



Diversity, Equity, and Inclusion; Social Justice; and Cancer Research

Clinical oncology research has revolutionized cancer care, producing cutting edge therapies that have improved cancer outcomes. But advances against cancer have not benefited everyone. One reason for this disproportionate disadvantage is a lack of diversity, equity, and inclusion (DEI) of patients participating in clinical trials. For every person in our country to have the best opportunities for cancer prevention, diagnosis, treatment, and survivorship, we must intentionally incorporate DEI and apply a social justice context in this field of research. Social justice is a framework that guides human research and possesses three vital research principles: respect, beneficence, and justice.¹ Cancer research, including clinical trials, is guided by these principles to treat participating patients respectfully and fairly, with their interest foremost, and to engage them as informed partners.

What do DEI and social justice have to do with clinical trials?

Historically, DEI was not a central focus for research at U.S. universities or institutes. Clinical trials or research studies aimed at proving the safety and effectiveness of potential therapies have overrepresented certain groups (white men) and underrepresented others (minorities, women, and children) in a way that is not representative of patient populations. The National Academies of Sciences, Engineering, and Medicines' 2022 report highlights this lack of representation or diversity and inequity, calling it a "critical shortcoming."²

Data from the U.S. Food and Drug Administration's (FDA's) 2020 Drug Trials Snapshot also identifies oncology as one of three "therapeutic areas" in which diversity and inclusion among patients participating in clinical trials needs improvement.³ For example, of almost 5,000 patients participating in studies leading to new drug approvals, three-quarters (73%) were white, 5% were Black, and 6% were Hispanic, despite the U.S. population being more varied with 61.6% white, 12.4% Black, and 18.7% Hispanic.

The lack of representation in cancer and other clinical trials research does not stop with racial and ethnic minorities. Other medically underserved populations, such as the Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ+) community, the disabled, and people living in rural settings tend to be underrepresented. Unfortunately, applying study results to these populations that were not appropriately included in trials is medically problematic. The "one-size-fits-all" approach is an unsafe norm in medicine, because it does not take into account patient variability. It is important for minority patients to participate in these clinical trials!

Even though medically underserved populations bear a disproportionate burden of chronic diseases that clinical trials are developed to address, they often receive the least benefit from them. This disproportionate representation widens the gap of health inequities. Radical changes are needed, which is why more awareness and consideration of DEI and social justice frameworks are needed.

Promoting DEI and social justice in clinical trials at Augusta University (AU)

AU and the Georgia Cancer Center are committed to engaging participants in clinical trials and research to improve health outcomes for all populations. Angela Toole, Interim Institutional Review Board (IRB) Director at AU instructs researchers to "listen to their [the community's] voice" to help build equitable research processes. She encourages researchers to utilize on-campus resources to develop inclusive recruitment strategies.

The Georgia Cancer Center has several programs intended to reduce health disparities and inequities. The long-standing [Georgia CaRES](#) (Georgia Cancer Research) serves as a Minority/Underserved Community Site of the NCI Community Oncology Research Program ([NCORP](#)) network.⁴⁻⁵ The newer [Teledermatology in Rural Georgia](#) program brings specialized dermatology care to rural communities using web-based and mobile cellular phone technology.⁶ A population study, *cancer Community Awareness & Access Research Education (c-CARE)*, aims to reduce cancer disparities among African American urban and rural communities by training lay community health workers and by partnering with churches, clinics, and community centers.⁷

Cancer Information and Awareness



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“The C Word” is a news brief of the Georgia Cancer Center at Augusta University. For cancer information, visit: augusta.edu/cancer/community. To request exhibits or speaking engagements, contact Christine O’Meara at comeara@augusta.edu or 706-721-8353. Arrange for virtual presentations in order to follow Coronavirus precautions.

Sources:

1. The Belmont Report Ethical Principles and Guidelines for the Protection of Human Subjects of Research. U.S. Department of Health & Human Services. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>
2. National Academies of Sciences, Engineering, and Medicine report. <https://nap.nationalacademies.org/catalog/26479/improving-representation-in-clinical-trials-and-research-building-research-equity>
3. U.S. Food and Drug Department (FDA)’s 2020 Drug Trials Snapshot <https://www.fda.gov/media/145718/download>
4. Georgia CAncer REsearch (Georgia CARES) <https://www.augusta.edu/cancer/clinical-trials/gacares/index.php> and <https://www.georgiacancerinfo.org/gancorp.aspx>
5. NCI Community Oncology Research Program (NCORP) A program of the National Cancer Institute (NCI), National Institutes of Health <https://ncorp.cancer.gov/about>
6. Telederm <https://www.augusta.edu/cancer/community/teledermatology-program>
7. Cancer Community Awareness & Access Research Education (c-CARE) augusta.edu/cancer/community/ccare/index.php

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