HEALTH AFFAIRS FOREFRONT

RELATED TOPICS:
HEALTH DISPARITIES | RESEARCHERS | DISEASES | HEALTH EQUITY | RACISM | GRANTS | LIFE EXPECTANCY | FOOD | MEDICAL RESEARCH

# NIH's Approach To Funding Biomedical Research Exacerbates Inequality And Health Disparities

A. Susana Ramírez

**NOVEMBER 4, 2024** **DOI:** 10.1377/forefront.20241031.331586


The United States' epidemic of diet-related illness, including cardiovascular diseases, cancer, diabetes, and obesity, is responsible for a significant portion of the nation's health

productivity. The impact of these diseases is not evenly distributed across the population. Historically marginalized communities bear a disproportionate burden of preventable disease as a result of broader social structures and systemic issues <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4306458/> such as economic inequality and racism. Research to better understand the causes and mechanisms of disparities and potential strategies to achieve health equity must address these broader determinants. The failure of the current biomedical research funding system to adequately consider these broader determinants perpetuates health inequities across the nation.

## Funding, Prioritization, And Framing Of Health

Funding agencies play a pivotal role in shaping the landscape of scientific research, effectively determining which health issues are prioritized and how they are framed. As the foremost public funder <https://www.nih.gov/grants-funding> of biomedical and public health research in the world, the National Institutes of Health (NIH) wields substantial influence. By directing billions of dollars annually toward specific research projects, the NIH not only sets the agenda for scientific inquiry but also constructs the very definition of health "problems." This power to prioritize certain diseases, conditions, and research approaches over others means that the NIH's funding decisions profoundly shape the direction and focus of health research. Yet, the processes by which funding decisions are made—often favoring well-established, resource-rich institutions and researchers while underrepresenting the perspectives and needs of communities experiencing the most significant inequities—marginalize primary cause and ecosocial intervention research.

In this article, I elaborate three distinct mechanisms through which the current model for biomedical research funding contributes to health disparities: the structure of the NIH itself; the NIH funding model that concentrates funds in affluent, predominantly White institutions and non-Hispanic White researchers; and the preference for certain types of science that reinforce a limited and individual understanding of health.

## The Organizational Structure Of The NIH Makes It Difficult To Obtain Funding For Primary Cause Research

To begin, the organizational structure of the NIH <https://www.nih.gov/about-nih/who-we-are/organization> makes it difficult to obtain funding for research to understand and intervene on fundamental causes <https://www.jstor.org/stable/2626958> —the

health and disproportionately negatively affect racial minorities. The NIH is an umbrella organization encompassing 27 distinct institutes and centers <https://nap.nationalacademies.org/catalog/10779/enhancing-the-vitality-of-the-national-institutes-of-health-organizational> , each with its specific research agenda. Most of these institutes and centers focus on a specific disease (for example, National Cancer Institute) or body system (for example, National Heart, Lung, and Blood Institute).

While the institutes and centers that fund research are all somewhat different, the impact of this organizational structure is similar in that their focus on specific diseases or body systems makes it challenging to get funding for things that affect multiple systems or diseases. An obvious example is nutrition: There is no National Institute of Food and Nutrition, even though we all know that food and nutrition are essential aspects of health <https://doi.org/10.17226/1222> . But it's hard to get funding to do nutrition research without articulating a specific link between a food or diet and a disease outcome—and then, the institute that "owns" that disease needs to be interested in funding that kind of nutrition research.

A less obvious example might be neighborhoods. We know that where people live impacts their health <https://doi.org/10.1111/j.1749-6632.2009.05333.x> . Studies have shown that neighborhoods within the same cities have dramatically different life expectancies, and these are, not surprisingly, more likely to be neighborhoods where many Black people, immigrants, and other marginalized populations live. But for researchers interested in neighborhoods and health, there is no "Institute for Life Expectancy." To apply for NIH funding, researchers interested in neighborhoods and health might choose a specific disease outcome or a specific mechanism for how neighborhoods might affect life expectancy that corresponds to a specific institute. This forces specific types of hypotheses that may be incomplete and obscure factors such as policies <https://www.nejm.org/doi/10.1056/NEJMms2025396> such as redlining that create segregated neighborhoods.

## The Funding Model Of The NIH Reinforces Inequalities

Beyond its structure, the funding model of the NIH contributes to health disparities. NIH funds are highly concentrated among a select few elite institutions: In fiscal year 2023 <https://nexus.od.nih.gov/all/2024/02/21/fy-2023-by-the-numbers-extramural-grant-investments-in-research/> , just 20 institutions accounted for one-third of the $38.14 billion <https://brimr.org/brimr-rankings-of-nih-funding-in-2023/> in research

grant applications are ranked privileges <https://dx.doi.org/10.2139/ssrn.3000020> these rich institutions, making it easier for them to continue to get a disproportionate <https://pnas.org/doi/full/10.1073/pnas.1909217116> share of the funding pie. The specific mechanism through which privileging occurs is the "Facilities and Other Resources" section of the research grant application, describing how the applicant's institutional resources will be leveraged to support the proposed work. The institutions receiving the most NIH funding are already wealthy—the 16 universities that received the most NIH funding also top the list of endowments <https://nces.ed.gov/programs/digest/d22/tables/dt22_333.90.asp> . Of course, they will have more resources than less-wealthy ones, making it easier to score highly on this metric and increasing their chances to be awarded funding.

But it's not just that the NIH grants disproportionately go to wealthy, White institutions. NIH funding also disproportionately goes to non-Hispanic White researchers. For example, non-Hispanic White researchers are nearly twice as likely as Black scholars to get major research project funding <https://doi.org/10.1371/journal.pone.0205929> , a statistic that has held steady for more than 20 years. Moreover, women and Black researchers are significantly less likely <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2801787> to get major research funding from the NIH.

Moreover, the fact that non-Hispanic White scholars are more likely to get funded remains, even when it comes to research on issues of diversity and equity. For example, during the early part of the COVID-19 pandemic, when disparities in COVID-19 incidence and impacts became apparent alongside a racial reckoning with police brutality as another epidemic, much attention was paid to health disparities. As funders found money for "health disparities research," many White scholars shifted their focus accordingly. More than egregious equity issues in the scientific workforce, these funding patterns are problematic for the health of the US public.

Dubbed "health equity tourism <https://link.springer.com/article/10.1007/s10916-022-01803-5> ," the opportunistic turn to disparities research by researchers with no commitment or experience in such leads to problematic conceptualizations of research that do not reflect the realities, interests, or needs of the populations that experience disparities. Researchers frame problems in ways that reflect their positionality: Those in privileged positions frame problems <https://doi.org/10.1080/10410236.2020.1838095> in ways that do not necessarily reflect the goals, needs, or perspectives of communities that experience disparities. This

intentions <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5392042/>.

Contributing to health equity tourism is that well-funded scholars are savvy and strong grant writers, speaking to people like themselves (that is, the peer reviewers). So, with the best of intentions, they come up with intuitively appealing projects. But, in the end, when researchers who do not come from the communities they purport to care for, or do not, at minimum, authentically engage with those communities, it is very easy to create solutions to problems that do not exist. This is a huge problem for advancing science because these failures paint inaccurate and incomplete understandings: The interventions do not meet the community's needs for whom they were ostensibly designed, so they do not get used. But the top-line story is: This intervention did not work. And it's far too easy to get from that to: Those people didn't want to be healthy.

## The Science Preferred By The NIH Fails To Center Health Equity

The third mechanism through which the NIH contributes to health disparities is through the type of research it funds. The types of science that are most likely to be funded by the NIH are not the kinds that are going to dismantle the systems and structures that perpetuate racism and contribute to disparities. Instead, the research most likely to be funded by the NIH conceptualizes illness as the result of genetic or immutable biological processes or the outcome of individual behavioral decisions, with educational or clinical/prescriptive interventions <https://academic.oup.com/jncimono/article/2013/47/133/960860> as the solution. For example, a review <https://doi.org/10.1212/WNL.0000000000207562> commissioned as part of strategic planning at the National Institute of Neurological Disorders and Stroke (NINDS) found that despite abundant evidence that so-called "upstream" factors—structural determinants of health—more profoundly impact health disparities, most clinical trials addressing neurologic diseases focused on health behaviors such as medication adherence and diet. Another study <https://doi.org/10.1212/WNL.0000000000207570> under the same strategic planning initiative analyzed 121 responses to the NINDS's request for information about health disparities in neurologic disease and care and found overwhelming consensus that while social and structural determinants drive health disparities, research addressing these determinants was not adequately supported by the NIH. The limited institutional support for research that centers health equity overlooks the systemic and structural factors that drive health disparities and serves instead to perpetuate health inequities across the nation.

Under the current structure, studying disparities is an effective strategy for researchers and institutions already privileged, exacerbating rather than alleviating the root causes of health disparities. To move the needle on health equity, we need structural action. The starting place is the NIH itself. To be sure, the NIH is heading in the right direction, since the former director's 2021 statement against structural racism <https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-stands-against-structural-racism-biomedical-research> and call to action with the establishment of the NIH UNITE <https://www.nih.gov/ending-structural-racism/unite> initiative. NIH UNITE aims to address structural racism through the NIH and external biomedical and behavioral research workforce, and to promote health disparities and minority health research.

An example worthy of note is the nine-year, $241 million commitment to the FIRST program <https://www.nimhd.nih.gov/programs/collab/first/> , an initiative to promote cultures of inclusive excellence by growing 15 cohorts of diverse scientific talent nationwide. This program is noteworthy in its efforts to get at the root of NIH funding inequities by providing tenure-track assistant professors with faculty development, sponsorship, and structured mentoring at the early stages of an academic career that are critical to achieving research independence. This program—and the scale at which it is being supported—has the potential to effect genuine positive change in the NIH-funded research workforce, with attendant impacts on the types of science and its impacts on health equity. Yet, it is at risk due to the broader politicized national attacks on diversity, equity, and inclusion <https://www.chronicle.com/package/the-assault-on-dei> . The NIH must continue to support this program and consider funding similar efforts in the future.

Moreover, the NIH should develop or endorse existing grant writing standards on how racism should be considered and discussed in grant applications focused on racial health disparities, as well as to the composition of the teams engaged in such research. Inclusion of such standards in the review process could be a straightforward mechanism: For example, just as we are asked to consider whether applications adequately account for sex as a biological variable, reviewers might be tasked with considering whether the application adequately accounts for racism and root causes of disparities. Similarly, the "institutional environment" could include questions about the composition of the team and their expertise working with communities and populations that experience health disparities and require justification when no such expertise is included. Health equity

partnership with experienced equity scholars as well as communities.

## Conclusions

The current system for funding scientific research perpetuates health disparities by privileging established, well-resourced institutions and reinforcing an individual-level focus on disease risk and intervention. This narrow approach not only overlooks the broader social and structural determinants that drive health inequities but also enables researchers and institutions already benefitting from the current system to continue to benefit. As a result, Black, Indigenous, and Latinx people continue to suffer and die disproportionately, while the root causes remain untouched.

To achieve health equity, the NIH and other stakeholders must adopt an equity-centered model that prioritizes research—including intervention research—on the root causes of health disparities. Reforms also should prioritize equitable distribution of research funds and strategic efforts to include marginalized voices in both the research funding and allocation of such, to encourage research that aligns with the needs of marginalized communities.

Racism

Grants

Life Expectancy

Food

Medical Research

## Cite As

"NIH’s Approach To Funding Biomedical Research Exacerbates Inequality And Health Disparities", Health Affairs Forefront, November 4, 2024.

DOI: 10.1377/forefront.20241031.331586