

Commentary: Enlightened Democracy in Practice

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Since 2012, the dramatically increased potential of genome editing techniques (particularly CRISPR-Cas9) in human therapeutics has created headlines, enthusiasm, and concern in genetic research not seen since the mapping of the human genome at the turn of the century. It is vital that a responsible debate on the issue of genome editing proceeds with a focus on human and nonhuman applications and that discussion is fostered that is critically reflective on the various emerging societal responses and policy recommendations. In “Regulating Genome Editing: For an Enlightened Democratic Governance,” Giulia Cavaliere, Katrien Devolder, and Alberto Giubilini outline the importance of involving the wider society in discussions surrounding the regulation of new forms of biotechnology with significant societal impact. Importantly, the form of such discussions, and the resulting regulations, should take the form of—what they term—the “enlightened democracy” approach which seeks to combine well-informed democratic engagement characterized by mutual respect for differing views. Their proposal is a theoretical framework that, as the authors acknowledge, would “most notably” need to be further developed to be translated into practice. Therefore, in this commentary, I wish to positively contribute to this particular development by outlining some important and relevant points from a recent paper in which I participated.¹

The perspective Cavaliere, Devolder, and Giubilini advocate is similar to many forms of public participation that, on the face of it, are increasingly integrated with the discourse of an expanding number of health, science, and political institutions today.² Some of the many examples arise in numerous forms of “deliberative polling,” “citizens’ jury,” and consensus conferences on relevant scientific, technological, and social issues, including genetically modified organisms (GMOs).³ Information and communication technology (ICT) is also expanding the forums that such participation can take. The executive summary of the United Nations E-Government Survey 2014 has noted global progress in governmental use of ICT technology to create better interconnected and more transparent and responsive policies, in particular by allowing citizens to engage effectively in decision-making processes [. . .] through decentralized governance.”⁴ In Latin America, digital democracy is extending the parameters of the more traditional offline forms of discussions.⁵ Closer to the context of gene editing, similar developments in citizen engagement can be noted in the growing presence of participant-centered research genetic testing initiatives.⁶ For instance, Eric T. Juengst et al. see the notion of patient empowerment as a central theme in their marketing as well as in the “enthusiastic writings of their customers.”⁷ Such initiatives are also considered by some to place participants “at the center of [the] decision-making process.”⁸ Christopher M. Kelty and Aaron Panofsky have analyzed the growing concept and practice of “participation” across a number of science and medicine research initiatives, including such ICT-based participant-centered initiatives

as Patientslikeme and 23andMe, and have outlined no less than seven dimensions that “participation” can take.⁹

Taken together, such examples appear to offer an emerging state of the art of potential practical forms of enlightened democracy that can be applied to genome editing. Rather than simply increasing participation in a numerical sense, some of the approaches attempt a deliberative turn and ascribe to an ideal where political decision making involves free and equal citizens that listen to and respect each other, reasonably reflect on issues, give good reasons for their positions, seek to understand the perspectives of others, and are willing to change their initial preferences during the process of deliberation.¹⁰ The overriding goal is to increase participation that is informed and the result of facilitated deliberation.¹¹ As argued elsewhere, it can be understood as exemplifying an overall ideal of seeking to increase the “quantity of quality” opportunities for the wider society to be better involved within and to contribute to decision-making processes over areas of significant societal importance, as is the case with genome editing developments arising from the advancement of CRISPR.¹² In this respect, it seems less the case that Cavaliere, Devolder, and Giubilini are proposing something entirely new and more that they are highlighting the key aspects of enlightened democracy already in place and rightly suggesting that they be applied to the new area of gene editing.

However, it should still be a suggestion with reservations. As noted by Jason Woolley et al., some participant-centered research initiatives can be seen to take place according to a much narrower definition of “participation”—where it is merely the case that such research initiatives have increased contact with participants through ICT but are otherwise nonparticipatory in any important normative sense of the word.¹³ In the narrower understanding, research participants can be seen simply as sources of data gathered “without being ‘engaged’ or ‘involved’ beyond informed consent.”¹⁴ In addition, there may be a more fundamental issue of an underlying “tension” where some, even James Fishkin, view deliberation and participation as being “irremediably in conflict,”¹⁵ especially where the quality of discussion is undermined by mass participation. It is not clear that such problems are unavoidable, as many participants in the examples noted above seemed open to be engaged in deliberative, and not just participative, terms. Of course, this may suggest a different difficulty where deliberation occurs amongst a group of possibly already like-minded individuals who may not generate the diversity of perspectives and arguments needed to be “fully deliberative.”

Ultimately, for the purposes of this commentary, it is sufficient to note that—while not to be simply taken at face value—there are a number of forms of “enlightened democracy” already in action in the contexts of science, medicine, and genetics that offer a framework to further develop genome editing—focused forms of deliberative dialogue. The goal would be to increase participation of various stakeholders in genome editing in a discussion that itself is deliberative. As Erika Blacksher notes, “proponents of both deliberative and participatory practices posit the potential for people to learn from one another and, importantly, for experts and decision-makers to learn from ‘the people.’”¹⁶ This is particularly important in the context of genome editing, as the rapid progress, as exemplified by CRISPR-cas9, is taking some of the more speculative normative discussions of the last decades in a more applied direction with an increasing influence on legislative and regulatory matters. Consequently, this area requires more balanced and

responsible form of discourse than simply speculation from well-meaning philosophers alone, but rather a more central role of various forms of “enlightened democracy” that would include deliberations between philosophers, sociologists, legal experts, scientists, medical practitioners, patients, and people from the wider society. It is also important for citizens of every country to have this opportunity. This is not guaranteed, even in Europe. For instance, in the United Kingdom, the Human Fertilisation and Embryology Authority and Nuffield Council on Bioethics have offered regulation and guidance on controversial and pressing bioethical issues of the day. This has entailed a robust approach to emerging genome-editing challenges and opportunities in the context of responsible licensing of research as well as the development of detailed reports and extensive discussions. On the other hand, Ireland defunded the Irish Council for Bioethics and the National Advisory Committee on Bioethics emerged with less independence and narrower terms of reference. As a result, and despite the international interest, recent developments in genome-editing have been largely unaddressed in the Irish context.

Overall, enlightened democratic governance is something that is not a new ideal, nor simply a theoretical proposal. Nevertheless, although it is something that is increasingly seen in practice, the reality is not necessarily as good as the rhetoric sometimes suggests nor as extensively practiced as it should be with regard to any area of significant societal impact, such as, but not only, the case of new genome editing possibilities.

Notes

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 9. See note 2, Kelty, Panofsky 2014.
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