



Bridging the Gap Between Bioethicists and the Public: A Living Ethics Perspective

Suzanne Metselaar, Giulia Inguaggiato & Eric Racine

To cite this article: Suzanne Metselaar, Giulia Inguaggiato & Eric Racine (2024) Bridging the Gap Between Bioethicists and the Public: A Living Ethics Perspective, The American Journal of Bioethics, 24:9, 30-32, DOI: [10.1080/15265161.2024.2377117](https://doi.org/10.1080/15265161.2024.2377117)

To link to this article: <https://doi.org/10.1080/15265161.2024.2377117>



© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 03 Sep 2024.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)

And bioethics needs to force attention to access to health care broadly defined. Only arguing about who gets a ventilator in a pandemic or who receives a rare face transplant is to elevate the trees beyond any ability to see the justice forest.

Bioethics in America is not simply the findings that Pierson reveal. It hasn't been for many years. To meet the challenges of the future requires more than diversification of the academic community. It also requires recalibrating the manner of work, its goals and the nature of the problems to be addressed (Caplan, 2023).

DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author(s).

FUNDING

The author(s) reported there is no funding associated with the work featured in this article.

THE AMERICAN JOURNAL OF BIOETHICS
2024, VOL. 24, NO. 9, 30–32
<https://doi.org/10.1080/15265161.2024.2377117>



OPEN PEER COMMENTARIES

 OPEN ACCESS  Check for updates

Bridging the Gap Between Bioethicists and the Public: A Living Ethics Perspective

Suzanne Metselaar^a, Giulia Inguaggiato^a and Eric Racine^b

^aAmsterdam University Medical Centers; ^bMontreal Clinical Research Institute (IRCM)

In the VIBeS study, Pierson et al. (2024) observe that the views of U.S. bioethicists do not align with views of clinicians or with broader U.S. public opinion. They also note that the bioethics community is much less diverse than the U.S. public and therefore not representative of the range of American people. This is problematic, they argue, because bioethicists risk being “out of touch” with the public, while being considered authorities on ethical matters. The authors therefore call on bioethicists to more openly share their views with the public and consider whether these views are (dis)agreed with. Also, they argue

ORCID

Arthur Caplan  <http://orcid.org/0000-0002-4061-8011>

REFERENCES

- Caplan, A. L. 2005. Who lost China: A foreshadowing of today's ideological disputes in bioethics? *Hastings Center Report* 35,3:12–3.
- Caplan, A. L. 2023. Science following Covid: The role of scientists. In *Time to rebuild: Essays on trust in health care and science*, ed. Lauren A. Taylor.
- Jecker, N., J. Savulescu, A. Caplan, A. Capron, J. McMillan, M. Ghaly, G. Ortiz Millán, C. Atuire, J. McMahan, V. T. Chuan, et al. 2024. Bioethics' duty to conference in Qatar: Reply to Magnus. *The American Journal of Bioethics* 24 (4):4–7. doi: [10.1080/15265161.2024.2326363](https://doi.org/10.1080/15265161.2024.2326363).
- Kaebnick, G. E., and M. Z. Solomon. 2023. Special report. *Hastings Center Report* 53 (5):S105–S9.
- Moreno, J. D. 2011. *The body politic*. New York, NY: Bellevue Literary Press.
- Pierson, L., S. Gibert, L. Orszag, H. K. Sullivan, R. Y. Fei, G. Persad, and E. A. Largent. 2024. Bioethicists today: Results of the views in bioethics survey. *The American Journal of Bioethics* 24 (9):9–24. doi: [10.1080/15265161.2024.2337425](https://doi.org/10.1080/15265161.2024.2337425).

that the bioethics community should become more diverse and inclusive.

We endorse both recommendations. However, we maintain that more vigorous action is needed to bridge the gap between bioethicists and the public, and thus to prevent misalignment between them. Merely informing the public about the *outcomes* of bioethics research, as the authors suggest, will not bring bioethics much closer to the lived experience of clinicians and the public. In this way, bioethicists forego on the chance to integrate meaningful experiences and insights of stakeholders into their

understanding of a moral problem and of how it should be dealt with. Rather, we argue that addressing the gap between bioethicists and the public requires collaboration in bioethics research with clinicians, patients, and citizens, as well as a focus on ethical problems as they are experienced in everyday life. This position is in line with an emerging “living ethics” stance.

Living ethics is an orientation committed to the recognition that, prior to academic reflection, ethics evolves within and is intertwined with the daily interactions between people, such as clinicians, patients, and family members. Hence, it positions bioethics as a way of life. It also proposes that bioethics research encourages growth and learning in ways that support various ways of human flourishing, thus positively impacting everyday life.

In contrast, the data reported by Pierson et al. speak to how bioethics, as a distinctive field of academic expertise, is rather disconnected from everyday life. However, this has not always been the case: For a long time, ethics was much closer to practice. For instance, medical ethics was something *by doctors for doctors*, and reflected the *mores* of the medical guild. It focused on the doctor–patient relationship and on the virtues and good conduct of the doctor in everyday practice. Thus, while it entailed reflection on the professional life, it was also *part of* that professional life.

A change of paradigm occurred in the second half of the 20th century, as a critical response to many developments in society and in medicine. The authority of physicians was called into question as important blind spots were put to light, for instance, with respect to the rights of patients, women, minorities, and people with disabilities. In response, the idea arose of an interdisciplinary field of ethics scholarship and, eventually, that academically trained bioethicists were needed, as they could uniquely contribute to questions of ethics in health care and public policy (Callahan 1973). Rapidly, institutions arose and bioethicists became a new and authoritative voice for ethics in medicine and health care policy, being consulted by government commissions, law reform bodies and professional organizations (Engelhardt 2002). Today, although bioethics still is about ought-questions that arise from practice, and ultimately seeks to improve practice by studying these questions (Sheehan and Dunn 2013), it is much less embedded in practice than it used to be, and it has expanded as a domain of theoretical scholarship. The discrepancy between the opinions of American bioethicists and the opinion

of the public highlighted by Pierson et al. could be an outcome of this development.

In fact, it is unsurprising that those who spend years training and discussing ethical issues—which for a majority of citizens remain matters of occasional conversations and tacit knowledge—develop different views. Since what we value and consider to be right and wrong is learned from the earliest moments of human life, human beings form habits of thinking and behaving that embody those values. Taking a step back to reflect on those habits through scholarship requires effort and critical inquiry, which may be at odds with the certainty required for everyday moral behavior.

However, bioethicists must remain mindful of how difficult questioning those habits and views can be, and how embodied and socially entrenched they are. There is great risk of moralization by bioethicists if they lose sight of these habits and lived experiences, and judge or evaluate from their rather unique standpoint the moral opinions of fellow citizens. There is also a risk that certain public opinions become new taboos and certain ideas become marginalized by the academic establishment, in particular because the bioethics community does not represent the cultural and socioeconomic diversity among the (U.S.) population, as Pierson et al. point out.

As a response to this development and out of a desire to make of ethics a more effective lever of human flourishing, living ethics seeks to bring greater proximity to everyday morality and moral concerns. It does so in ways that allow for a pluralism of accounts of human flourishing. At the same time, living ethics recognizes that ethicists cannot *only* be representatives of public opinions. They are committed to the idea that the domain of morality is a domain of inquiry and discovery, that is, a domain of learning and growth; otherwise, research in this area would be nonsensical. This commitment requires openness, critical thinking, and sometimes discomfiting questions about entrenched habits, beliefs, and behaviors (Racine et al. 2024b).

A crucial issue is how bioethicists can support and organize discussions where these kinds of inquiries fruitfully take place. A living ethics stance therefore promotes participatory and dialogical approaches to doing bioethics research, by means of which ethicists can better relate to stakeholder experiences but also move toward co-learning and joint ethical problem solving. These approaches are methodically structured in such a way that they require a productive interaction between academic bioethicists and diverse groups

of nonbioethicist stakeholders (Inguaggiato et al. 2019; Metselaar 2024).

An example is living ethics labs. Living labs are interdisciplinary and participatory initiatives aimed at bringing research closer to practice by involving stakeholders in all stages of research. Living labs align with the principles of participatory research methods, as well as with recent insights about how participatory ways of generating knowledge help to change practices in concrete settings with respect to specific problems (Racine et al. 2024a).

Another example is dialogical approaches to empirical ethics. Empirical ethics designates “methodologies that seek to use empirical data about stakeholder values, attitudes, beliefs and experiences to inform normative ethical theorizing” (Davies, Ives, and Dunn 2015). It departs from the assumption that exploring stakeholder attitudes, beliefs, and experiences informs and enhances ethical analysis itself, as it makes ethicists—and other experts—more contextually aware, that is, more grounded in the realities of lived experience, in order to provide better, more workable solutions for ethical problems (Leget, Borry, and de Vries 2009). A dialogical approach to empirical ethics allows stakeholders and members of society to be directly involved in the interpretation of the data and in reaching the creation of an ethical response, such that normative conclusions (also) reflect the priorities of those affected (Metselaar, Geurts, and Meynen 2020).

These methodologies have in common that they take stakeholders’ lived experience as their point of departure and reference point, yet do not discard academic bioethics expertise. In this way, they prevent a situation where society’s perspectives are at odds with the “ivory tower perspectives” of the experts who worked on an ethical response, which is what Pierson et al. caution against. Rather, by fostering processes of joint moral learning among bioethicists and diverse members of the public—with specific attention to the perspectives of groups that are underrepresented in bioethics—a living ethics stance seeks to bridge the gap between bioethics and those who live in the realities of the moral issues that are explored.

DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author(s).

FUNDING

The author(s) reported there is no funding associated with the work featured in this article.

REFERENCES

- Callahan, D. 1973. Bioethics as a discipline. *Studies—Hastings Center* 1 (1):66–73.
- Davies, R., J. Ives, and M. Dunn. 2015. A systematic review of empirical bioethics methodologies. *BMC Medical Ethics* 16 (1):15. doi: [10.1186/s12910-015-0010-3](https://doi.org/10.1186/s12910-015-0010-3).
- Engelhardt, H. T. 2002. The ordination of bioethicists as secular moral experts. *Social Philosophy & Policy* 19 (2):59–82. doi: [10.1017/s026505250219203x](https://doi.org/10.1017/s026505250219203x).
- Inguaggiato, G., S. Metselaar, G. Widdershoven, and B. Molewijk. 2019. clinical ethics expertise as the ability to co-create normative recommendations by guiding a dialogical process of moral learning. *The American Journal of Bioethics* 19 (11):71–3. doi: [10.1080/15265161.2019.1665735](https://doi.org/10.1080/15265161.2019.1665735).
- Leget, C., P. Borry, and R. de Vries. 2009. ‘Nobody tosses a dwarf!’ The relation between the empirical and the normative reexamined. *Bioethics* 23 (4):226–35. doi: [10.1111/j.1467-8519.2009.01711.x](https://doi.org/10.1111/j.1467-8519.2009.01711.x).
- Metselaar, S. 2024. Translational bioethics as a two-way street. Developing clinical ethics support instruments with and for healthcare practitioners. *Bioethics* 38 (3):233–40. doi: [10.1111/bioe.13225](https://doi.org/10.1111/bioe.13225).
- Metselaar, S., J. Geurts, and G. Meynen. 2020. Responding to human brain surrogates research: The value of empirical ethics. *The American Journal of Bioethics* 21 (1):64–6. doi: [10.1080/15265161.2020.1845865](https://doi.org/10.1080/15265161.2020.1845865).
- Pierson, L., S. Gibert, L. Orszag, H. K. Sullivan, R. Y. Fei, G. Persad, and E. A. Largent. 2024. Bioethicists today: Results of the views in bioethics survey. *The American Journal of Bioethics* 24 (9):9–24. doi: [10.1080/15265161.2024.2337425](https://doi.org/10.1080/15265161.2024.2337425).
- Racine, E., B. D’Anjou, C. Dallaire, V. Dumez, C. Favron-Godbout, A. Hudon, M. Montreuil, C. Olivier, A. Quintal, V. Chenel, et al. 2024a. Developing a living lab in ethics: Initial issues and observations. *Bioethics* 38 (2):153–63. doi: [10.1111/bioe.13246](https://doi.org/10.1111/bioe.13246).
- Racine, E., S. Ji, V. Badro, A. Bogossian, C. J. Bourque, M.-È. Bouthillier, V. Chenel, C. Dallaire, H. Doucet, C. Favron-Godbout, et al. 2024b. Living ethics: A stance and its implications in health ethics. *Medicine, Health Care, and Philosophy* 27 (2):137–54. doi: [10.1007/s11019-024-10197-9](https://doi.org/10.1007/s11019-024-10197-9).
- Sheehan, M., and M. Dunn. 2013. On the nature and sociology of bioethics. *Health Care Analysis* 21 (1):54–69. doi: [10.1007/s10728-012-0234-z](https://doi.org/10.1007/s10728-012-0234-z).