Did recent efforts to develop policy for genome editing have adequate public engagement?

“No,” says Baker Institute fellow Kirstin Matthews in an article co-authored by nonresident scholar Ana Iltis and student intern Sarah Hoover. “Public and stakeholder engagement is an important part of science policy development, especially when reviewing controversial areas that concern deeply moral and religious beliefs and areas where there are significant ambiguities or uncertainties,” say the authors. However, the recommendations of three separate commissions charged with making globally influential recommendations for policies on human embryo genome editing fell short of this goal.

Recent advances in biotechnology have allowed scientists to more effectively and accurately edit the human genome. However, these advances raise questions about how the technology should and can be used. While questions concerning the development and improvement of technology predominantly involve the domains of science and engineering, discussions on whether to use a technology at all or how it should be regulated require broader engagement with the public and interested stakeholders. This is particularly important as we explore the types of heritable human genome editing we should permit, if any.

Public and stakeholder engagement is not just about teaching or conducting outreach. It also requires “multi-way communication or a dialogue among scientists, stakeholders and/or the public, such as a presentation of new ideas (a lecture or publication) followed by facilitated discussion,” the authors write. In addition, it “requires listening and synthesizing outside information, perspectives, and thoughts in the process of developing recommendations or policy.”

The authors recommend five ideals for effective public and stakeholder engagement of controversial scientific areas — comprehensive, transparent, inclusive, methodologically sound and accountable — based on a critical review of literature on the subject. Using these five ideals, the authors assessed the three consensus reports related to heritable human genome editing: the 2017 U.S. National Academies report, the 2018 UK Nuffield Council of Bioethics report and the 2020 joint UK Royal Society-U.S. National Academies report. Work on all three reports began after human embryos were edited (2015); the 2020 report was written in response to the birth of the first babies whose genomes had been manipulated (2018). As a result, the reports were not comprehensive enough; they responded to previous research instead of guiding future research. In addition, only the Nuffield Council report inclusively engaged a broad set of individuals by directly requesting their comments to recommendations; the report authors also advertised widely to obtain public feedback. In contrast, the authors of the other reports passively expected interested individuals to contact them.

Since the public funds a majority of biomedical research in the United States, public participation in setting goals and establishing boundaries for research is important. It can ensure that science adequately serves the public interest and helps improve public acceptance and support. To be effective, institutions developing policies for emerging technologies should continuously assess their methods for public engagement and learn new ways, and new technologies, to help engage the public.
HEALTH POLICY research presents a summary of findings on current health policy issues. It is provided by Vivian Ho, Ph.D., the James A. Baker III Institute Chair in Health Economics at Rice University’s Baker Institute for Public Policy, in collaboration with Laura Petersen, M.D., MPH, chief of the Section of Health Services Research in the Department of Medicine at Baylor College of Medicine.

This publication aims to make research results accessible to regional and national health policymakers. The views expressed herein are those of the study authors and do not necessarily represent those of the Baker Institute or of Baylor College of Medicine.

The Baker Institute and Baylor College of Medicine’s Section of Health Services Research work with scholars from across Rice University and Baylor College of Medicine to address issues of health care — access, financing, organization, delivery and outcomes. Special emphasis is given to issues of health care quality and cost.

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