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The Overlooked Cost of Exclusion: Genetic Databases, Structural Inequality, and the Missed Role of Intersectionality

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In 2025, the rapid growth of genetic testing continues to raise critical legal and ethical questions. When 23andMe, the widely recognized at-home DNA testing company, filed for bankruptcy, much of the public discussion focused on concerns around genetic privacy. But one pressing issue remains largely ignored: the underrepresentation of non-European

ancestry groups in genetic databases is a structural oversight that both reflects and deepens existing inequalities in the field of medical science.

Genetic databases, which serve as the foundation for disease risk prediction and personalized medicine, are still overwhelmingly dominated by data from people of European descent. As of 2021, 86% of participants in genome-wide association studies (GWAS) were of European ancestry, leaving populations of African, Asian, and Indigenous descent severely underrepresented. This underrepresentation has profound effects: medical tools built on biased datasets are less effective, and sometimes harmful, for people outside the majority demographic.

The roots of this exclusion are deeply systemic. Historical injustices and structural inequalities have long discouraged participation in genetic research among marginalized groups. Mistrust stemming from unethical medical experiments, ongoing racial bias in medicine, and barriers to healthcare access contribute to this divide. For instance, disparities in access to genetic testing for breast and ovarian cancer remain persistent among Black and Latino women in the U.S., despite similar medical needs.

Crucially, this exclusion doesn't exist in isolation. It intersects with other forms of marginalization based on race, ethnicity, gender, and income, which scholars refer to as "intersectionality." The term, first coined by legal scholar Kimberlé Crenshaw in 1989, captures how different layers of discrimination overlap and compound disadvantages for affected groups. While the scientific community often prefers the term "ancestry" over "race," the lived experience of individuals often places them at the intersection of both categories, and ignoring this overlap blinds policy and research to the full picture.

Unfortunately, the legal frameworks meant to guarantee equitable access to scientific progress have not kept pace. The *International Covenant on Economic, Social and Cultural Rights* (ICESCR), a foundational human rights treaty, affirms in Article 15(b) that all individuals have the right "to enjoy the benefits of scientific progress." In 2020, the UN Committee on Economic, Social and Cultural Rights attempted to strengthen this guarantee through General Comment 25 (GC 25), which reaffirms the obligation of governments to eliminate barriers to science and ensure inclusivity.

GC 25 does mention the need to protect "vulnerable and marginalized groups" and highlights systemic discrimination against women, people with disabilities, LGBTQ+ individuals, Indigenous peoples, and those in poverty. However, the document treats these

groups as separate categories rather than considering how multiple forms of discrimination often overlap. Aside from one brief reference to "multiple discrimination" faced by women with disabilities, the term "intersectionality" is absent. This omission matters. Without addressing how structural disadvantages intersect, the promise of equal access to scientific progress remains hollow.

The underrepresentation of marginalized groups in genomic data is a clear example of this failure. Excluding diverse populations from research reduces diagnostic accuracy, worsens treatment outcomes, and limits participation in medical advances. It's not just a data issue—it's a human rights concern. A true commitment to equal access would mean not only increasing representation but also tackling the overlapping systems of exclusion that prevent full participation in science and medicine.

Legal scholars like Susan Marks and Theilen have long critiqued international human rights law for focusing too narrowly on individual abuses while ignoring the broader systems that produce them. The case of genetic databases underscores this critique. By neglecting to fully incorporate intersectional analysis, frameworks like GC 25 risk reinforcing the very inequalities they aim to dismantle.

If the U.S. and the broader international community are serious about ensuring that scientific progress benefits everyone, not just the majority, then intersectionality must move from the margins of academic theory to the core of legal and medical practice. Until then, the promise of genetic medicine will remain unevenly distributed, leaving too many on the outside looking in.