

The American Journal of Bioethics



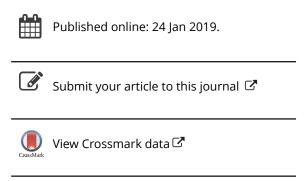
ISSN: 1526-5161 (Print) 1536-0075 (Online) Journal homepage: https://www.tandfonline.com/loi/uajb20

Response to Open Peer Commentaries on "Health Research Priority Setting: The Duties of Individual Funders"

Joseph Millum & Leah Pierson

To cite this article: Joseph Millum & Leah Pierson (2019) Response to Open Peer Commentaries on "Health Research Priority Setting: The Duties of Individual Funders", The American Journal of Bioethics, 19:1, W5-W7

To link to this article: https://doi.org/10.1080/15265161.2018.1536769



The American Journal of Bioethics, 19(1): W5-W7, 2019

ISSN: 1526-5161 print / 1536-0075 online DOI: 10.1080/15265161.2018.1536769

Correspondence



Response to Open Peer Commentaries on "Health Research Priority Setting: The Duties of Individual Funders"

Joseph Millum, National Institutes of Health **Leah Pierson,** Harvard Medical School

We thank all the commentators who took the time to carefully read and respond to our article. We express our particular appreciation to the commentaries that extended or applied our framework, including to contexts that we had not previously considered (Afolabi and Sodeke 2018; Garba et al. 2018; Mann and Schmid 2018).

We also agree with much of what was said by several of the commentators. For example, we agree with Bierer and colleagues (2018) that research projects should be judged on their novelty, scientific rigor, and impact. We agree with Dresser that much more work needs to be done, including empirical work, in order to actually implement our recommendations at funding organizations. Last, we agree that the wholesale adoption of our recommendations would entail substantial changes to the status quo (Pratt and Hyder 2018). Of course, it is highly unlikely that such wholesale adoption would occur. That is why we concentrate on what individual actors ought to do in the nonideal world in which we live. Each of us has some leeway to act and ought to use that leeway to make the world a better place. One way employees of research funding organizations can do so is by bringing research funding into greater alignment with global health needs.

Here we address four important challenges raised by the commentaries: (1) assessing social value; (2) the obligations of for-profit research funders; (3) the role of procedural justice; and (4) why funders should default to supporting socially valuable research.

ASSESSING SOCIAL VALUE

Resnik (2018) and Dresser (2018) both express skepticism about the ability of funders to assess social value. Resnik

writes: "The road from research funding related to a health problem (such as cancer) to social benefits (such as reduction in mortality and morbidity) is seldom direct, steady, or predictable." As he points out, sometimes vast sums of money appear to have little impact and at other times chance discoveries yield breakthroughs.

It is true that measuring the social value of research is extremely hard. This is due to the nature of research, which deals with what is not yet known. However, while it is impossible to render precise estimates of a project's social value, we should not be pushed to the other extreme of thinking that rough or comparative judgments of social value are impossible. For example, cancer research—even preclinical research—is more likely to benefit cancer patients than Alzheimer's patients. Research into bone-marrow transplants is more likely to benefit patients in high-income countries than those in low-income countries. Implementation research conducted in health facilities in Rwanda is more likely to benefit Rwandan patients than patients in Peru, and vice versa. Insofar as such judgments can be made, research funders can make use of them in setting priorities. As Dresser suggests, there is also much more work to be done in evaluating the effects of funding decisions. Such evaluations could inform assessments of the expected social value of new research proposals.

THE OBLIGATIONS OF FOR-PROFIT RESEARCH FUNDERS

Jecker and Hurst (2018) both address our conclusions about the obligations of for-profit research funders.

This work was authored as part of the Contributor's official duties as an Employee of the United States Government and is therefore a work of the United States Government. In accordance with 17 USC. 105, no copyright protection is available for such works under US Law. The views expressed are the authors' own. They do not represent the position or policy of the National Institutes of Health, the U.S. Public Health Service, or the Department of Health and Human Services.

Address correspondence to Joseph Millum Department of Bioethics & Fogarty International Center, National Institutes of Health, 10/1C118, 10 Center Drive, Bethesda, MD 20892, USA. E-mail: joseph.millum@nih.gov

Jecker's (2018) critique appears to rest on a misreading of our view. In describing the case of Pfizer and fluconazole, she writes: "Rather than assigning responsibility to Pfizer for the exorbitant price it charged, Pierson and Millum lay blame on the South African government ... According to these authors, Pfizer not only had moral license to charge inordinate prices, it was doing what it should." This is the opposite of the view we defend in the article. On our view, for-profit research funders act wrongly when they take advantage of market failures. The fluconazole case illustrates such a failure, so taking advantage of it to jack up prices was wrongful.

The confusion might have arisen because we are also critical of the actions of the South African government, which at the time did not do what it should to ensure access to treatment for HIV/AIDS. But, of course, the fact that one agent has acted wrongly does not absolve others from wrongdoing. In this case, both parties were to blame for South Africans not getting access to treatment to which they had a right.

Hurst (2018) points out that corporate social responsibility activities by pharmaceutical companies may be largely driven by self-interest rather than a sense of duty. We do not disagree. Indeed, the reason why market actors need to be regulated is precisely because they are expected to engage in self-interested behaviors. Like Hurst, we want to resist the widespread view that forprofit companies' only obligations are to follow the rules and enrich their shareholders. We have argued that under non-ideal conditions—wherein the benefits generated by research are unfairly distributed—companies have much wider duties to fund socially valuable research. Our analysis of corporate obligations can be helpful in two ways. First, it can help by providing a standard against which for-profit research funders can be judged. Second, it can provide a framework for individuals working in the private sector to assess how they should use their influence for the better.

PROCEDURAL JUSTICE

Important questions related to procedural justice are raised by MacKay (2018) and by Pratt and Hyder. MacKay presses us on the question of what to do when the demands of substantive and procedural justice conflict. A legitimate elected government may enact policies that are unjust. What should individuals working for that government do? We think that the answer depends on the nature of the injustice. Government workers should not engage in torture at the behest of their superiors, no matter how far doing so would express the popular will. But the case for civil disobedience is much harder to make for less egregious policies—civil servants should not lay down their pens every time the government proposes a tax break that they judge unfair. This problem is underexplored in political philosophy and we punt on it again here: We do not know how unjust a policy must be in order to legitimize disobedience. We propose two rules of thumb for individuals working within government research funders. First, follow the policies made by legitimate elected representatives, unless they are egregiously unjust. Second, insofar as one's role allows some discretion, use that discretion to fulfill the state's ethical obligations.

Pratt and Hyder ask whether funders ought to use "inclusive and participatory processes" for priority setting and allocation decisions. Insofar as doing so is likely to lead to allocation decisions that better fulfill funders' substantive obligations, we think the answer is clearly yes. For example, research is likely to be more socially valuable if it is responsive to the needs of patients, which can often be best assessed through direct engagement with those patients. Whether there are noninstrumental reasons to use such processes for research priority setting is a more difficult question. It is more difficult because of the problem identified by MacKay: The results of fair procedures may yet be substantively unjust. A priority-setting process that included representatives from potential beneficiaries of the research might produce results that reflected societal prejudices; for example, mental health might receive unjustly low priority because of widespread beliefs that mental health problems are not real, are not amenable to medical treatment, or are the fault of the sufferer.

WHY SHOULD FUNDERS DEFAULT TO SUPPORTING SOCIALLY VALUABLE RESEARCH?

Finally, MacKay questions our claim that "except insofar as other duties apply, research funders should support the most socially valuable projects." In the article, we argue that the best allocation of research resources is the one that maximizes the social value of the research. Though this provides a reason for anyone funding research to allocate resources in this way, it does not establish a duty to do so. For example, we typically think that individuals have some discretion regarding how they spend their money. If this is right, then individuals who support medical research plausibly also have some discretion about what research they support. I can choose to donate money to breast cancer research over lung cancer research if I so choose. The question that MacKay rightly presses us on is whether the discretion that individuals possess is also possessed by organizations that fund research.

In brief, our view is that government research funders do not have discretion about how to spend their funds. This is because the way that states allocate resources should be governed by principles of distributive justice. Further, in the case of allocating research funds, where special obligations do not apply, we think that maximizing social value is likely to be a good approximation to what distributive justice requires. The key issue for debate in this regard is whether governments should be primarily focused on maximizing social value for a national or international population.

For nonstate funders, as MacKay points out, the case is less clear. Consider a charitable foundation that has

been set up to support research into heart disease for Americans. If it were permissible for the founders to set up the charitable foundation with that mission—rather than the mission to research, say, neglected tropical diseases—then why wouldn't it also be permissible to support heart disease research that is mostly expected to benefit, say, wealthy, well-insured patients? The charity seems like it should inherit the discretion of the individuals who found it or fund it.

However, we do think that nonprofit organizations (and for-profit organizations) have more obligations than individuals. This is because of the subsidies and support that they receive from governments, such as tax breaks and protections from liability. Such support can only be justified if these organizations promote social justice. We acknowledge that more work needs to be done to either defend this view or articulate its limits.

REFERENCES

Alofabi, M. O. S. and S. O. Sodeke. 2018. Public health disasterrelated research: A solidaristic ethical prism for understanding funders' duties. *American Journal of Bioethics* 18(11):37–40.

Bierer, B. E., D. H. Strauss, S. A. White, and D. A. Zarin. 2018. Universal funder responsibilities that advance social value. *American Journal of Bioethics* 18(11):30–33.

Dresser, R. 2018. Conceptual, structural, and practical challenges to ethical allocation of research funds. *American Journal of Bioethics* 18(11):23–25.

Garba, I., L. Barraza, and E. Hall-Lipsy. 2018. Acquired duties for ethical research with American Indian/Alaska Native populations: An application of Pierson and Millum's framework. American *Journal of Bioethics* 18(11):40–42.

Hurst, D. J. 2018. Is there a business case for constitutive duties of for-profit research funders? *American Journal of Bioethics* 18(11):35–37.

Jecker, N. S. 2018. Pfizer's corporate citizenship. *American Journal of Bioethics* 18(11):18–21.

MacKay, D. 2018. Health research priority setting: A duty to maximize social value? *American Journal of Bioethics* 18(11):25–27.

Mann, S. P. and M. M. Schmid. 2018. Health research priority setting: State obligations and the human right to science. *American Journal of Bioethics* 18(11):33–35.

Pratt, B. and A. A. Hyder. 2018. Priority setting is more than resource allocation: Reflecting on the content of funders' duties and their implications for current practice. *American Journal of Bioethics* 18(11):27–30.

Resnik, D. B. 2018. Practical problems related to health research funding decisions. *American Journal of Bioethics* 18(11):21–23.