

## Editorial: Examining the Links

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The topic of this special section, Causation and Moral Responsibility, was suggested to us by our ongoing research project Bioeconomy and Justice (BioEcoJust), funded by the Academy of Finland and the Finnish Ministry for Agriculture and Forestry. Bioeconomy, simply put, is a future alternative to the contemporary fossil-based economy, which, alongside the industrial revolution and the rise of global capitalism, has brought us our current coal, oil, and gas dependencies, pollution, environmental decay, and climate change. Bioeconomy has many connections to bioethics, given, of course, that we allow bioethics a remit beyond the immediate professional and organizational concerns of healthcare workers and authorities. Van Rensselaer Potter, one of the founders of the approach, thought that such a remit was essential,<sup>1</sup> although later developments have moved the cause, or discipline, into other directions.

In our project, we continue our two-decade research program, which has taken us through genetic engineering,<sup>2,3,4,5</sup> cloning,<sup>6,7,8,9,10,11,12,13,14</sup> genetic information,<sup>15,16,17,18,19,20,21,22,23</sup> human genetic databases,<sup>24,25,26,27</sup> systems biology,<sup>28</sup> genetic selection,<sup>29,30,31,32,33,34,35,36</sup> neuroethics,<sup>37,38,39,40,41</sup> synthetic biology,<sup>42,43,44</sup> and emerging technologies more generally,<sup>45,46,47</sup> back to the basics of rights, responsibilities, harm, justice, and the environment.<sup>48,49,50</sup> Our present focus on bioeconomy enables us to draw on work already done. Technological bioeconomy solutions often find their foundation in genetics, molecular biology, and synthetic biology. Forests and forestry are focal to the forthcoming bioeconomy in many ways, and issues like shrinking coal sinks and decreased biodiversity are, according to some, best encountered by genetic plant selection and cloning. Dietary choices, especially meat eating, produces a significant portion of our carbon footprint in the more affluent countries, and our studies into lifestyle restrictions,<sup>51,52</sup> coercion,<sup>53</sup> and paternalism<sup>54</sup> help us in this corner of the bioeconomy.<sup>55</sup>

These substantial matters will be the topic of a future special section. In this collection of articles, however, we focus on one of the basic ethical questions of our project, namely, responsibility. Among our other research tasks, we aim to identify agents who promote or hinder the emergence of the bioeconomy, to determine the extent of their responsibilities, and to evaluate the normative meaning and impact of these responsibilities. To move in on the theme, we have gathered, and present here, a collection of articles, which approach responsibility and its moral implications from many different angles. Let us begin by contemplating the place and nature of responsibility in the bioethics institution that has the official duty of assessing the matter: ethics committees.<sup>56,57,58</sup>

Most people working in bioethics have experience of hands-on ethical decision-making in these institutional review boards, or ethics committees as they are known

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outside the United States. Within the past few decades, institutional review boards have become standard practice in medicine and the biosciences. Research in the humanities and social sciences is also increasingly subjected to ethical review. This has improved the standing of research subjects, and contributed to the equality of researchers. Pretty much the same rules and protocols are upheld in institutions all over the world, which means that publishers and other interested parties can know that certain agreed standards of research ethics have been respected.

There is, however, a downside to institutionalized ethics. This is that there is very little ethics left, in particular from a consequentialist or utilitarian viewpoint. Much of the work in institutional review boards consists of checking that the proposal on the table right now follows national and international laws and regulations, and complies with institutional guidelines. The regulations and guidelines look at individual research proposals in isolation, which raises the question of how to keep an eye on the overall benefits and harms of research. It is, of course, good to ascertain that the participants of research projects are always protected, and that benefits always outweigh the associated harms. We do not, however, think that this is sufficient. If the goal is to achieve good outcomes—maximize preference satisfaction, minimize preference frustration, or the like—addressing research proposals one at a time is not enough.

Much of this boils down to research funding, and turns into a question of science policy. What kind of research gets funded, and why? How are the funding bodies—institutional, national, independent, and industry—allocating the funds available for research, and on what grounds? Are research funds allotted to projects that will benefit the greatest number? We do not think anyone could claim this. Rather, the growing trend seems to be that research with the highest short-term innovation and business potential gets the go-ahead. This raises a concern for the plight of poor people, people without powerful groups representing their interests, and people living in poorer countries more generally. The development of, say, medicines, treatments, and diagnostic tools for conditions effecting these people is unlikely to meet the threshold of commercial viability, and is, therefore, less likely to receive funding.

If we believe in the credo of classical liberalism, that economic prosperity will also benefit the worse-off, this would be an indirect route to “benefitting the greatest number.” We doubt that the credo is tenable. There is, as things stand, enough wealth in the world to feed everyone and to meet everyone’s basic health needs. The current uneven distribution of wealth, however, prevents this from happening, and there is no reason to think that this would change in the future. A far more probable scenario is that researchers develop more and more expensive treatments and medicines for the better-off (because this is where the profits that further benefit the wealthy are made), and this means that less and less becomes available for the worse-off.

From an ethical point of view, research fund allocation, in the bigger picture, can be seen as a variation of the trolley problem.<sup>59</sup> In a world of limited resources, funding research project A (advancing the wellbeing of group X) regularly implies not funding research project B (advancing the wellbeing of group Y), which means that one group of beneficiaries is chosen over another. To put the matter more provocatively, in the context of life-saving measures, funding allocation decisions are decisions about who lives and who dies. This being the case, we believe that it would be reasonable for someone, somewhere, to consider, among other things, the

relative sizes of these groups, and the overall allocation of expected harms and benefits.

The matter of who, and at what level, should oversee these decisions is, of course, a tricky question. What would give legitimacy to the power of any such overseeing body? Why would independent funding organizations have to comply? These are complicated issues, and instead of trying to solve them here, let us start with two suggestions to make research ethics more ethical. First, and at minimum, we call for empirical studies on the allocation of research funding nationally and globally, to see to what extent our concerns are warranted. Who, under the current trend, would fund such studies remains uncertain. Second, we call upon our colleagues to come up with ideas on how to make the allocation of research funding more ethical and more just.

In some ways, what is happening in research ethics is symptomatic of many of the problems that face us in current times. Institutional structures, governmental and nongovernmental alike, are fragmented to the degree that when something goes wrong or grave injustice occurs, no one is, or can be, held accountable. For injustice to emerge, no wrongdoing by an accountable agent is needed. For moral wrongs to take place, no identifiable agent needs to commit the wrong, because the mechanism for letting them happen is inbuilt in the underlying structures. However, stubbornly holding on to the thought that ethics should be about equally considering the wellbeing of all, we would like to see something done about this. In the field of research ethics, a start would be to get people to care about the overall allocation of research funds.

In the first article of the collection, "The Undeserving Sick: An Evaluation of Patients' Responsibility for their Health Condition," Christine Clavien and Samia Hurst study the current tendency to hold individuals responsible for their lifestyle-related illnesses. In their thorough analysis, they show how the morally responsible parties could in fact be found elsewhere. Dr. Clavien and Prof. Hurst argue that, rather than the individuals, we should be looking at public health agencies and private industries as holders of much of the responsibility. In many cases, holding the individuals responsible would not only be morally wrong, but it would add further injustice to the injury they have already encountered.

In his commentary on Dr. Clavien and Prof. Hurst's article, Thomas Douglas questions some of their psychological presuppositions, worries about further implications of their approach, and reminds us of the benefits of responsibility-sensitive health funding. In the end, however, he, at least tentatively, sides with the general thrust of their argument and policy conclusions.

Greg Bognar's article, "The Mismatch of Personal Responsibility and Health," continues on the theme of the previous article. However, the approach here is quite different. Dr. Bognar scrutinizes the individual and population strategies, and studies their relative merits in addressing population health issues. He argues that the current responsibility-sensitive theories of distributive justice, together with the epidemiological change from communicable to noncommunicable diseases, have distorted our intuitions and resulted in us putting too much emphasis on personal responsibility in public health matters.

In her article, "The traditional Definition of Pandemic, Its Moral Conflation, and Its Practical Implications: A Defense of Conceptual Clarity in Global Health Laws and Policies" Thana C De Campos expands the theme of public health to global health. She studies the established notion of *pandemic*, and shows how it fails to

differentiate between global emergencies and nonemergencies. This, she argues, is a result of the definition not being nuanced enough, and results in inadequate abilities to prepare for and respond to pandemics.

Commenting on De Campos' article, Eduardo A Undurraga agrees with De Campos' tenet that the current definition of *pandemic* might be inadequate for theoretical and practical purposes. He, however, notes that defining 'severe' might not be as straightforward as De Campos seems to believe, and further, that there are other factors contributing to insufficient ability to respond to global pandemics. For instance, while the International Health Regulation (IHR) treaty went into effect some twelve years ago, many low- and middle-income countries, due to insufficient funds, are yet to comply with the IHR and, more generally, in the absence of a coordinating institution, global preparedness is difficult to secure.

Scott Gelfand, in his "The Nocebo Effect and Informed Consent—Taking Autonomy Seriously," discusses the phenomenon where learning about the possible side effects of a medical treatment increases the likelihood that one will suffer those side effects. He submits that there are two types of cases; those where there is only one treatment option and those where a choice needs to be made between several options. He argues that, based on ethical analysis, with the former, the default answer is nondisclosure, and with the latter, disclosure. However, there can be exceptions based on the intrinsic value the patient gives to her autonomy. To identify the exceptions, Dr. Gelfand would like to see a tool, similar to the Universal Pain Assessment Tool, developed to help physicians in their task of assessing their patients' own concepts of autonomy.

In his response to Gelfand, Dien Ho challenges both Gelfand's objections and the solution he proposes. Ho's main criticism arises from his stance that the Nocebo Effect and the related ethical questions should not be dealt with isolated from clinical practice more generally. He concludes by stating that in order to better understand the tensions between respecting autonomy and nonmaleficence created by nocebos, we should look at the vast literature on conventional tensions in clinical practice.

Matti Häyry brings the harm caused to nonhuman animals to the table. His contribution, "Causation, Responsibility, and Harm: How the Discursive Shift from Law and Ethics to Social Justice Sealed the Plight of Nonhuman Animals" starts by analyzing different types of harm, and how they apply to human and nonhuman animals. Even though many of the categories overlap, when it comes to responsibility for harm, the two groups are treated very differently. Harm caused to humans creates an urgency to find the guilty parties, while harm inflicted on nonhuman animals, not so much. Prof. Häyry attributes this to the discursive shift from ethics to justice that took place in Western moral and political philosophy, and moral thought more generally in the late 1980s. He explains how, before the turn, the normative grounds for solving ethical issues were fairly straightforward, and were based on the wrongness of violating rights and causing harm. These normative assumptions were equally applicable to human and nonhuman animals. However, with the rise of complex theories of social justice, humans became a clear priority. While nonhuman suffering is still considered objectionable, each of the theories has its own reasons why human concerns take precedence, and nonhuman animals remain marginalized.

This special section closes with Fabrizio Turoldo's two contributions to remind us that when discussing the matters of causation and moral responsibility, we might

benefit from widening our horizons toward Continental philosophy and even psychoanalysis. In his first article, "The Cannibals that We Are: For a Bioethics of Food," Dr. Turolto studies the deeper social and psychological meanings that food and eating have for humans, and how this, for instance, affects our consumption habits. In his second contribution, "The Cannibal's Gaze: A Reflection on the Ethics of Care Starting from Salvador Dalí's Oeuvre," Dr. Turolto explores the importance of how we are seen. Understanding this is important for caring relationships in particular, and for human relationships in general.

## Notes

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55. A new issue that we are tackling is the inadequacy of perpetual economic growth as one of the cornerstones of “sustainable development.” For some of our views on this, see the recent presentation in a Finnish Ministry for Agriculture and Forestry organized conference EU Bioeconomy Scene, related to the Finnish late 2019 Presidency of the European Commission, Matti Häyry’s part beginning at 2:34:26; available at <https://mmm.videosync.fi/eubioscene19> (last accessed 28 July 2019).
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59. See, for example, note 54, Häyry 1994, at 101–4, 145–6.



Small bars of silver formed into a chain from the Tod treasure. Egypt, El-Tod, reign of Amenemhat II (1898-1866 (BCE). E15128. Location Musée du Louvre, Paris, France, Photo: Christian Decamps, Photo Credit: © Musée du Louvre, Dist. RMN-Grand Palais / Art Resource, New York Reproduced by Permission.