



Public participation in human genome editing research governance: what do scientists think?

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Abstract

Within the numerous policy and governance recommendations for human genome editing research, anticipatory public engagement seems universally agreed upon as a vital endeavor. Yet it is unclear whether and how scientists whose research involves genome editing see value in engaging the public in discussions of genome editing research governance. To address this question, we interviewed 81 international scientists who use genome editing in their research. The views of our scientist interviewees about public engagement occupied a broad spectrum from enthusiastic support to strong skepticism. But most scientists' views landed somewhere in the middle, seeing public engagement as merely informing the public about the science of genome editing. We argue that such a stance reflects the traditional “knowledge-deficit model.” Beyond addressing the operational difficulties of public engagement, many scientists' adherence to the deficit model is a deeper barrier that needs to be addressed if public engagement is to occur and be successful.

Keywords Public engagement · Human genome editing · Governance · Interviews

Introduction

The rapid rise of genome editing applications in bench and translational research, coupled with He Jiankui's 2018 controversial use of heritable genome editing in human embryos that led to the birth of children in China, has renewed interest in the proper boundaries or limits of human genome editing. Despite many countries already having legislation that limits human genome editing to somatic cell editing for the treatment and prevention of disease (Baylis et al. 2020), numerous national and international organizations have developed policy recommendations to assist in determining such boundaries and the associated governance of human genome editing research (WHO Expert Advisory Committee 2021; National Academies of Sciences, Engineering and

Medicine 2017; European Group on Ethics in Science and New Technologies 2021; The Royal Society et al. 2020). Within these policy-focused documents, anticipatory public engagement seems universally agreed upon as a vital endeavor. Proponents argue that engaging with the public can increase the public's understanding and support of genome editing research, as well as influence policy (Adashi et al. 2020; Gusmano et al. 2021; Iltis et al. 2021; Kuzma and Cummings 2021).

If policy recommendations regarding public engagement are to be employed, scientists whose work would be impacted by the findings of such engagement must be supportive of these engagement efforts. However, it is unclear whether and how bench and translational scientists whose research involves genome editing see value in engaging the public in discussions of human genome editing governance. To address this question, we interviewed scientists from around the world who use genome editing in their research. We spoke with them about their views on the governance of human genome editing research, including their thoughts on public engagement and the public's possible role in governance efforts. Our results will be useful to organizations as they endeavor to assess whether, how, and why to engage with the public on human genome editing research governance.

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Methods

Participants

Results presented in this paper are part of a larger study examining international efforts to develop and implement governance of human genome editing research (Conley et al. 2023). For the larger study, we interviewed scientists whose research involves genome editing as well as professionals involved with organized group efforts to influence the governance of human genome editing research (“governance group members”). Governance group members represented diverse disciplinary backgrounds, such as law, philosophy, medicine, and various types of bench science. This paper reports on interviews with scientists, including those who were also members of a governance group. Eligible scientists were identified through (1) targeted literature searches using PubMed and Google Scholar; (2) a review of abstracts and presentations from conferences, webinars, or in-person meetings related to human genome editing; and (3) a review of the biographies of the members of the governance groups germane to our project. Eligible scientists were invited to participate in an interview via email. At least two follow-up emails were sent, at 2-week intervals, to those who did not initially respond.

After agreeing to an interview, participants were emailed a study information sheet containing the basic elements required for informed consent. Prior to the start of the interview, participants provided verbal consent to participate. This study was ruled exempt by the University of North Carolina at Chapel Hill Institutional Review Board and was completed in accordance with the Declaration of Helsinki.

Interview guide

The interview guide was developed based on our research questions outlined in our grant proposal and review of the relevant literature and governance reports (Table 1). Our multidisciplinary team, which included social scientists, philosophers, ethicists, geneticists, and lawyers, met to discuss interview aims, topics, and potential questions. All team members had an interest in the governance of emerging

technologies and had been observing scientific conferences and governance group activities related to gene editing either as outsiders or as participant observers. The interview guide was then drafted by two PhD-level social scientist team members (MW and RJC) with vast experience and training in qualitative interviewing, with the larger team providing feedback. The two social scientists then piloted the guide with gene editing scientists at our institution to revise questions for clarity and interview length.

Before the interview began, the goals of our study were reviewed with participants. After briefly discussing their research using genome editing, participants were asked questions regarding their views on human somatic and heritable editing, including uses of genome editing for treatment, prevention, and enhancement, and whether and how human and animal applications of genome editing should be governed. This latter topic included specific questions about whether and why the general public should be involved in the oversight of human genome editing research and, if so, how it might occur.

Procedure

Semi-structured interviews were conducted between April 2021 and January 2023. Interviews were approximately 60 min on average, conducted via Zoom, and recorded. They were then transcribed for analysis.

Data analysis

To begin data analysis, the research team read a subset of transcripts and met several times to identify themes and develop an analytic memo template to be used with each transcript. The memo template was revised as team members worked through transcripts and new themes were identified. These memos summarized how each theme occurred in the interviews, identified representative quotes, and offered notes on how themes related to each other (Patel et al. 2016; Groenewald 2008). Transcripts were divided among team members for memoing. When necessary, questions were brought to the lead author, and clarifications, changes, or additions were discussed among team members to finalize the memos. For the present paper, data were analyzed to

Table 1 Relevant interview questions related to the governance of genome editing

Interview questions

- How generally do you think human gene editing should be regulated?
- In what ways, if any, should the general public be involved in oversight?
- Do you think scientists can oversee gene editing research themselves? Why or why not?
- What socially controversial issues around gene editing have been a focus of discussion in your field?
- Does your field have any official statements or policies related to gene editing? Do you think they focus on the right issues? How so/why not?
- How should science policy best anticipate emerging scientific developments?

identify how respondents viewed the general public's role in oversight of human genome editing research and describe respondents' reasoning about their views. Two authors (MW and MF) reviewed themes across all finalized memos and reread the transcripts to identify and confirm the contextual validity of illustrative quotes used to represent themes presented in this paper.

Results

Table 2 reports the demographic characteristics of the 81 scientist interviewees included in this analysis, 22 of whom participated in a genome editing governance group. We use the term “human genome editing research” as shorthand for our interviewees' scientific efforts, which existed all along the translational pathway from basic bench science on gene editing techniques, to translational research using animal models, to preclinical research with human cells and tissues, to clinical research with patients. Some (5) also worked on pathways leading to the modification of animals for agricultural purposes, which may pave the way for modifications in humans (Lehman 2017). But the majority (64) conducted research ultimately aimed at human applications, including 13 who conducted clinical research. Most interviewees were PhD scientists (69), and 9 were physician-scientists (MD or MD, PhD). Interviewees worked in 23 different countries, predominantly in North America (34) or Europe (30). Most (65) worked solely in academia, 7 worked solely in industry, and 9 worked in both academia and industry.

Table 2 Demographics of interviewees

	Variable	Frequency	Percentage
Interviewee Group	Scientist	59	72.8
	Scientist in governance group	22	27.2
Institution Type	Academic	65	80.2
	Industry	7	8.6
	Academic and industry	9	11.1
Region	Africa	2	2.5
	Asia	9	11.1
	Europe	30	37.0
	Middle East	1	1.2
	North America	34	42.0
	Oceania	3	3.7
	South America	2	2.5
Degree	PhD	69	85.2
	MD	4	4.9
	MD, PhD	5	6.2
	Master's	2	2.5
	Bachelor's	1	1.2

Overall, interviewees differed on whether and how the public should be involved in genome editing governance. Their views existed on a spectrum from being skeptical about the public's ability to contribute meaningfully to science policy development to fully endorsing public engagement. Most scientists' views fell somewhere in the middle, recognizing that public engagement may be useful, but concerned about its possibility for meaningful impact.

Skeptics of public engagement

Scientists skeptical of public engagement offered varied reasons for their view that the general public has no place in deliberating on human genome editing. Some seemed to imagine that the public might be voting on the permissibility of genome editing and worried about their decision-making abilities to cast informed votes. Others suggested that the COVID-19 pandemic and vaccine hesitancy point to people's inability to understand science and willingness to accept and act on misinformation.

The public's decision-making deficits

This group of scientists offered arguments for limiting public engagement when it comes to genome editing governance. Sometimes, these limitations resulted from doubts about the public's ability to make big decisions. For example, one scientist said frankly, “It's dangerous asking the public. If you would ask the public 200 years ago about electricity, they [would] probably say no to electricity” (Scientist (S) 1). Another pointed to a recent US election as evidence of why the public should not be included in genome editing oversight, saying, “I don't think that the general public should decide on anything if you understand what I'm saying... I think that it's really, really important to hear what the general public have to say...but I don't think that you should vote for, you know, if to do or not to do...genome engineering and studies” (S2).

Other scientists questioned the public's ability to make decisions about genome editing due to their lack of knowledge and found that shortcomings were so fundamental as to make public education futile. One scientist said:

I think the general public should never be involved with oversight... The general public doesn't have knowledge that allows for reasonable involvement into such deliberations. Now, the public needs to be informed and educated, but you cannot do it by consensus of the general public. If we do that, today we probably wouldn't have any technology. And, I'm not talking about gene editing. We probably wouldn't have trains running... (S3).

Another noted, “I can understand [the public’s] concern in wanting to have a voice, but in the end it’s just genetics... So, I don’t see where, if they don’t know what the process is, and they don’t have the knowledge background to comment about the process, then why are they judging it? It seems unfair. I can understand concern, but that’s concern of the unknown” (S4).

COVID-19 and vaccine hesitancy

Experiences with the COVID-19 pandemic also served as justification for limiting participation in genome editing oversight. For these interviewees, COVID-19 illustrates that the public may simply refuse to understand, which they see as having implications for how genome editing is viewed. One such scientist referenced COVID-19 as a reason the public should not be included in genome editing oversight at all, stating:

I wouldn’t include the general public, actually. No... it was quite obvious from the pandemic... It seemed that everyone is an expert in virology and epidemiology... It’s quite obvious that everyone knows better than even the doctors or scientists, everyone... So, I would be very careful when giving some information to the general public because even if you try to explain to the people with really, really basic words then all the time there is someone who will not get the point... I wouldn’t ask for advice in the general public. Definitely not. (S5)

The tensions between experts and the lay public were also highlighted in discussions of vaccine hesitancy. For one interviewee, the polarizing views of vaccination are akin to the ways that genome editing is, or could be, (mis)understood by the general population. This problem magnifies the need for clarity when communicating with the public. They said:

I also have a background in vaccines, and I just can tell you when someone is against vaccines, you never can convince the person you shouldn’t be against vaccines. It’s almost like religion... And, I could see similar problems with having a discussion around gene editing where you...have 50% of the population saying no and 50% saying yes, and no good communication between. It would block and destroy everything... I also don’t think a non-expert, or when the majority are non-experts, that they should dictate what should be going on in an area where you need a certain expertise... (S6).

Proponents of public engagement

At the other end of the spectrum, scientists who were clear proponents of public engagement saw it as a valued part of living in a democracy. While many acknowledged the difficulty of public engagement, they held fast to the belief that the public could be informed and educated enough to contribute to discussions about the future of human genome editing.

Democratic and collaborative purposes

For many scientists, the importance of public engagement can be understood as a reflection of democratic ideals of shared participation, although recognizing universal agreement may not be possible. One explained:

Since we live in a democratic society, and we value democracy, I think that genome editing should be regulated in a way that all people can agree upon... We need to engage the public in a more open and honest bidirectional dialogue about science and technologies, about the products, benefits, but also limits, barriers and pitfalls. We need to respect taking in the public’s perspectives even if sometimes we do not fully agree on them (S7).

Another scientist, who was involved in a genome editing governance group, said that determining the uses of genome editing “wasn’t just for clinicians and scientists to decide. It’s for a democracy to decide,” while taking care to acknowledge that “not all countries are democracies” (S8).

While not invoking democratic ideals, other interviewees saw a collaborative role for the public in helping to determine the applications of genome editing as it pertains to societal ideals. For example, in discussing public engagement, one scientist involved in governance efforts said, “I’m not a big proponent of going out and evangelizing on how CRISPR works to do this. I think starting with the types of worlds we want to live in and having a discussion about that and then seeing where gene editing intersects with that is the orientation we’ve been taking. I think it’s one of the grand challenges not only for genome editing, but really for much of science: What are the modes in which we can deliberate on the proper aims and uses of types of technologies?” (S9). The view that the public and the scientific community share responsibility for the governance of human genome editing research was also invoked as a way to address some ethical concerns about genome editing technologies. For instance, a member of a governance group reflected on public engagement for heritable germline editing, saying that “unlike the medical and agricultural uses, the germline treatment brings up broader social issues, more challenging social issues, and those are going to have to be dealt with largely

by non-scientists” (S10). Similarly, when asked in what ways the public should be involved in oversight, another scientist involved in governance efforts said, “I think that all sectors of society need to be involved, especially if you’re talking about something as new as, you know, heritable germline editing because I think that all kinds of things...play into that, be it cultural issues or inequality... Their views are important because they are society at large, and we need to know what they think and what their wishes are, too” (S11).

For many interviewees, the social impact of these technologies demands a reciprocal relationship between the public and the scientific community. This relationship serves not only to allow public input, but also to regulate those doing the research. For example, when asked if scientists can oversee genome editing themselves, an interviewee involved in a governance group noted that “scientists are certainly not enough” (S12). Instead, “laws evolve based on [the] needs of society, and science is one part of that. But then, it’s the rest that need to make the difficult decisions that should be made by all of us, definitely.”

Even when it is hard

While supportive of public engagement, proponent scientists highlighted the difficulties of such engagement, questioning whether it was within scientists’ scope of work. One interviewee offered ways to introduce genome editing technologies to general audiences including “open discussions, open forums,” but acknowledged that scientists would have to “divide your energies and how you would prioritize the different things that you’re doing” (S13). Additionally, scientists typically lack training to conduct public engagement. One commented:

Most scientists stay out of the public eye. Most research is not high profile or controversial enough to have anybody outside science really care about it. You could say that’s a bad thing, or maybe it’s fine. But we’re definitely not trained on how to interact with reporters or press or anything like that. I don’t know if that should change... (S14).

In addition to the difficulty in conveying their work to the public, some scientists pointed out the limits on public understanding of the science itself as a barrier to engagement. For many proponents of public engagement, the need to educate the general population on the science behind genome editing was viewed as a precondition for their involvement. For instance, one scientist involved in public engagement efforts said that their team’s goal was to “have a feel for how ordinary people, very ordinary people, are thinking about these issues when we try and provide the basic information which allows them to comment. We’re not saying, we’ll tell you and you’ll believe us. We’re saying,

we think this is what it is. You tell us how you react to it” (S15). Similarly, a scientist and governance group member noted a goal of creating “this inclusive multi-directional/multi-sectoral dialogue in the field of human genome editing” (S16), adding:

You need to know what is the topic, what is the subject, so you need a first step which is information. So, it’s education. It’s engaging the public to know something about genome editing to fight against illiteracy in the field. And then, you move to dialogue. So, you have public engagements and debates, listening to the people. (S16)

While educating the public may be necessary, another interviewee involved in public engagement added that “even if people participating...don’t have a high level of knowledge, they shouldn’t be underestimated... Ordinary members of the public can engage with these topics given the opportunity and given appropriate assistance, they can really reach a high level, a nuanced level of understanding” (S17). While none of these scientists claimed to have the silver bullet to bridge the gap between public engagement and scientific progress in genome editing, they shared the view of much of the existing guidelines that the public plays an integral role in the advancement of this technology.

Supportive of a certain public engagement for certain purposes

Most scientists’ views fell somewhere in between strong skepticism and robust support. These scientists saw public engagement as a practical way to possibly benefit science by avoiding conflicts with the public later. Some also suggested that the “public” in public engagement be limited to those with the knowledge and experience to have informed discussions.

For the benefit of science

For many, engagement with the public about genome editing issues was less about serving democratic ideals but served a much more pragmatic purpose in helping bolster support for the science itself. As one interviewee stated, the public “should be involved from the beginning and openly because the more you involve the general public in science in general, the more important science is for them” (S18). Another scientist described the public’s understanding as necessary for the long-term success and public acceptance of genome editing technology. In this view, if the public is not informed upfront, scientists are opening themselves up to the possibility that the technology will be rejected:

[The public] must be told whatever is going on; how harmful it is; how it is going to be useful in [the] short term; what would be our sacrifice, in the long term; how it is going to be beneficial... At the end, society is going to be benefited. It is better that way [to inform the public] ... rather than being rejected later. Or regret it. So this is what I would say...we should—we must educate our public in their simpler language that they understand” (S19).

For this subset of scientists, public engagement is less about democratizing science and meeting social and cultural ideas; rather, informing the public serves as a practical research step to avoid future conflicts and restrictions on the science itself.

Only the informed public

For other scientists, balancing the need for public engagement in oversight efforts with perceptions of public knowledge led to a compromise, wherein only well-informed members of the public should be included in engagement efforts. Exemplifying this viewpoint, one scientist said, “I think the public need to play a role, but it has to be an informed public. You need to make sure that the people making the decisions from the public actually know what they’re deciding about and that they’re not in any way biased through misinformation...” (S20). Like the scientists who espouse public engagement based on democratic ideals, these interviewees touted democratic principles but with boundaries. For example:

Much like you would choose a jury...why wouldn't you choose members of the public who are similarly unbiased? [I]f you're able to select out the people who clearly would have a strong bias one way or the other, and then just have the people who have a balanced view, I think that could be a way forward to allowing the public to make decisions like this. I mean, we like to think that...we live in a democracy. So, I think that removing people from these decision-making processes is wrong, and we need to involve the public in this as part of democracy. (S20)

This perspective embraces democratic ideals of public engagement but applies an asterisk of sorts. That is, democratic participation ought to be limited to those who possess the capacity for unbiased and unprejudiced evaluation of the science. Similarly, a scientist embraced the idea of public engagement to ensure the ethical acceptability of genome editing but did not have full faith in the general public to be able to engage:

Engagement with the public, to my mind, is absolutely essential. It's not negotiable. You have to carry

the public after a proper discussion, not with people being misled—with the risks being minimized or basically where people are being lied to... I think that the first principle is that it should be as consultative as possible, because the only way that it's gonna be ethically acceptable is if we carry the vast majority of public support.... But, I certainly think that there should be discovery about how much people know. If they don't know anything, then they don't deserve to hold an opinion and you can't have a meaningful debate...I think it actually needs to be put back to a well-informed, well-educated [public]. (S21)

One scientist suggested that oversight mechanisms should take a page from animal research oversight for how to involve only certain members of the public:

You have to have representation but, again, you need representation from the public like our public member on [the animal research review board]. Someone who is open minded, inquisitive, interactive, not axes to grind, and there are too many axes to grind in the general public. They need to be involved, a public member but, again, carefully selected for citizenship. (S22)

Another went further to say that genome editing could be regulated “in large part by the scientists themselves” because “the general public should have an input, but it should be conditional to their ability to have an understanding of what they are regulating or the actual risks” (S23). Similar to the examples of COVID-19 and vaccine hesitancy as reasons to limit public engagement, this scientist points to the public opposition to genetically modified organisms (GMOs), which they say have been “proven” to be better for the environment. He said, “we can clearly see... how public opinion can drive difficult decisions and not necessarily and not objectively give direction” (S23).

One solution to selecting only an informed public was offered by some of our interviewees, proposing engagement with patients who have direct experience with diseases that could be a target of genome editing. For these interviewees, patients were arguably the most informed members of the public and possibly the most supportive of genome editing. One scientist imagined that “there would be a forum of patient organizations that would have a say in this. So, not the general public, but actually members of the general public that are not scientists but have a vested interest in being informed and that also have a stake in the development of this” (S24). Another noted:

I think that families and patients who have experience with the disease, their input is very, very valuable. I think the general public, that input is very, very valuable, too, but...they're, for the most part, not as well informed as families that are affected by the disease

that you are trying to address. So, I think it's important to get the input from the general public, but...gene editing has been prone to be made into sci-fi films. And so, if you're getting the input from individuals that have their main fund of knowledge on the therapy coming from a fictional film, it's not as valuable as if they really had the knowledge of what's being proposed, the risks and benefits. (S25)

Discussion

One of the striking features of recent efforts to develop governance for human genome editing has been the widespread call for robust public engagement. Both national and international efforts have emphasized the need for “careful societal decision-making,” “broad societal consensus,” and “inclusive and transparent societal debate” (WHO Expert Advisory Committee 2021; European Group on Ethics in Science and New Technologies 2021; The Royal Society et al. 2020). To have an impact on research in this domain, however, it will be critical that the scientists involved adopt and implement these ideals. That prospect, in turn, will depend in large part on what scientists think about the public's role in human genome editing governance.

One key finding in this study is that there is no one dominant view on whether, why, and how to engage the public to guide human genome editing research oversight. The views of our scientist interviewees about public engagement occupied a spectrum from enthusiastic support to strong skepticism. At the far end of the spectrum, the most skeptical scientists doubted the capacity of the public to understand science enough to appreciate its value. This group seems to see the public as just *beneficiaries* of scientist-driven research, appearing to prefer to maintain the traditional “grand bargain” model of scientific governance in which the public entrusts scientific decision-making to the scientific community in exchange for the benefits science can provide (Abbott 2014; Gorman et al. 2011; Susskind and Susskind 2015). At the other end are the proponents, those who agree with advocates outside the scientific community who argue that the public has the right to be involved in scientific governance as the stakeholders who ultimately will be most affected by research results. Advocates for this level of engagement emphasize that the public should have a role in decision-making about the directions and pace of research (Irwin 2001). In this way, the public may be seen as *partners*. Most of our proponent scientists were participants in governance groups that advocate this idea. These scientists' views usually reflected the enthusiasm for public engagement expressed by their groups. We cannot conclude whether the scientists acquired their views through

participating in governance or brought those views to the groups, but their endorsement of their groups' conclusions echoes views that the “democratization” of science will promote a collaborative and mutually beneficial relationship between scientists and the public (Jasanoff et al. 2019).

For many other scientists, public engagement means merely *informing* the public about the science of genome editing. This view reflects the “knowledge-deficit model,” which scientists in many fields have subscribed to for quite some time (Davies 2008; Dudo and Besley 2016). This model conceptualizes public engagement as a unidirectional process in which scientists educate the public about their research, contrasting with the more bidirectional model employed by those who see the public as partners and key informants. The knowledge-deficit model places the public in a *student* role, on the assumption that if the public's knowledge deficit can be remedied, their unfounded fears can be alleviated and their support for science will increase (Reincke et al. 2020; Brunk 2006). The model has been critiqued for its one-way education from scientists to non-scientists but also for its privileging of scientific knowledge over other forms, including experiential knowledge (Jasanoff et al. 2019; Brunk 2006), which was reflected in some of our interviewees' arguably patronizing comments.

Our findings indicate that this deficit model continues among many scientists, although there appear to be differences in how they subscribe to it. Some noted that educating the public about genome editing would lead to public acceptance of the science, a key assumption of the deficit model (Nisbet and Scheufele 2009). Yet other scientists only wanted to engage members of the public who did not have negative views about the science. These scientists could be seen as merging the popular bidirectional model of public engagement with their deficit thinking: engage with and learn from members of the public who have experiential knowledge that will make them likely proponents of the technology. Alternatively, scientists' desire to limit engagement to members of the public who already have positive views on the science could be due to a lack of trust that educating the general public will lead to acceptance of the science. These scientists' distrust stemmed from recent waves of misinformation about COVID-19 and elections. But declining trust in scientific and expert knowledge is not new (Brunk 2006), so attributing a decline in the public's trust in science to a decrease in scientific literacy or, as Brunk (2006) argues, “a fundamental failure to understand what scientific and other expertise has established as true” indicates a further entrenchment of scientists into the deficit model of thinking.

The findings of this study should be considered in light of its limitations. It is possible that our sampling strategy, which included targeting governance group members, resulted in an oversampling of proponents. Future research should investigate

whether and how participation in scientific governance efforts shifts scientists' views of public engagement. We did not see evidence that the country or region of our respondents correlated with how they viewed the value of public engagement. However, most respondents were from the USA or Europe, despite our efforts for a more global representation. We also only offered interviews in English, limiting who we could recruit and who could accept our invitations. These limitations may indicate that we did not have enough diversity across and within countries (particularly ones not often represented in science policy discussions), which should be a focus of future research. Having interviewers who speak additional languages and more robust methods of recruiting researchers outside of the USA and Europe may help to ensure that more diverse views are represented.

Beyond how public engagement is viewed by scientists, how public engagement is approached globally is important to consider as public engagement varies across countries in terms of whether it is done and whether it influences policy. Indeed, much of what we know about public attitudes regarding human gene editing is from polls conducted in the US and UK, leaving a severely limited understanding of public views on human gene editing on a global scale (Howell et al. 2020). Additionally, most public engagement efforts regarding human gene editing occur in the Global North. For example, a 2022 report of a study on public engagement of human heritable genome editing in South Africa noted the study to be the first public engagement effort on human genome editing in all of Africa (Thaldar et al. 2022). The authors remarked that the study's "most critical finding" is how much local context drives public opinion (Thaldar et al. 2022), underscoring the need for public engagement in globally diverse contexts. We should be careful, however, to recognize that simply residing in a place does not necessarily imply that the presiding values of that place are shared by all (Nyamnjoh and Ewuoso 2023).

In addition to scant public engagement efforts about human gene editing in the Global South, evidence suggests that far fewer professionals are trained in science communication outside the Global North and that existing training programs are predominantly conducted in English (Massarani et al. 2023), limiting the likelihood that public engagement efforts expand globally. Without knowledge of public views on human gene editing in most parts of the world, policymakers face tremendous challenges in developing governance mechanisms that reflect the views of those who are subject to the effects of that governance.

Conclusion

Whatever their view on public engagement, scientists can agree on one thing—public engagement is difficult. Interviewees described difficulties engaging the public due to

scientists' lack of time, lack of training in engagement, the need to educate the public, or even the possibility of uncovering views that would be inconvenient for the science itself. Beyond addressing the operational difficulties of public engagement, adherence to the deficit model is a deeper barrier that needs to be addressed for public engagement to occur and be successful (Nisbet and Scheufele 2009). While many scientists described events leading to their distrust in the public, their distrust, ironically, may only serve to further public distrust in science. As Brunk (2006) argues, "Until experts become aware of their own 'knowledge deficit,' this distrust [in science] is not likely to be alleviated." So while some scientists may currently question whether public engagement is their job, it appears that the successful translation of their research may depend on its pursuit.

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Data availability The participants of this study did not give consent for their data to be shared publicly, so supporting data is not available.

Declarations

Ethics approval and consent to participate All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients included in the study.

Competing interests The authors declare no competing interests.

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