The American Journal of Bioethics

Taylor & Francis
Taylor & Francis Group

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/uajb20

Bioethics, (Funding) Priorities, and the Perpetuation of Injustice

Rachel Fabi & Daniel S. Goldberg

To cite this article: Rachel Fabi & Daniel S. Goldberg (2022) Bioethics, (Funding) Priorities, and the Perpetuation of Injustice, The American Journal of Bioethics, 22:1, 6-13, DOI: 10.1080/15265161.2020.1867934

To link to this article: https://doi.org/10.1080/15265161.2020.1867934

THE AMERICAN JOURNAL OF BIOETHICS
2022, VOL. 22, NO. 1, 6–13
https://doi.org/10.1080/15265161.2020.1867934

Taylor & Francis
Taylor & Francis Group

TARGET ARTICLE

Bioethics, (Funding) Priorities, and the Perpetuation of Injustice

Rachel Fabi[a] and Daniel S. Goldberg[b]

[a]State University of New York Upstate Medical University; [b]University of Colorado Anschutz Medical Campus

ABSTRACT
If funding allocation is an indicator of a field's priorities, then the priorities of the field of bioethics are misaligned because they perpetuate injustice. *Social* justice mandates priority for the factors that drive systematic disadvantage, which tend not to be the areas supported by funding within academic bioethics. Current funding priorities violate social justice by overemphasizing technologies that aim to enhance the human condition without addressing underlying structural inequalities grounded in racism, and by deemphasizing areas of inquiry most frequently pursued by Scholars of Color. This lack of attention to upstream determinants of health in bioethics research perpetuates a gap in the resources needed to understand the experiences of communities disproportionately experiencing poor health, which is itself a form of *epistemic injustice*. Both social and epistemic injustices are apparent in the impact of these funding priorities on people of color, both in the public and in the bioethics community.

KEYWORDS
Justice; population; priority setting; public health; race and culture/ethnicity; rationing/resource allocation

The field of bioethics is vast; it contains multitudes of rich and exciting areas of inquiry. It is composed of scholars and practitioners of every stripe, from physicians and nurses to theologians and lawyers, and many flavors of bioethicist in between. Although the field is wildly diverse and encompasses these many different areas concerned with the ethical considerations of health, medicine, and science, there are doubtless certain topic areas that receive more scholarly attention than others. In this paper, we argue that the funding priorities of institutions that fund bioethics research in the United States create and perpetuate injustice. We argue, through a lens of structural racism, that priorities emphasizing the ethics of biomedical and technological advances, to the exclusion (or minimization) of population health considerations, lead to socially and epistemically unjust outcomes. We conclude by proposing a set of actions that bioethics funders could take to begin to rectify these injustices.

FUNDING ALLOCATION & PRIORITIES

How organizations allocate their resources is a reasonable indicator of an organization's priorities, and these allocation decisions are arguably subject to ethical critique. In bioethics in particular, the most prominent body of work addressing this concern generally relates to research allocation. For example, in 1990 the Commission on Health Research and Development ignited discussion on the so-called "10–90 gap," drawing attention to the fact that "less than 10% of global funding for research is spent on diseases that afflict more than 90% of the world's population" (Vidyasagar 2006). In 2005, Michael Selgelid decried an analogous 10–90 gap within the field of bioethics, observing that 90% of what Western bioethicists discuss is relevant to 10% of the world's health problems (Selgelid 2005; see also Farmer and Campos 2004).

In the domestic context, there is no structured or centralized allocation mechanism for the disbursement of research funding in the U.S. In the public sector, which sponsors a diminishing percentage of biomedical and scientific research, disease areas with the best-funded advocacy initiatives tend to receive more research funding (Dresser 1999; Resnik 2001). With only limited exceptions, private for-profit sector sponsorship tends to fund research that presents a return on corporate investment (Dorsey et al. 2010). Nonprofit and philanthropic foundation funding tends to more closely resemble public-sector funding, with allocations being driven by a variety of factors unrelated to disease burden (Best 2012; Kamath, Sheetal, and Benson 2019).

CONTACT Rachel Fabi fabir@upstate.edu Center for Bioethics and Humanities, State University of New York Upstate Medical University, Syracuse, NY, USA.

While a specific organization's resource allocation decisions are open to critique, there remains a question whether academic fields as a whole maintain sufficient coherence to constitute a legitimate object of critique.[1] We note that our argument does not depend on the existence of a central authority or actor in the field of bioethics that deliberately sets out to structure funding priorities in any particular manner, and we do not seek to assign moral responsibility to any given actor for the funding priorities of the field. Instead, we submit that the collective decisions of funders and scholars create a funding ecosystem that itself drives research, sponsorship, and career development in the field of bioethics to a very great extent. Moreover, the absence of any centralized or planned allocation scheme implies that in the absence of overt and collective resistance to existing allocations, there is little reason to believe these structures will change. Notwithstanding the above, to avoid the conceptual quagmire of establishing that a decentralized academic field enjoys appropriate agency to warrant moral critique, we limit our specific critique here to organizations that specifically fund and sponsor research and activity within the field of bioethics. Relatively few such organizations exist, but examples in the Anglophone world include the National Institutes of Health ("NIH") and The Greenwall Foundation in the U.S., The Wellcome Trust in the U.K., the Social Science Research Council in Canada, and the National Health and Medical Research Council in Australia.[2]

Funding is one of the main drivers of the priorities of an academic field.[3] Given the relative paucity of funding in bioethics compared to other fields and disciplines doing health-related research, the available funding arguably exerts an outsized influence in shaping the priorities of the field as a whole. Furthermore, there are multiple channels through which funding streams in academia shape priorities. One path of course is the direct sponsorship of research projects via grants, but arguably more important for its downstream and future impact are career development grants. This mechanism not only supports scholarship, research, and publication, but also subsidizes training and faculty development, builds professional networks, and aims to establish a groundwork through which the awardee will eventually be in a position to nurture and train the awardee's own mentors and trainees in the future.

Therefore, to the extent individual actors or even individual institutions are simply chasing available funding, it may not be entirely fair to critique these stakeholders for their role in establishing priorities in research and scholarship for the field as a whole. If there is funding available for bioethicists doing research in genetics and informed consent but not for the social determinants of health, it would be surprising indeed if the former did not constitute a priority area for research and scholarship in bioethics. And given the role and significance of career development grants, the priorities set in the field are likely to replicate intergenerationally within a field, as newer scholars and researchers are presumably likely to be trained and pursue research in the areas their mentors and teams are advancing. From a US perspective, The National Academies of Science, Engineering, & Medicine (NASEM) released a recent report from a workshop on emerging bioethics issues. In the report, the chair of the workshop planning committee, Jeffrey Kahn, noted that

> the majority of bioethics-related NIH research funding has been focused in three main areas: genomics, funded through the ethical, legal, and social implications (ELSI) portfolio that is administered by the National Human Genome Research Institute … the ethics of biomedical research, supported by several institutes of NIH; and bioethics capacity building outside the United States, funded by the Fogarty International Center (NASEM 2020).

Graduate students and early career researchers often experience various forms of structural disadvantage and economic precarity, often relying on mentors and grant support to make ends meet and achieve professional stability. This precarity creates the conditions in which vulnerable persons are hard-pressed to pursue fields of study and subjects well outside the specific subjects and priorities of their mentors, training programs, and available research funding. Indeed, in the NASEM report, Kahn went on to note that the funding priorities in the US "also had the predictable effect of focusing bioethics research specifically in these [three] areas" (NASEM 2020).[4]

---

[1] We explicitly situate this paper in context of the body of literature that treats bioethics per se as an object of inquiry (Azétsop and Rennie 2010; Benatar 2004, 2006; Dawson 2010; DeVries et al. 2007; Sreenivasan and Benatar 2006; Turner 2003; Turner 2005).

[2] That this list is so short is itself an issue. While this essay critiques the priorities of those organizations and agencies that do choose to fund bioethics research, we also believe it is equally imperative for more funders to recognize and fund bioethics work.

[3] We recognize, of course, that other exogenous drivers (like, e.g. a global pandemic) also affect scholarly priorities, often because they determine the direction of funding! Because those exogenous factors themselves are usually beyond the control of institutions, we focus here on the decision of where to allocate funding, inclusive of funding decisions that are driven by external factors.

[4] It is worth noting that private foundations, like those named above (e.g. the Greenwall Foundation) also play a role in shaping the priorities of the field. Greenwall does significantly better than NIH on supporting research into health disparities, public health, and health care costs and resource

We acknowledge that a significant proportion of bioethics scholarship remains unfunded, and that arguably larger proportions of health humanities research & scholarship is unsupported by grants or career development awards. The same is likely true for much work in law & bioethics, which in the US is traditionally supported by "hard" salary support and protected research time independent of extramural funding. While it is certainly possible that scholars who have the resources to pursue scholarly inquiry absent external funding have more freedom in framing their research agenda, there is little question that funding allocations drive priorities for the field as a whole. It follows that such allocations have a downstream effect in setting research priorities even for scholars who neither obtain nor even necessarily seek extramural funding.

Moreover, Rosalind Edwards (2020) notes that carving out space for unfunded research in increasingly "entrepreneurial" cultures of higher education is challenging enough to be conceptualized as a form of resistance. Edwards explains that while some unfunded research can be sufficiently supported through salary and small caches of money, much *unfunded* research is actually *self-funded*. This has significant implications for women in particular, insofar as they are more likely to have caretaking responsibilities and "may not have the flexibility to undertake unfunded research by fitting it into evenings and weekends" (p. 6). Funding allocations therefore not only shape priorities in the field of bioethics for researchers without external funding, but they also have significant equity implications which we explore further below. For this reason, we enthusiastically support calls to increase the availability of "hard" money positions in bioethics that depend less on extramural support. We urge, however, that the "hard" money support for any such new positions ought to reflect the priorities recommended in this paper lest these opportunities simply perpetuate the status quo.

While the normative issue itself is the scholarly and research priorities for the field of bioethics, the specific critique we develop here is pointed at the institutions and organizations with the most power to set those priorities: those that directly fund scholarship, research, and training earmarked for specific work in bioethics.

IMPLICATIONS FOR JUSTICE

Any social context in which there are concerns about an inequitable distribution of resources evokes justice concerns. Although there are many models of justice from which to choose, we center our analysis on two considerations of justice: social justice and epistemic justice. We consider each through the lens of structural racism.

Social justice is at the core of health care, public health, and health policy (Gostin and Powers 2006; Powers and Faden 2006; Wiley 2014). Yet, we submit that there is far less clarity on what a commitment to social justice entails. Fortunately, there are several available models that provide appropriate weight and content to render the concept applicable to specific moral problems. To illustrate one approach, we examine Powers and Faden's health sufficiency model of social justice, which is arguably most useful here, for several reasons.[5] First, it is a theory of justice designed for the nonideal world in which we live. It takes actors, groups, and communities where they are, encouraging the integration of social context, history, and patterns of domination and subordination that shape health across the lifespan for so many people around the world. Second, its empirical foundations are rooted in the same social epidemiologic evidence base that accounts for structural inequalities between and within nation-states that track race, class, gender, and disability status (inter alia). Third, it embraces a twin aims approach, implying that ethically optimal policies and interventions are those which *simultaneously* (1) improve overall population health; and (2) compress social and/or health inequalities. Fourth, Powers and Faden's model strives to answer the following crucial normative question: which inequalities matter most?

Their answer is that factors which drive "densely-woven patterns of disadvantage" (Powers and Faden 2006, 193) should receive priority, since it is those factors which are most responsible for creating insufficiencies in health and other "essential dimensions of wellbeing." While Powers and Faden's model is directed at the factors driving population health outcomes, it is also explicitly nonexceptional with regards to health. That is, sufficiency is desirable not simply in health, but in the five other essential dimensions of wellbeing: personal security, reasoning, respect, attachment, and self-determination.

Take, for example, the relative prevalence of conditions that may be worthy of bioethical inquiry.

---

allocation. These categories are represented by approximately 30% of all of Greenwall's "Making a Difference" grants (The Greenwall Foundation 2020a) and about 40% of their "Faculty Scholars" career development awards (The Greenwall Foundation 2020b).

[5] While we follow accepted practices in bioethics scholarship in specifically adopting a single ethical framework for our analysis, there is of course a much wider literature on sufficientarianism, justice, and health (see, e.g. Fourie and Rid 2017; Gosseries 2017; Shields 2017; Wouters et al. 2017).

One such condition, mitochondrial disease, has been the subject of significant research and investment by the Wellcome Trust and other bioethics funding entities (including the NIH and FDA) (National Academies of Science, Engineering, and Medicine 2016; Wellcome Trust 2020). Scholarship around the ethics of creating embryos with the genetic material of three "parents" in order to prevent the birth of children with mitochondrial disease, through a technique known as "mitochondrial replacement therapy," received significant funding and substantial attention within the academic bioethics community. Another such condition, food insecurity in the United States, has received considerably less attention from academic bioethics, although some attention has been devoted to *global* food security. The stark reality, however, is that one of these conditions affects 12.5 per 100,000 of the population (Schaefer, Lim, and Gorman, 2019) while the other affects 14,300 per 100,000 of the population (Gundersen and Ziliak 2015). And while mitochondrial disease can certainly produce devastating health outcomes, the amount of ink spilled over the ethics of policies that lead families to go to bed hungry is a drop in the bucket relative to the ink devoted to the ethics of a specific genetic technique that would enable people with mitochondrial disease to have biologically-related children.

Of course, some may view the funding disparities in these two areas as the natural product of what falls within the scope of bioethics as a field. Narrowly construed, some might argue, bioethics is the study of the ethics of science and medicine. Mitochondrial replacement therapy, that argument may suggest, is clearly within the domain of bioethics. Food insecurity, on the other hand, may be too far afield of bioethics' purview, straying instead into the murky territory of some other branch of applied ethics. We do not propose to hash out here what is or is not bioethics, but we believe, and are not alone in believing, that the field can and does encompass the ethics of those policies and practices that affect health and other non-health dimensions of well-being. This is in part why Powers and Faden's nonexceptionalist theory of social justice is so important. Resources needed to address the densely-woven patterns of disadvantage that create insufficiencies in any of the six dimensions of well-being are worth scholarly and—we submit—bioethical attention. This is especially the case when the sources of structural disadvantage drive insufficiencies in health *as well as* in other essential dimensions of well-being.

Our argument that the current prioritization schemes for allocating bioethics research funding are fundamentally unjust extends beyond considerations of social injustice writ large to include a specifically *racial* injustice. We contend that bioethics funders' focus on genetics, genomics, neuroethics, and the ethics of other emerging technologies disproportionately harms People of Color, who are more likely to experience inequities in health care and the social determinants of health. Neglecting to fund bioethics research into questions of population health in favor of flashier topics means that ethical questions about the root causes of, for instance, the egregiously high rates of maternal mortality among Black women in the United States are less fundable and therefore less likely to receive scholarly attention (Ho 2016; Hoberman 2016).

This is not to say that People of Color are not affected by the same ethical issues as the general population, nor to suggest that they are somehow uninvested in research into questions of, say, gene-editing or artificial intelligence. A broad and growing body of literature has examined, for instance, the role of machine learning algorithms in perpetuating bias and health inequities (Benjamin 2019; Gianfrancesco et al. 2018). Research into these and other issues is undoubtedly important for People of Color, whose health will be affected by technologies in large and small ways, many of which we may not yet know. The importance of research into future ethical challenges that may come into existence as technologies advance should not, however, outweigh bioethical inquiry into the unjust distribution of existing health and health-promoting resources. Funders of bioethics must acknowledge that a narrow focus on emerging technologies, such as genetic and genomic technologies, reflects a priority set that does not always represent the needs of all sectors of society. As bioethicist Dorothy Roberts argued in the NASEM workshop:

> To make structural change a reality, it will be necessary to understand who has an investment in keeping things the way they are and who is invested in changing society … [T]hose conducting the research typically have little stake in structural change and, in fact, often benefit from preserving the status quo. Those engaged in gene-editing research have a greater stake in promoting genetic enhancement as a method to improve the human condition … and less of a stake in promoting societal change. (NASEM 2020)

We share Roberts' concern that current bioethics funding priorities reflect the interests of those who have benefited and continue to benefit from existing structures, perpetuating racial and socioeconomic injustice.

Beyond this macro-level of social injustice within racist structures, the current priorities of bioethics funders also risk perpetuating racial injustice on a smaller scale within the academy itself. For years, there have been obvious and alarming racial disparities in the rates of receipt of NIH funding (Ginther et al. 2011). Although these disparities are likely multifactorial, there is some evidence that a major driver of the funding gap is the difference in the topics that minority scholars propose to study. A recent paper in *Science Advances* reported findings that up to 20% of the gap could be explained by the differences in choice of topic; the authors found that white scholars were more likely to propose research on biological mechanisms, whereas Black scholars tended to focus their proposals at the community and population health level, and that these differences led to fewer grant proposals by minority scholars making it through successive rounds of review (Hoppe et al. 2019).

By prioritizing research on emerging technologies to the detriment of bioethics at the community and population levels (Azétsop 2011; Brock 2000; Wikler and Brock 2008), bioethics funders (including the NIH) risk perpetuating these same disparities.[6] Emphasizing technological solutions to medical problems, rather than unfair distributions of the social determinants of health, has the potential to marginalize those bioethics scholars, many of whom are Scholars of Color, whose interests lie outside the current mainstream mode of anticipating and responding to technological advances. This danger is compounded by the tendency, described earlier, of academic researchers to replicate themselves through their advisees, as many graduate students receive funding through an agreement that requires the student to work on their mentors' projects. If current funding incentives continue, prospective students whose interests lie beyond biomedical applications of new technologies are disadvantaged in their pursuit of admission to or ability to compete within graduate programs. The underrepresentation of Scholars of Color among tenured faculty and recruited trainees is intimately tied to this cycle, both resulting from, and perpetuating, the underfunding of population health ethics. This self-perpetuating academic cycle is not exclusive to bioethics, of course, but we restrict our analysis to the incentive structures of this field. The importance of diversifying the bioethics workforce was also noted by the NASEM workshop proceedings cited above. One panelist who spoke about the bioethics research workforce called for training more transdisciplinary bioethics scholars and noted that although "public health ethics had not been addressed by the workshop… in-depth expertise on ethics should include public health ethics" (NASEM 2020).

There are additional justice-related concerns that flow from the negligible funding streams made available for work in population-level and public health ethics. For example, Miranda Fricker's notion of epistemic injustice suggests that injustice is not simply a function of unequal distributions in goods and services, but that it is possible to *wrong persons in their capacity as knowers*. Denying a person's capacity to give voice to their own experiences and knowledge can be a form of injustice, especially where it tracks existing problematic social structures (Medina 2012; Mills 2013). Fricker distinguishes between two main forms of epistemic injustice: testimonial and hermeneutical. "[T]estimonial injustice happens when a prejudice causes a hearer to give less credibility to a speaker's testimony and interpretations than they deserve" (Buchman, Ho and Goldberg 2017). "[A] hermeneutical injustice occurs when there is a deficit in our shared tools of social interpretation (the collective hermeneutical resource), such that marginalized social groups are at a disadvantage in making sense of their distinctive and important experiences" (Goetze 2018, citing Fricker 2007).

While either dimension could be applicable in the misallocation problem with which we are concerned here, we argue that hermeneutical injustice is especially relevant. Essentially, where there is extremely limited funding made available to research and teach issues central to population and public health, as a field bioethics perpetuates a deficit in the shared tools of social interpretation needed to comprehend, analyze, and evaluate interventions for ameliorating macrosocial determinants of health and its unequal distribution. In turn, the same deficit makes it less likely that the existing priorities in allocation will change; where the collective hermeneutical resource needed to understand the significance of structural determinants is thin or absent, there is no reason to suppose moral agents with the power to shape funding priorities and determinations will alter their preferences toward population-level and public health ethics.

The hermeneutical injustice that relates to population-level and public health ethics is an injustice

---

[6] In an important 2011 paper, Azetsop argued that the same misallocation problems are replicated within African bioethics, to the particular detriment of LMICs whose health priorities are even more dramatically linked to insufficiencies in public and population health infrastructure.

specifically for its implications for marginalized groups subjected to historical patterns of domination, subordination, and oppression. That is, the lack of shared resources needed to interpret and comprehend the significance of population-level and public health issues, including the prime determinants of health and its distribution, is self-evidently problematic because it means these topics and areas are perpetually less likely to be studied and taught in bioethics. What makes this unjust in particular is the extent to which these gaps also result in the de-prioritization of issues, concerns, and factors most relevant to racial health inequities in the U.S. Racism is a public health issue (Ford et al. 2019; Garcia and Sharif 2015) and unless public and population health concerns are included—if not centered—in funding streams and training opportunities, structural factors driving racial health inequities will continue to be relegated and deprioritized in bioethics. Moreover, to the extent that, as noted above, factors related to structural determinants of health are a particular research emphasis for Scholars of Color, the hermeneutical gap outlined above contributes to injustice in the structure and composition of academia as an institution.

CONCLUSION

Many bioethicists are less concerned with the potential future misuse of CRISPR or neurological enhancement than with the existing injustices of the current distributional mechanisms that affect population health. This is not to say that funders should wholly abandon forward-looking ethical research, but rather that there should be some semblance of parity between the funding of speculative biomedical ethics and population health ethics.

Population-level health concerns are of signal importance. The primary drivers of health and its distribution are inextricably linked to historical patterns of domination, subordination, and oppression. These drivers are the chief causes of health inequities across “social fault lines” like race, class, gender, and disability status. Under virtually any model of justice worth the name, their compression is an ethical priority. Accordingly, there is a strong moral justification for changing the allocation of funding streams in bioethics to support scholarship, training, and research addressing structural determinants of health and population-level bioethics. The current exigencies of COVID-19 in the US, and its disproportionate impact on People of Color, are clarion reminders of the powerful connections between structural racism and adverse health. While we are heartened to see more attention to these connections in current bioethical analysis of COVID-19, such a focus ought to be sustained beyond the immediate duration of the pandemic itself.

We therefore call upon public and private funders of research at the intersection of health, ethics, and social policy, to support the work and careers of scholars who are dedicated to the exploration of ethical issues that arise in the context of population health. Specifically, we urge these funders to first establish and support mechanisms to fund research that seeks to answer bioethical questions beyond those generated by genetics, neurotechnology, and other emerging technologies. Second, we urge these same funders to create career development and training opportunities for junior scholars, and especially Scholars of Color, who seek to study bioethical challenges in population health.

There are myriad specific mechanisms through which funders could implement these adjustments. For example:

- RFPs can be designed and issued to signal the funding body’s interest in sponsoring research and career development on population and public health concerns (e.g. the US National Institute for Environmental Health Research’s Environmental Health Disparities & Environmental Justice program)
- Where applicable, guidelines and scoring criteria for study sections and grant review committees can be changed and/or designed as above;
- Membership on study sections and grant review committees can be changed to include more scholars and researchers expert on and conversant in population and public health concerns; and
- Techniques drawn from community-based participatory research and deliberative democracy models can be used to guide priorities in funding schemes and allocations (see Blacksher 2013; Pesce, Kpaduwa, and Danis 2011).

More broadly, we encourage our colleagues in the wider bioethics community to expand their view of the boundaries of those topics deemed worthy of bioethical inquiry, as well as the methods that we employ in pursuit of answers to bioethical questions. Our community must endeavor to lift up the voices of those most affected by health inequities, including through community-based participatory research and other methods that bring to the fore the lived experiences of the victims and survivors of social injustice. We will continue to fall short in such efforts if we do not alter the prioritization schemes that have long-governed research allocations within bioethics.

Disclosure Statement

Rachel Fabi received the National Academy of Medicine Greenwall Fellowship in Bioethics in 2019, which is funded by the Greenwall Foundation.

ORCID

Rachel Fabi http://orcid.org/0000-0003-3027-7812
Daniel S. Goldberg http://orcid.org/0000-0003-1843-7422

REFERENCES

Azétsop, J. 2011. New directions in African bioethics: Ways of including public health concerns in the bioethics agenda. *Developing World Bioethics* 11 (1):4–15. doi:10.1111/j.1471-8847.2009.00271.x.

Azétsop, J., and S. Rennie. 2010. Principlism, medical individualism, and health promotion in resource-poor countries: Can autonomy-based bioethics promote social justice and population health? *Philosophy, Ethics, and Humanities in Medicine: PEHM* 5 (1):1. doi:10.1186/1747-5341-5-1.

Benatar, D. 2006. Bioethics and health and human rights: A critical view. *Journal of Medical Ethics* 32 (1):17–20.

Benatar, S. R. 2004. Blinkered bioethics. *Journal of Medical Ethics* 30 (3):291–2. doi:10.1136/jme.2003.007294.

Benjamin, R. 2019. Assessing risk, automating racism. *Science* 366 (6464):421–2. doi:10.1126/science.aaz3873

Best, R. K. 2012. Disease politics and medical research funding: Three ways advocacy shapes policy. *American Sociological Review* 77 (5):780–803. doi:10.1177/0003122412458509.

Blacksher, E. 2013. Participatory and deliberative practices in health: Meanings, distinctions, and implications for health equity. *Journal of Deliberative Democracy* 9 (1):6. doi:10.16997/jdd.158.

Brock, D. W. 2000. Broadening the bioethics agenda. *Kennedy Institute of Ethics Journal* 10 (1):21–38. doi:10.4324/9781315253510-5.

Buchman, D. Z., A. Ho, and D. S. Goldberg. 2017. Investigating trust, expertise, and epistemic injustice in chronic pain. *Journal of Bioethical Inquiry* 14 (1):31–42. doi:10.1007/s11673-016-9761-x.

Dawson, A. 2010. The future of bioethics: Three dogmas and a cup of hemlock. *Bioethics* 24 (5):218–25. doi:10.1111/j.1467-8519.2010.01814.x.

De Vries, R., L. Turner, K. Orfali, and C. Bosk. 2007. *The view from here: Social science and bioethics*. Malden, MA: Blackwell Publishing.

Dorsey, E. R., J. de Roulet, J. P. Thompson, A. Thai, Z. White-Stellato, C. A. Beck, B. P. George, and I. I. H. Moses. 2010. Funding of US biomedical research, 2003–2008. *Journal of American Medical Association* 303 (2):137–43. doi:10.1001/jama.2009.1987.

Dresser, R. 1999. Public advocacy and allocation of federal funds for biomedical research. *The Milbank Quarterly* 77 (2):257–74. doi:10.1111/1468-0009.00133.

Edwards, R. 2020. Why do academics do unfunded research? Resistance, compliance and identity in the UK neo-liberal university. *Studies in Higher Education* :1–11. doi:10.1080/03075079.2020.1817891.

Farmer, P., and N. G. Campos. 2004. New malaise: Bioethics and human rights in the global era. *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics* 32 (2):243–51. doi:10.1111/j.1748-720X.2004.tb00471.x.

Ford, C. L., D. M. Griffith, M. A. Bruce, and K. L. Gilbert. 2019. *Racism: Science & tools for the public health professional*. Washington, DC: American Public Health Association Press.

Fourie, C, and Rid, A. (Eds). 2017. *What is enough?: Sufficiency, justice, and health*. New York, NY: Oxford University Press.

Fox, R. C., and J. P. Swazey. 2008. *Observing bioethics*. New York, NY: Oxford University Press.

Fricker, M. 2007. *Epistemic injustice: Power & the ethics of knowing*. New York, NY: Oxford University Press.

García, J. L., and M. Z. Sharif. 2015. Black lives matter: A commentary on racism and public health. *American Journal of Public Health* 105 (8):e27–e30. doi:10.2105/AJPH.2015.302706.

Gianfrancesco, M. A., S. Tamang, J. Yazdany, and G. Schmajuk. 2018. Potential biases in machine learning algorithms using electronic health record data. *Journal of American Medical Association Internal Medicine* 178 (11):1544–7. doi:10.1001/jamainternmed.2018.3763.

Ginther, D. K., W. T. Schaffer, J. Schnell, B. Masimore, F. Liu, J. L. Haak, and R. Kington. 2011. Race, ethnicity, and NIH research awards. *Science* 333 (6045):1015–9. doi:10.1126/science.1196783.

Goetze, T. S. 2018. Hermeneutical dissent and the species of hermeneutical injustice. *Hypatia* 33 (1):73–90. doi:10.1111/hypa.12384.

Gosseries, A. 2017. Intergenerational justice, sufficiency, and health. In *What is enough?: Sufficiency, justice, and health*, ed. C. Fourie and A. Rid, 121–143. New York, NY: Oxford University Press.

Gostin, L. O., and M. Powers. 2006. What does social justice require for the public's health? Public health ethics and policy imperatives. *Health Affairs* 25 (4):1053–60. doi:10.1377/hlthaff.25.4.1053.

Gundersen, C., and A. Ziliak. 2015. Food insecurity and health outcomes. *Health Affairs* 34 (11):1830–9. doi:10.1377/hlthaff.2015.0645.

Ho, A. 2016. Racism and bioethics: Are we part of the problem? *The American Journal of Bioethics* 16 (4):23–5. doi:10.1080/15265161.2016.1145293.

Hoberman, J. 2016. Why bioethics has a race problem. *The Hastings Center Report* 46 (2):12–8. doi:10.1002/hast.542.

Hoppe, T. A., A. Litovitz, K. A. Willis, R. A. Meseroll, M. J. Perkins, B. I. Hutchins, A. F. Davis, M. S. Lauer, H. A. Valantine, J. M. Anderson, et al. 2019. Topic choice contributes to the lower rate of NIH awards to African-American/Black scientists. *Science Advances* 5 (10):eaaw7238. doi:10.1126/sciadv.aaw7238.

Kamath, S. D., M. K. Sheetal, and A. Benson. 2019. Comparison of cancer burden and nonprofit organization funding reveals disparities in funding across cancer types. *Journal of the National Comprehensive Cancer Network: JNCCN* 17 (7):849–54. doi:10.6004/jnccn.2018.7280.

Medina, J. 2012. Hermeneutical injustice and polyphonic contextualism: Social silences and shared hermeneutical responsibilities. *Social Epistemology* 26 (2):201–20. doi:10.1080/02691728.2011.652214.

Mills, C. W. 2013. White ignorance and hermeneutical injustice: a comment on Medina and Fricker. *Social Epistemology Review and Reply Collective* 3 (1):38–43. http://wp.me/p1Bfg0-1ce.

National Academies of Sciences, Engineering, and Medicine. 2016. *Mitochondrial replacement techniques: Ethical, social, and policy considerations*. Washington, DC: The National Academies Press.

National Academies of Sciences, Engineering, and Medicine. 2020. *An examination of emerging bioethical issues in biomedical research: Proceedings of a workshop*. Washington, DC: The National Academies Press.

Pesce, J. E., C. S. Kpaduwa, and M. Danis. 2011. Deliberation to enhance awareness of and prioritize socioeconomic interventions for health. *Social Science Medicine* 72 (5):789–97. doi:10.1016/j.socscimed.2011.01.002.

Powers, M., and R. R. Faden. 2006. *Social justice: The moral foundations of public health and health policy*. New York, NY: Oxford University Press.

Resnik, D. B. 2001. Setting biomedical research priorities: Justice, science, and public participation. *Kennedy Institute of Ethics Journal* 11 (2):181–204. doi:10.1353/ken.2001.0017.

Schaefer, A., A. Lim, and G. Gorman. 2019. Epidemiology of mitochondrial disease. In *Diagnosis and management of mitochondrial disorders*, ed. M. Mancuso and T. Klopstock, 63–79. Cham: Springer.

Selgelid, M. J. 2005. Universal norms and conflicting values. *Developing World Bioethics* 5 (3):267–73. doi:10.1111/j.1471-8847.2005.00125.x.

Shields, L. 2017. Some questions (and answers) for sufficientarians.I. In *What is enough? Sufficiency, justice and health*, ed. C. Fourie and A. Rid, 85–100. New York, NY: Oxford University Press.

Sreenivasan, G., and S. R. Benatar. 2006. Challenges for global health in the 21st century: Some upstream considerations. *Theoretical Medicine and Bioethics* 27 (1):3–11. doi:10.1007/s11017-005-5752-3.

The Greenwall Foundation. 2020a. Making a difference grants. Accessed October 22, https://greenwall.org/making-a-difference-grants/mad-grants.

The Greenwall Foundation. 2020b. Our faculty scholars. Accessed October 22, https://greenwall.org/faculty-scholars-program/our-faculty-scholars.

Turner, L. 2003. Zones of consensus and zones of conflict: Questioning the “common morality” presumption in bioethics. *Kennedy Institute of Ethics Journal* 13 (3):193–218. doi:10.1353/ken.2003.0023.

Turner, L. 2005. From the local to the global: Bioethics and the concept of culture. *The Journal of Medicine and Philosophy* 30 (3):305–20. doi:10.1080/03605310590960193.

Vidyasagar, D. 2006. Global notes: The 10/90 gap disparities in global health research. *Journal of Perinatology: official Journal of the California Perinatal Association* 26 (1):55–6. doi:10.1038/sj.jp.7211402.

Wellcome Trust. 2020. Mitochondrial donation. Accessed December 2, 2020. https://wellcome.org/what-we-do/our-work/mitochondrial-donation.

Wikler, D., D. Brock, 2008. Population-level bioethics: Mapping a new agenda. In *Global bioethics: Issues of conscience for the twenty-first century*, ed. R. M. Green, A. Donovan, and S. A. Jaus. New York, NY: Oxford University Press.

Wiley, L. F. 2014. Health law as social justice. *Cornell Journal of Law and Public Policy* 24 (1):47.

Wouters, S., N. N. J. A. van Exel, K. I. M. Rohde, J. J. Vromen, and W. B. F. Brouwer2017. Acceptable health and priority weighting: Discussing a reference-level approach using sufficientarian reasoning. *Social Science & Medicine* 181:158–67. doi:10.1016/j.socscimed.2017.03.051.