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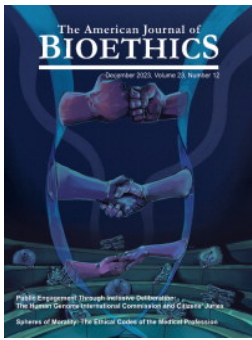
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Public Engagement with Human Germline Editing Requires Specification

Boy Vijlbrief , Sam Riedijk , and Eline M. Bunnik 

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Scheinerman (2023) proposes a Citizen's Jury on human germline genome editing (HGGE) to promote more inclusive public engagement, agenda setting and governance. She argues these juries should work in tandem with governing institutions to inform agenda-setting and resource allocation, to provide substantive contributions to the development of policy recommendations, and to increase not only trust, but trustworthiness of institutions involved in HGGE. While Scheinerman specifically proposes that a Citizen's Jury be conducted as part of the International Commission on the Clinical Use of Human Germline Genome Editing's summits, we argue that it is crucial to organize public engagement in many different settings and with diverse publics, ranging from global efforts, such as the summits, to national and local contexts, because HGGE puts our shared human genome at stake. Although Scheinerman's proposal for public engagement is laudable, we offer three recommendations to improve the design and set-up of public engagement efforts to strengthen their impact. In doing so, we build on our experiences with the Dutch DNA Dialogues (van Baalen et al. 2021).

First, monolithic understandings of the term human germline genome editing—not unique to Scheinerman's proposal but prevalent in public engagement activities on the topic, around the world—hinder meaningful deliberation. HGGE is an umbrella term, but its potential future applications may be diverse, and may serve various ends. We argue that to facilitate meaningful public engagement with HGGE, its context and applications should be specified. HGGE can be applied for the purposes of disease prevention or human enhancement, which call upon different moral frameworks. Moreover, applications can vary in the genes they target, the organ systems they affect, whether or not the intervention aims to treat or prevent hereditary disease, and the severity of these diseases targeted. This, in turn, may affect our considered judgments about particular types

of HGGE. For instance, families affected by hereditary heart disease may want to apply HGGE to prevent this disease in future generations, while families affected by hereditary deafness may challenge the perception of their condition as a pathology and reject the use of HGGE to alter it (Padden and Humphries 2020). Prospective parents who are both affected by the same recessive disease may choose HGGE as their only option for conceiving healthy, genetically related offspring, but HGGE can also be offered as an optional add-on for a couple who are already conceiving through IVF due to fertility problems. These different contexts raise diverging and specific moral questions which are easily overlooked when HGGE is discussed only in broad terms. By specifying the context in which HGGE may be used, we may more readily draw upon existing guidance while developing governance, and discuss more specific questions which emerge only in sharper focus. Governance of HGGE for Huntington's disease, for instance, may be informed by existing rich frameworks for genetic counseling for Huntington's disease (Evans 2006). Effective public engagement should acknowledge the important contextual differences between applications of HGGE, so that the questions we try to answer with public engagement emerge during engagement, and not after.

Second, a Citizens' Jury as proposed by Scheinerman consists of members of the general public, and does not include specific stakeholder groups, such as patients, patient families or (prospective) parents. Such stakeholder groups, however, have experiential knowledge that may not only be relevant, but indispensable to agenda setting and governance of specific applications of HGGE. While these groups of people clearly have stakes in the conversation on HGGE, they are not often involved (Vijlbrief et al. 2020; Houtman, Vijlbrief, and Riedijk 2021b). Therefore, we argue that effective public engagement requires the continuous inclusion of specified groups of people. For example, when discussing applications

of HGGE to prevent severe monogenic diseases, members of patient organizations can be invited to share their personal experiences of living with these diseases. Inclusion of these groups will ensure that agenda setting is based on the needs and concerns of people who have a stake in potential future applications of HGGE. By consulting representatives of patient organizations, there is also a possibility that we discover that there is no demand for certain applications of HGGE, for instance, because alternatives like preimplantation genetic testing are sufficient in specific patient groups (Houtman et al. 2023). Inclusion of specific stakeholder groups may enhance one of the goals of public engagement that Scheinerman endorses: by specifying potential future applications of HGGE and involving specific stakeholder groups, the substantive input of public engagement in governance can be enhanced. In addition, it would break the dichotomy between expert and non-expert: instead, it would recognize that general publics include many experts on HGGE, not of its technical aspects, but on the lived experience of the diseases it may target, which may translate to fervent wishes or deep fears concerning HGGE (Houtman, Vijlbrief, and Riedijk 2021a). Insight in these wishes and fears is important so that governance can be aligned accordingly, guiding the implementation of HGGE—if at all—in ways that are ethically sound.

Third, while the product of public engagement is often—automatically—assumed to take the form of a “report,” we are concerned that by using this form, public engagement activities may fail to contribute fruitfully to policy making. Instead we propose an additional focus on investing in stakeholder relationships. Results of public engagement are typically captured in a report, and presented as an overview of perspectives of those consulted, pointing out where consensus and disagreement exist. Such overviews of perspectives, which may be at odds or contradictory, are of limited use in governance development, and reductive in light of the goals of public engagement. Moreover, such reports may not help advance the discussion: many public engagement activities concerning HGGE have been criticized for recording public views that are already well-known (Conley et al. 2023). The report based on the Dutch DNA-dialogues, for example, showed an inclination of the Dutch public toward accepting the use of HGGE to prevent severe hereditary disease, on the condition that it is as safe as possible. However, another strongly voiced conviction was that HGGE research should not be

conducted on embryos older than 14 days, even though such research is necessary to assess the safety of HGGE, and required to eventually apply the technology (van Baalen et al. 2021). Such contradictions are difficult to translate into clear governance and raise more questions than answers. Thus, to meaningfully engage publics in policy making, a one-off report will not suffice, but an ongoing and iterative approach will be required. This means that institutions involved in HGGE should invest in and cultivate standing relationships with publics and stakeholder groups, so that they can be consulted for follow-up questions and involved in decision-making in relation to specific potential future applications of HGGE. As HGGE develops as a technology, so does the meaning we give to it and the questions we ask about it. Keeping stakeholders engaged after public engagement events such as citizens’ juries enhances trustworthiness of institutions, which is another important goal of public engagement as described by Scheinerman. An additional product of maintaining public engagement relationships is to help build capacity among participating institutions and stakeholders (Scheufele et al. 2021). By normalizing long-term and iterative public engagement based on trusting relationships, initiatives can lead to approaches for public engagement which contribute to a healthy deliberative democracy in which institutions and publics become experienced mutual learners.

Scheinerman argues that public engagement should lead to agenda setting informed by the public, make substantive and diverse contributions to deliberation, and foster institutional trustworthiness. By breaking up our monolithic understanding of HGGE, we may further diversify and enrich the yield of public engagement. To achieve this, we recommend that public engagement should be designed and organized with specific points of attention in mind: potential future applications of HGGE should be specified, and alongside members of the public, specific groups of stakeholders should be invited to contribute based on their lived experiences. The aims of public engagement should reach beyond producing a report, and should include ongoing, trusting relationships with stakeholders, so that public engagement may feed fruitfully and sustainably into governance of HGGE.

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Inclusion by Invitation Only? Public Engagement beyond Deliberation in the Governance of Innovative Biotechnology

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From their interpretation of the Australian Citizens’ Jury on genome editing, Scheinerman (2023) concludes that inclusive and diverse deliberative processes of public engagement have salient beneficial effects: both the substantive impact of the benefits of policy recommendations that reflect a wider range of lived experience and identity, and the cultivation of governance institutions’ trustworthiness.

This interpretation of public engagement, however, seems to narrowly focus on *organized* engagement. By only focussing on organized engagement, this approach fails to adequately address how these practices impose framings of biotechnological issues on publics and the way this lends control of the debate to science-policy institutions. Furthermore, organized engagement risks framing public engagement as an

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