should not be collected and reported in isolation; they should always be gathered as an intersectional measure alongside ethnicity, gender, country of origin, and other individual characteristics that are critical in public health.⁴ The data should be collected such that they can be studied in the aggregate at the national level, but also disaggregated at state and local levels, in order to understand how geography and context impact public health outcomes by race and ethnicity. Such detailed information will be useful to researchers and policy-makers as governmental and societal standards regarding race and ethnicity categories continue to evolve (Khoshkhoo et al. 2022).

Training

Medical professionals should receive training so that they understand (1) the value and importance of intersectional data, (2) the best ways to obtain race and ethnicity data, and (3) the scientific and ethical problems with conflating, ignoring, or assuming an individual's race, ethnicity, or other relevant characteristics. This training should be provided alongside the ethics and confidentiality training that medical professionals typically receive.

Enforcement

Racial and ethnic public health data practices should be overseen by a centralized ethics board responsible for regularly promulgating and updating data practices. The ethics board should also be tasked with monitoring compliance with new and existing data

collection and reporting policies. Where official policies have thus far been ignored, the board should consider the use of incentives and additional scrutiny.

CONCLUSION

Racial and ethnic demographic data gaps are pervasive both within and beyond public health (Khoshkhoo et al. 2022). Here, we have shown that in strictly statistical terms, some of the most comprehensive public health data in the U.S.:

- a. Lack sensitivity to race and ethnicity;
- b. Lead to *false negative* descriptions of racial and ethnic health disparities;
- c. *Underestimate the value* of lives lost for specific races and ethnicities; and
- d. Relegate intersectional identities to *marginal totals*.

It is critical that clinicians and bioethicists act quickly on the moral imperatives outlined by Russell (2022), but the effectiveness of their actions will depend on the quality of the research they act upon. Currently, official data available for such research are plagued by a number of statistical problems that may be traced back to—and quite literally described in the language of—structural racism. These problems are sufficiently deep, widespread, and historically resistant to change as to merit significant further attention and effort not only from clinicians and bioethicists, but also from researchers and policymakers.

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⁴Federal policy has in principle—though not in practice—required intersectional reporting of mortality data since 1977: “When race and ethnicity are collected separately, the number of white and Black persons who are Hispanic must be identifiable, and capable of being reported in that category” (OMB Directive No. 15).

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Making Structural Discrimination Visible: A Call for Intersectional Bioethics



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In her evocative article “Meeting the Moment: Bioethics in the Time of Black Lives Matter,” Camisha Russell (2022) comprehensively illustrates why racism should be considered an important bioethical issue. Her position is based on three main arguments. The first argument is a rather direct one in that racism works as a barrier to health itself. The daily experience of racism thus negatively impacts one’s health, for example, in leading to higher levels of chronic stress. More indirect aspects include barriers to health care in the realm of social and economic factors related to “the long history of legal and political discrimination that deliberately stripped BIPOC communities of material resources and capacities for self-determination” (11). Second, racism functions as a barrier to good health due to “poorer-quality medical care” and “unconscious bias on the part of health care providers” (12) when treating, for example, Black people. Third, racism also poses barriers to better health care systems through creating opposition to reforms as part of large-scale conservative politics and public resentment. Beyond all that, Russell explains how the *concept* of race is a bioethical issue itself. She further points toward the individual commitment against structural racism in research as well as in health care

provision. In this commentary we would like to underline Russell’s argumentation in adding two main aspects from an intersectional perspective and strengthen the role of bioethics in working against structural discrimination.

In her article Russell refers to powerful stereotypes and “racial myths” (13) creating a “category of the undeserving poor” (14) when it comes to health care. These stereotypes such as the “Black welfare mother” (13) or the “Mexicans or welfare queens” (14) are not only racialized but gendered at the same time and are thus best captured in taking an intersectional perspective. The concept of intersectionality points to the importance of looking at the overlap and interaction between categories such as race, sex, gender, or class, for example, in the reproduction of stereotypes. It is important to highlight that biases might be unconsciously present in everyday work, for example, of health care workers and other professionals, but also manifest in actual discriminatory behavior. Intersectionality shows that the convergence of multiple social dimensions shapes actual lived experiences (Crenshaw 1989). In referring to Ikemoto, Russell underlines that for health care personnel the need to

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