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Published online: 20 Jun 2023.

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Hypervisibility, Surveillance, and Bounded Justice through Data-Driven Health Equity Efforts

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In the era of precision medicine and expanding health information technologies, large representative datasets are considered necessary for addressing health inequities. Partially in response to groundbreaking research on racism and bias in information technologies (Buolamwini and Gebru 2018; Le Bui and Noble 2020), data-driven health equity efforts have come to emphasize inclusion in health datasets as a solution. Building on Ferryman's (2023) application of bounded justice to inclusion in precision medicine and biomedical research, we identify important ways that data-driven equity efforts that focus on inclusion and representativeness are deeply bounded and threaten to expose racially marginalized groups of people to unwanted surveillance and potential harm.

To that end, we focus on two illustrative examples: algorithmic fairness and expanding collection of social determinants of health (SDOH) data. We discuss how an exclusive focus on including racially minoritized patients in these data-driven equity efforts represents bounded justice because of (1) the dialectical of invisibility and hypervisibility (Ferryman 2023), (2) surveillance, and (3) racial realism.

BOUNDED JUSTICE AND RACIALIZATION THROUGH DATA

Ferryman describes, and ELSI scholars increasingly recognize, that "erasure is a key and central aspect of racialization" (Ferryman 2023). Through the process of erasure, the needs, histories, values, and complexities of individuals and whole groups of people are collapsed and obscured. This invisibility has led to a wide variety of harms and barriers to needed healthcare. It has also led to information technologies that center and valorize whiteness (Buolamwini and Gebru 2018). However, as Ferryman explains, racialization also includes hypervisibility, especially when visibility can lead to harm.

Despite the ways that data inclusion can be important for health equity as a solution to racism, these efforts can be bounded by (1) the external forces of racism permeating surveillance and (2) the vulnerability inherent in being made legible or visible to an untrustworthy or exploitative system. Similar to the facial recognition software being implemented across public spaces that leads to the unjust arrest and detention of Black people at disproportionate rates, the ubiquitous collection and use of data can have disproportionately negative effects on racially marginalized people and groups. Data-driven equity efforts that fail to account for this will result in examples of bounded justice because they will reflect and entrench the patterns of structural racism (Creary 2021).

DATA-DRIVEN HEALTH EQUITY AND ALGORITHMIC FAIRNESS

There is considerable excitement about the idea of algorithmic fairness as an approach to prevent some harms of digital racism. Algorithmic fairness is a developing field of study focused on the creation of unbiased algorithmic decision-making systems and is increasingly conceptualized as essential to achieving digital health equity, particularly given evidence that healthcare algorithms can be racially discriminatory. Methodologically, algorithmic fairness frameworks aim to quantify and mitigate bias in the data and design choices underlying model development to

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ensure equal treatment of all patients (Andrus and Villeneuve 2022; Hanna et al. 2020).

Importantly, as described by Hanna et al. (2020), fairness "can only be understood in reference to the different social groups that constitute the organization of society," meaning that algorithmic fairness approaches are contingent on these social groups being adequately included and represented in data. To that end, effort is being undertaken by healthcare organizations, government entities, and corporations to collect and operationalize race and ethnicity data in the form of discrete, mutually exclusive categories, alongside the intentional curation of racially and ethnically diverse datasets. Within this data work, racially and ethnically-minoritized patients are centered as data subjects who, as Ferryman describes, are "valuable for the categories of difference that they represent." The outsized focus on extracting minoritized patients' data to optimize algorithmic decision-making systems makes them hypervisible within an increasingly commercially-mediated biomedical surveillance infrastructure, while simultaneously doing little to address their health care needs (Andrus and Villeneuve 2022). Furthermore, the use of race and ethnicity categories to de-bias algorithms contributes to a dialectical racialization of risk by reifying race and ethnicity as risk factors for poor health and obscuring the mechanisms through which racism shapes health outcomes (Hanna et al. 2020, Ferryman 2023). Algorithmic fairness is thus bounded by the ways data reifies race, obscures the force of racism, and renders minoritized patients hypervisible.

SOCIAL DETERMINANTS OF HEALTH

As health systems become increasingly interested and invested in collecting comprehensive data on SDOH and a variety of other downstream social factors, the implications for surveillance and oppression become stark. While SDOH-related data is often collected from patients in the form of unmet social needs, data on social factors is increasingly obtained and utilized without patient consent or knowledge. Social media and technology companies scrape and aggregate patient social and behavioral data, such as purchasing history, and provide the data or risk profiles built from that data as a product to guide tailored healthcare interventions (Ostherr 2022). Healthcare organizations can even impute SDOH-related data by creating computable phenotypes developed by mining patient medical records for readily available structured and unstructured sociodemographic and clinical data

points that, when considered together, are indicative of a social risk factor such as food insecurity (Parikh, Jain, and Navathe 2019).

The collection of data on social factors such as socioeconomic status or a person's history of incarceration could provide helpful information for providers interested in holistically serving their patients' needs. However, it could also expose those same patients to stigma, prejudiced care, predatory billing practices, and higher risks of staff involving armed security or police in their care (Sun et al. 2022; Tsai 2020; van Ryn et al. 2011). This kind of hypervisibility, as part of the racialization Ferryman describes, individualizes and obfuscates how racism structures SDOH, while further exposing patients of color to institutional racism in healthcare in the form of discriminatory treatment, decreased access to quality care, and increased proximity to carceral systems. Thus, even though it may be well-intentioned, the work of rendering racialized patients visible can perpetuate racism and is therefore a case of bounded justice.

REFLECTING RACIAL REALISM IN DATA-DRIVEN HEALTH EQUITY EFFORTS

The emphasis on inclusion or representation of racialized people in health datasets can reflect the racial realism Ferryman (2023) critiques. The underlying logic of these efforts is that inclusion or visibility in healthcare data will lead to more equitable outcomes. This falls short of addressing the fundamental inequities identified by scholars of racism and technology. Put another way, the idea that proportional representation in datasets is health equity relies on the "reality" of race as a meaningful and permanent identity upon which inequity is based. This is problematic because racism, not race, is the cause of inequities (Boyd et al. 2020). Without acknowledging this, data-driven health equity efforts will continue to reify race and fall short of understanding the dialectical invisibility—hypervisibility of racialization explained by Ferryman (2023).

CONCLUSION

Data collection and visibility can imply serious risk. Attempts to increase representation or inclusion in health datasets must be balanced with an understanding of the ways visibility via data can make patients vulnerable. Data-driven health equity efforts must balance potential benefits and risks by accounting for

racism and safeguarding patients from exploitative or oppressive surveillance that can lead to harm.

Inclusion is not an end in and of itself. It is meant to be a mechanism through which underrepresented groups can be served, but the value of inclusion is bounded by the threats of surveillance, hypervisibility, and racism. Efforts to render racialized marginalized people visible through data collection are not limited to representation. Precisely because of how racism functions through the invisibility-hypervisibility of racialization, it makes these patients hypervisible. Health equity efforts that fail to engage with this aspect of racialization will run the risk of reproducing racism.

DISCLOSURE STATEMENT

FUNDING

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