



## Handservant of Technocracy: Public Engagement and Expertise in Heritable Human Genome Editing

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# Handservant of Technocracy: Public Engagement and Expertise in Heritable Human Genome Editing

Christian H. Ross

**Abstract** The place of scientific expertise in democracy has become increasingly disputed, raising question who ought to have a say in decision-making about science and technology, with what authority, and for what reasons. Public engagement has become a common refrain in technoscientific discussions to address tensions in the rightful roles of experts and the public in democratic decision-making. However, precisely what public engagement entails, who it involves, how it is performed, and to what extent it is desirable for democratic societies remain contested matters. Nevertheless, strong commitments to greater public engagement in the governance of science and technology persist. This essay examines expert discussions about heritable human genome editing beginning from the 2015 International Summit on Human Genome Editing through the controversies surrounding of the first CRISPR-edited humans in late 2018 and the subsequent renewed calls for a moratorium on heritable human genome editing. I examine these discussions as example cases in which the right relations among experts, the public, and technoscientific decision-making are actively reconfigured. I argue that rather than expanding the range of included stakeholders, public engagement serves as an enabling handservant of technocracy that reinforces the position of scientific experts in decision-making as both epistemic and normative authorities.

In recent years, scientific expertise in democracy has become increasingly disputed. Science and technology are fraught with uncertainties and technical, political, and ethical complexities, which require specialized knowledge to navigate accurately and effectively. Yet, the status of expertise as a source of legitimate authority remains disputed in public discussions about who ought to have a say about science and technology, with what authority, and for what reasons. Such tensions about the right relations between experts and the public present acute challenges for effective and democratic technoscience decision-making.

In response to such challenges, scientific institutions have committed to promoting greater public engagement with science and technology.<sup>1</sup> In particular, public engagement scholars have directed substantial attention to understanding public engagement as an essential component of democratic governance and the rightful place of expertise and public participation in modern democracies.<sup>2</sup> Public engagement

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<sup>1</sup> American Association for the Advancement of Science, "AAAS CEO Alan I. Leshner: A New Vision for Science Engagement with the Public," *AAAS News* (October 2006); Leshner, Alan, "Public Engagement with Science," *Science* 299, no. 5609 (2003): 977; The National Academy of Sciences, "NAS Announces the Launch of the LabX Public Engagement Program," *News from the National Academy of Sciences* (February 2018).

<sup>2</sup> Michel Callon, Pierre Lascoumes, and Yannick Barthe, *Acting in an Uncertain World: An Essay on Technical Democracy* (The MIT Press, 2001); Anthony Giddens, *The Third Way: The Renewal of Social Democracy* (Polity Press, 2001); Melissa Leach, Ian Scoones, and Brian Wynne, *Science and*

scholars and practitioners alike have often treated the idea that “increased participation and interactive knowledge-making may improve accountability and lead to more credible assessments of science and technology” as a first principle of sorts.<sup>3</sup> Such calls for public engagement marshal democratic values of transparency, participation, and inclusion of diverse perspectives as ways to improve technoscience decision-making.<sup>4</sup> Advocates of public engagement have invoked it as a remedy to the ease tensions between expert authority and democratic representation in technoscience decision-making. However, despite the significant attention given to public engagement, precisely what public engagement entails and seeks to achieve vis a vis expertise and decision-making lacks unified consensus.<sup>5</sup>

While understandings of the public have largely moved beyond the deficit portrayals of the public as merely ignorant, disinterested, or distrusting of science,<sup>6</sup> answering the question of who constitutes “the public” is itself a messy task. “The public” is not a singular, monolithic group but a plurality of multiply realizable publics with diverse interests, values, and attitudes towards technoscientific issues.<sup>7</sup> However, publics qua publics are not preexistent, natural entities out in the world but are the result of thoroughly social and generative activities. In practice, publics often are the result of solicitation of particular “invited” publics<sup>8</sup> by convening institutions and governments around technoscientific issues in the formation of “mini publics”<sup>9</sup> as units of democratic deliberation. Accordingly, “the public” is better understood less as an aggregate of

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*Citizens: Globalization and the Challenge of Engagement* (Zed Books, 2005); Brian Wynne, “Public Uptake of Science: A Case for Institutional Reflexivity,” *Public Understanding of Science* 2, no. 4 (1993): 321-337; Jack Stilgoe, Simon J. Lock, and James Wilsdon, “Why Should we Promote Public Engagement with Science?” *Public Understanding of Science* 23, no. 1 (2014): 4-15.

<sup>3</sup> Sheila Jasanoff, “Technologies of Humility: Citizen Participation in Governing Science,” *Minerva* 41 (2003): 243.

<sup>4</sup> Daniel Barben, Erik Fisher, Cynthia Selin, and David H. Guston, “Anticipatory Governance of Nanotechnology: Foresight, Engagement, and Integration,” in *The Handbook of Science and Technology Studies*, eds. Edward J. Hackett, Olga Amsterdamska, Michael Lynch, and Judy Wajcman (The MIT Press, 2008): 979-1000; Andy Stirling, “Opening Up or Closing Down? Analysis, Participation and Power in the Social Appraisal of Technology,” in *Science and Citizens: Globalization and the Challenge of Engagement*, eds. Melissa Leach, Ian Scoones, and Brian Wynne (Zed Books, 2005): 218-220.

<sup>5</sup> Ana Delgado, Kamilla Lein Kjølberg, and Fern Wickson, “Public Engagement Coming of Age: From Theory to Practice in STS Encounters with Nanotechnology,” *Public Understanding of Science* 20, no. 6 (2011): 826-845.

<sup>6</sup> Geoffrey Evans and John Durant, “The Relationship Between Knowledge and Attitudes in the Public Understanding of Science in Britain,” *Public Understanding of Science* 4, no. 1 (1995): 57-74; Brian Wynne, “Knowledges in Context,” *Science, Technology, & Human Values* 16, no. 1 (1991): 111-121; John Ziman, “Public Understanding of Science,” *Science, Technology, & Human Values*, 16, no. 1 (1991): 99-105.

<sup>7</sup> Sheila Jasanoff, *Science and Public Reason* (Routledge, 2012): 178.

<sup>8</sup> Ulrike Felt and Maximilian Fochler, “Machineries for Making Publics: Inscripting and De-scripting Publics in Public Engagement,” *Minerva* 48, no. 3 (2010): 219-238.

<sup>9</sup> Robert E. Goodin, “Making Use of Mini-Publics,” in *Innovating Democracy: Democratic Theory and Practice After the Deliberative Turn* (Oxford University Press, 2008): 11-37; Alan Irwin, “Constructing the Scientific Citizen: Science and Democracy in the Biosciences,” *Public Understanding of Science* 10, no. 1 (2001): 1-18.

naturally occurring, smaller sub-publics already out in the world and more as a shared, societal space of collective decision-making.<sup>10</sup>

Similarly, what constitutes “engagement” with publics, however constructed, is not a priori obvious nor widely agreed upon. Review of the literature reveals a plethora of often contradictory definitions, models, and practices for engagement, ranging from one-directional, educational interventions to and more bi-directional, participatory modes of governance.<sup>11</sup> Though some have drawn sharp distinctions between notions of participation versus engagement,<sup>12</sup> usage of the terms “participation” and “engagement” more commonly appears without clear differentiation as “synonyms of uncertain equivalence.”<sup>13</sup> There has been some convergence around the notion that “public engagement with science [has] to do with linking science with politics”<sup>14</sup> and that public engagement “is better understood as a series of credibility struggles that are performative and eventful,” rather than as inherently contributing to social consensus.<sup>15</sup>

Much of public engagement work, in-practice, has centered instead on understanding the methods, mechanisms, and modes of designing, implementing, and evaluating public engagement interventions in-practice.<sup>16</sup> However, further exploration

<sup>10</sup> Sheila Jasanoff, “A Mirror for Science,” *Public Understanding of Science* 23, no. 1 (2014): 23.

<sup>11</sup> Michael M. Burgess, “From ‘Trust Us’ to Participatory Governance: Deliberative Publics and Science Policy,” *Public Understanding of Science* 23, no. 1 (2014): 48-52; Gene Rowe and Lynn J. Frewer, “A Typology of Public Engagement Mechanisms,” *Science, Technology, & Human Values* 30, no. 2 (2005): 251-290; Gene Rowe, Tom Horlick-Jones, John Walls, Wouter Poortinga, and Nick F. Pidgeon, “Analysis of a Normative Framework for Evaluating Public Engagement Exercises: Reliability, Validity and Limitations,” *Public Understanding of Science* 17, no. 4 (2008): 419-441; James Wilsdon and Rebecca Willis, *See-Through Science: Why Public Engagement Needs to Move Upstream*, Demos (2004); Barben et al., “Anticipatory Governance of Nanotechnology,” 979-1000.

<sup>12</sup> Brian Wynne, Brian, “Public Participation in Science and Technology: Performing and Obscuring a Political–Conceptual Category Mistake,” *East Asian Science, Technology and Society: An International Journal* 1, no. 1 (2007): 99-110.

<sup>13</sup> Rowe and Frewer, “A typology of public engagement mechanisms,” 252.

<sup>14</sup> Helga Nowotny, “Engaging with the Political Imaginaries of Science: Near Misses and Future Targets,” *Public Understanding of Science* 23, no. 1 (2014): 17.

<sup>15</sup> Ruha Benjamin, *People's Science: Bodies and Rights on the Stem Cell Frontier* (Stanford University Press, 2013), 30.

<sup>16</sup> e.g. Wylie Carr, Laurie Yung, and Christopher Preston, “Swimming Upstream: Engaging the American Public Early on Climate Engineering,” *Bulletin of the Atomic Scientists* 70, no. 3 (2014): 38-48; David H. Guston, “Building the Capacity for Public Engagement with Science in the United States,” *Public Understanding of Science* 23, no. 1 (2014): 53-59; Alan Irwin, “The Politics of Talk: Coming to Terms with the ‘New’ Scientific Governance,” *Social Studies of Science* 36, no. 2 (2006): 299-320; Daniel Lee Kleinman, Jason A. Delborne, and Ashley A. Anderson, “Engaging Citizens: The High Cost of Citizen Participation in High Technology,” *Public Understanding of Science* 20, no. 2 (2011): 221-240; Carolyn P. Neuhaus, “Community Engagement and Field Trials of Genetically Modified Insects and Animals,” *Hastings Center Report* 48, no. 1 (2018): 25-36; Gene Rowe, Tom Horlick-Jones, John Walls, Wouter Poortinga, and Nick F. Pidgeon, “Analysis of a Normative Framework for Evaluating Public Engagement Exercises: Reliability, Validity and Limitations,” *Public Understanding of Science* 17, no. 4 (2008): 419-441; David Tomblin, Zachary Pirtle, Mahmud Farooque, David Sittenfeld, Erin Mahoney, Rick Worthington, Gretchen Gano et al., “Integrating Public Deliberation into Engineering Systems: Participatory Technology

of the reasons for whether, and under what conditions, engagement with science and technology is desirable have led to tensions regarding how publics and experts ought to be involved in democratic decision-making.<sup>17</sup> Democratic theorist Alfred Moore summarizes the rationale for why public engagement is important for decision-making as a straightforward commitment to the idea that “the technical is political, the political should be democratic, and the democratic should be participatory.”<sup>18</sup> Accordingly, science and technology studies (STS) scholars Harry Collins, Robert Evans, and Martin Weinel strongly argue that some deference to technical experts on the basis of specialized knowledge are both justified and necessary for prosperous democratic societies.<sup>19</sup> Darrin Durant further extends those arguments, noting that the fact that experts are fallible and susceptible to corruption and conflicts of interest is no sufficient reason to reject a privileged role for expertise in decision-making where said expertise is salient.<sup>20</sup> Moreover, Collins, Evans, and Weinel maintain that apparent declines in public trust of experts in the wake of growing anti-science and anti-intellectual social movements further validate their skepticism of activities like public engagement as a democratic panacea apart from expertise.<sup>21</sup>

Others STS scholars, such as Sheila Jasanoff, however, argue that reliance on experts to inform public decision-making as potentially dangerous for democratic societies if left unchecked and not kept within a narrow area of delegated authority to render expert judgements<sup>22</sup> or, as Brian Wynne argues, as definitely dangerous because the power of experts undermines the potential for extended discussion outside of technoscientific frameworks.<sup>23</sup> Though expertise is a common marker to differentiate between of “ordinary citizens” and experts with specialized, technical knowledge and credentials,<sup>24</sup>

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Assessment of NASA’s Asteroid Redirect Mission,” *Astropolitics* 15, no. 2 (2017): 141-166.

<sup>17</sup> e.g. Wiebe E. Bijker, “The Need for Public Intellectuals: A Space for STS: Pre-Presidential Address Annual Meeting 2001, Cambridge, MA,” *Science, Technology, & Human Values* 28, no. 4 (2003): 443-450; Harry Collins, Martin Weinel, and Robert Evans, “The Politics and Policy of the Third Wave: New Technologies and Society,” *Critical Policy Studies* 4, no. 2 (2010): 185-201; Darrin Durant, “Models of Democracy in Social Studies of Science,” *Social Studies of Science* 41, no. 5 (2011): 691-714; Arie Rip, “Constructing Expertise: In a Third Wave of Science Studies,” *Social Studies of Science* 33, no. 3 (2003): 419-434.

<sup>18</sup> Alfred Moore, “Beyond Participating: Opening Up Political Theory in STS,” *Social Studies of Science* 40, no. 5 (2010): 793.

<sup>19</sup> Harry Collins and Robert Evans, “The Third Wave of Science Studies: Studies of Expertise and Experience,” *Social Studies of Science* 32 no. 2 (2002): 235-296; Harry Collins and Robert Evans, *Rethinking Expertise* (University of Chicago Press, 2008). Harry Collins, Robert Evans, and Martin Weinel, “STS as Science or Politics?” *Social Studies of Science* 47, no. 4 (2017): 580-586.

<sup>20</sup> Darrin Durant, “Ignoring Experts,” in *The Third Wave in Science and Technology Studies*, eds. David S. Caudill, Shannon N. Conley, Michael E. Gorman, and Martin Weinel (Palgrave Macmillan, 2019), 33-52.

<sup>21</sup> Collins et al., “STS as Science or Politics?,” 580-586.

<sup>22</sup> Sheila Jasanoff, “American Exceptionalism and the Political Acknowledgment of Risk,” *Daedalus* (1990): 75-78.

<sup>23</sup> Brian Wynne, Brian, “Ghosts of the Machine: Publics, Meanings and Social Science in a Time of Expert Dogma and Denial,” *Remaking participation: Science, Environment and Emergent Publics* (2016): 99-103.

<sup>24</sup> Maria Powell, Mathilde Colin, Daniel Lee Kleinman, Jason Delborne, and Ashley Anderson, “Imagining Ordinary Citizens? Conceptualized and Actual Participants for Deliberations on

Wynne shows how bright lines between laypersons and experts often fade under scrutiny of the ways in which non-expert publics generate their own forms of lay expertise with distinct experiences and specialized knowledge that traditional experts lack.<sup>25</sup> Other examples of bottom-up, grassroots publics such as activist movements around the AIDS epidemic in the mid-1980s further problematize the sharp distinguishing between expert and layperson in scientifically and politically consequential ways.<sup>26</sup>

Privileging the perspectives of technical experts is reflective of prior judgements about who ought to have standing in technoscientific decision-making and fails to recognize how appeals to expertise render expert judgments as naturalized, objective knowledge and not as subjective matters to which experts ought to be held accountable.<sup>27</sup> Public engagement with science and technology, then, ostensibly serves as a democratic and epistemic check on technocratic power and authority in matters of public decision-making.

My intention is not, as others have done,<sup>28</sup> to plant my flag on one side or the other of these disputes regarding the rightful place of expertise in democracy per se. Rather, I want to call attention to the contestation of public engagement itself as a site where the right relations among expertise, publics, and technoscientific decision-making are actively reconfigured. In this essay, I examine expert discussions about heritable human genome editing beginning from the 2015 International Summit on Human Genome Editing through the controversy surrounding the first CRISPR-edited humans in 2018 and the subsequent renewed calls for a moratorium on heritable human genome editing, as an example case of such contestations. In these discussions, summit organizers, scientists, and other experts argued that greater public engagement would expand the range of stakeholders included in decision-making about the future of human genome editing applications, enabling better governance of the technology.<sup>29</sup> However, I argue that rather than including and empowering publics in collective decision-making, public engagement, in fact, serves as an enabling handservant of technocracy that reinforces the position and authority of scientific experts. Specifically, I argue that expert discussions around heritable human genome editing frame public engagement primarily as a means of resolving public controversy and building societal consensus about heritable human genome editing. By calling for meaningful public

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Emerging Technologies," *Science as Culture* 20, no. 1 (2011): 37-70.

<sup>25</sup> Brian Wynne, "A Reflexive View of the Expert-Lay Knowledge Divide," *Risk, Environment and Modernity: Towards a New Ecology* 40 (1996): 44-82.

<sup>26</sup> Steve Epstein, "The Construction of Lay Expertise: Aids Activism and the Forging of Credibility in the Reform of Clinical Trials," *Science, Technology, & Human Values* 20, no. 4 (1995): 408-437.

<sup>27</sup> Sheila Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton University Press, 2005); Brian Wynne, "Seasick on the Third Wave? Subverting the Hegemony of Propositionalism: Response to Collins & Evans 2002," *Social Studies of Science* 33, no. 3 (2003): 401-417; Brian Wynne, "Public Participation in Science and Technology: Performing and Obscuring a Political-Conceptual Category Mistake," *East Asian Science, Technology and Society: An International Journal* 1, no. 1 (2007): 99-110.

<sup>28</sup> Darrin Durant, "Accounting for Expertise: Wynne and the Autonomy of the Lay Public Actor," *Public Understanding of Science* 17, no. 1 (2008): 5-20; Durant, "Models of Democracy," 691-714; Sergio Sismondo, "Casting a Wider Net: A Reply to Collins, Evans and Weinel," *Social Studies of Science* 47, no. 4 (2017): 587-592.

<sup>29</sup> National Academies of Science, Engineering, and Medicine, *Human Genome Editing: Science, Ethics, and Governance* (The National Academies Press, 2017), 133.

engagement, experts thereby assert themselves as socially responsible actors, while at the same time stabilizing their positions of influence in decision-making as both epistemic and normative authorities.

### Setting the Stakes for Human Genome Editing and Public Engagement

Since the development of CRISPR gene editing<sup>30</sup> there has been much attention paid to the potential human applications of the technology, including numerous meetings and international summits convened around the technology's potential for unprecedented biological innovation as well as specters of social catastrophe.<sup>31</sup> Applications of human genome editing tend to fall into two main categories: somatic editing and germline editing. Somatic editing targets fully-developed, human body cells, similar to gene therapy. The effects of any genetic edits are therefore localized to the areas of the body of the treated individual. Somatic editing applications are thought to be less controversial<sup>32</sup> and broadly addressed by existing regulations<sup>33</sup> with clinical trials greenlit in the United States.<sup>34</sup> Germline editing, however, has been much more contentious.<sup>35</sup> Unlike somatic editing or gene therapy, germline editing targets reproductive cells before fertilization or embryos in the earliest stages of development to alter genetic mutations or genes associated with genetic diseases before they fully

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<sup>30</sup> Martin Jinek, Krzysztof Chylinski, Ines Fonfara, Michael Hauer, Jennifer A. Doudna, and Emmanuelle Charpentier, "A Programmable Dual-RNA-Guided DNA Endonuclease in Adaptive Bacterial Immunity," *Science* 337 (2012): 816-821.

<sup>31</sup> National Academy of Medicine, National Academy of Sciences, and the Royal Society of the United Kingdom, "International Commission on the Clinical Use of Human Germline Genome Editing," *The National Academies of Science, Engineering, and Medicine* (2019); National Academy of Medicine, National Academy of Sciences, and the Royal Society, *Heritable Human Genome Editing* (The National Academies Press, 2020); National Academy of Sciences, National Academy of Medicine, Royal Society of the United Kingdom, and Academy of Sciences of Hong Kong, "Second International Summit on Human Genome Editing: Continuing the Global Discussion," November 27-29, 2018, Hong Kong; Committee on Science, Technology, and Law, Policy and Global Affairs and the National Academies of Sciences, Engineering, and Medicine, *The International Summit on Human Gene Editing: A Global Discussion: Meeting in Brief*, ed. Steven Olson (The National Academies Press, 2016), 1-8; Nuffield Council on Bioethics, *Genome Editing and Human Reproduction*, Nuffield Council on Bioethics (2018); World Health Organization, "WHO-RUSH Human Genome Editing 1st Advisory Committee Virtual Press Conference," *World Health Organization* (2019).

<sup>32</sup> Sarah Polcz and Ann Lewis, "CRISPR-Cas9 and the Non-Germline Non-Controversy," *Journal of Law and the Biosciences* 3 (2016): 413-425.

<sup>33</sup> National Academies of Science, Engineering, and Medicine, "Human Genome Editing," 83.

<sup>34</sup> Cormac Sheridan, "Go-ahead for First in-body CRISPR Medicine Testing," *Nature Biotechnology* 36 (2018): 907-908.

<sup>35</sup> e.g., Roberto Andorno, Françoise Baylis, Marcy Darnovsky, Donna Dickenson, Hille Haker, Katie Hasson, Leah Lowthorp et al., "Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction," *Trends in Biotechnology Trends in Biotechnology* 38, no. 4 (2020): 351-354; Françoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Harvard University Press, 2019); Edward Lanphier, Fyodor Urnov, Sarah Ehlen Haecker, Michael Werner, and Joanna Smolenski, "Don't Edit the Human Germ Line," *Nature News* 519 (2015): 410.

manifest in more developed individuals. Any germline genetic edits are therefore, in principle, present in every cell throughout an individual's body, including their reproductive cells. As a result, genetic edits of an individual's germline can be inherited by future generations of their progeny, in the same manner as any other genetic trait.

The stakes surrounding such heritable human genome editing have remained scientifically complex, socially controversial, and ethically fraught. In the wake of the 2018 announcement of the birth of twin girls, the first gene edited humans, in China,<sup>36</sup> scientists, governments, and international organizations<sup>37</sup>condemned the use of gene editing as a premature and unethical act of a so-called "rogue scientist," He Jiankui.<sup>38</sup> The news precipitated renewed calls for a moratorium on heritable human genome editing research<sup>39</sup>and proposals of international oversight organizations.<sup>40</sup> Yet more severely, in the final days of 2019, Chinese courts convicted and sentenced He Jiankui for the procedures which they found to be "illegal medical practices," carrying a three-year prison sentence and three million yuan fine.<sup>41</sup> Nevertheless, that same year another scientist in Russia announced plans to edit human egg cells continued with the goal of altering genes associated with deafness.<sup>42</sup> To date, the appropriate, responsible governance of heritable human genome editing remains a socially unsettled and ethically complex matter.

Regarding heritable human genome editing, public engagement has been appealed to as way to grapple with its ethical, legal, and social implications by promoting diverse, inclusive participation in those deliberations. Although, in-practice, what public engagement around heritable human genome editing entails or would intend to achieve has been less certain.<sup>43</sup> STS and bioethics scholars Sheila Jasanoff, J. Benjamin Hurlbut,

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<sup>36</sup> Cyranoski, David, and Heidi Ledford, "Genome-Edited Baby Claim Provokes International Outcry," *Nature* 563 (2018): 607-608; Marilynn Marchione, "Chinese Researcher Claims First Gene-Edited Babies," *Associated Press*. November 26, 2018; Antonio Regalado, "EXCLUSIVE: Chinese Scientists are Creating CRISPR Babies," *MIT Technology Review*. November 25, 2018.

<sup>37</sup> National Academies of Sciences, Engineering, and Medicine, *Second International Summit on Human Genome Editing: Continuing the Global Discussion: Proceedings of a Workshop-in Brief* (The National Academies Press, 2019): 1-10; S. Wee, "China Halts Work by Scientist Who Says He Edited Babies' Genes," *The New York Times*. November 29, 2018; Linqi Zhang, Ping Zhong, Xiaomei Zhai, Yiming Shao, and Shan Lu, "Open Letter From Chinese HIV Professionals on Human Genome Editing," *The Lancet* 393 (2018): 26-27.

<sup>38</sup> Jon Cohen, "Inside the Circle of Trust," *Science* 365, no. 6452 (2019): 430-437.

<sup>39</sup> Eric S. Lander, Françoise Baylis, Feng Zhang, Emmanuelle Charpentier, Paul Berg, Catherine Bourgain, Bärbel Friedrich et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567 (2019): 165-168.

<sup>40</sup> Sheila Jasanoff and J. Benjamin Hurlbut, "A Global Observatory for Gene Editing," *Nature* 555 (2018): 435-437; World Health Organization, "WHO-RUSH"; National Academy of Medicine, National Academy of Sciences, and the Royal Society of the United Kingdom, "International Commission."

<sup>41</sup> Normille, Dennis, "Chinese Scientist who Produced Genetically Altered Babies Sentenced to 3 Years in Jail," *Science News*, December 30, 2019.

<sup>42</sup> David Cyranowski, "Russian Biologist Plans More CRISPR-Edited Babies," *Nature* 570 (2019): 145-146.

<sup>43</sup> Simon Burall, "Rethink Public Engagement for Gene Editing," *Nature* 555 no. 7697 (2018): 438-439; Nature Editors, "Germline Gene-Editing Research Needs Rules," *Nature* 567 (2018): 145.

and Krishanu Saha<sup>44</sup> as well as Françoise Bayliss<sup>45</sup> have criticized the particular framings of public engagement around human genome editing as being perfunctory, one-off events that serve more as box-checking exercises than as democratic deliberations. They argue further that they are exclusionary, in as much as scientific and technical proficiency are prerequisites to participation. Such framings of public engagement, they argue, constrain the terms and agenda of public engagement in ways that innately privilege the knowledge and interests of scientists.

However, such scholarship has not fully attended to questions of how human genome editing discussions have come to understand public engagement as essential for good and democratic governance of the technology while at the same time the specifics of that engagement remain contested. Closely examining the framings of public engagement provides opportunities to analyze the stakes of heritable human genome editing, the epistemic authority of scientific experts, and the participation of publics come to be negotiated, disrupted, and reinforced. Scrutiny of public engagement, then, provides opportunity not only to whose voices are amplified or silenced in technoscientific decision-making, but also the forms of democratic order that are simultaneously underwritten.

#### Not for Science Alone

In the fall of 2015, the US National Academies of Sciences and Medicine, the Chinese Academy of Sciences, and the British Royal Society convened a joint summit in Washington, D.C. to discuss growing questions regarding advances in gene editing and its potential use in humans. The three-day summit brought experts from across the globe—from scientific and non-scientific backgrounds—for a series of thoughtful panel and round-table discussions focused on the “scientific, ethical, and governance issues associated with human gene editing research.”<sup>46</sup>

In the lead up to the summit, several prominent members of the organizing committee published initial guidelines for decision-making about human genome editing, and germline editing in particular, to find a “prudent path forward.”<sup>47</sup> A “prudent path forward”, they argued, centered first on discouraging attempts at heritable human genome editing until frameworks were developed for open discussion to “consider the risks and rewards of using such powerful technologies...and the attendant ethical, social, and legal implications of genome modification.”<sup>48</sup> The summit organizers stated that there was an “urgent need for open discussion of the merits and risks of human genome modification by a broad cohort of scientists, clinicians, social scientists, the general public, and relevant public entities and interest groups,” and they

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<sup>44</sup> Sheila Jasanoff, Benjamin Hurlbut, and Krishanu Saha, “CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation,” *Issues in Science and Technology* 32, no. 1 (2015): 37; Sheila Jasanoff, Benjamin Hurlbut, and Krishanu Saha, “Democratic Governance of Human Germline Genome Editing,” *The CRISPR Journal* 2, no. 5 (2019): 266-271.

<sup>45</sup> Françoise Bayliss, “Questioning the Proposed Translational Pathway for Germline Genome Editing,” *Nature Human Behaviour* 3 (2019): 200.

<sup>46</sup> National Academies of Science, Engineering, and Medicine, “Human Genome Editing,” 218.

<sup>47</sup> David Baltimore, Paul Berg, Michael Botchan, Dana Carroll, R. Alta Charo, George Church, Jacob E. Corn et al., “A Prudent Path Forward for Genomic Engineering and Germline Gene Modification,” *Science* 348, no. 6230 (2015): 36-38.

<sup>48</sup> *Ibid*: 37.

discouraged “any attempts at human germline genome modification for clinical application in humans, while societal, environmental, and ethical implications of such activity are discussed.”<sup>49</sup> They presented deliberations in broader society as necessary first steps to “enable pathways to responsible uses of this technology.”<sup>50</sup> In so doing, they presented deliberation about the social implications and permissibility of human germline gene editing as an essential part of pursuing that “prudent path forward.”

The prevailing attitude the authors expressed was that genome editing held enormous opportunity for social benefit in its “promise of curing genetic disease, while in other organisms it provides methods to reshape the biosphere for the benefit of the environment and human societies.”<sup>51</sup> On that framing, the authors characterized the responsible development of human genome editing as a virtuous pursuit for the public good. While the ethical, legal, and social ramifications of heritable human genome editing needed to be attended to, they equated the technical development of genome editing with the opportunity for social progress.

The summit began in a similar tone. The organizers argued that “the range of stakeholders for human gene editing is very broad” and that, therefore, “everyone has a stake in [human genome editing].”<sup>52</sup> Likewise, the president of the US National Academies of Science, Ralph J. Cicerone, noted that there was a “critical need to engage the public on this rapidly advancing area of science.”<sup>53</sup> The summit organizers further asserted that “the decision as to whether to go ahead with any specific application or type of applications is not one for scientists to make alone.”<sup>54</sup> The refrain of “not for science alone” would be reaffirmed through the close of the summit, when the chair of the organizing committee, Nobel laureate David Baltimore, identified “broad societal consensus” about heritable human genome editing as a prerequisite for moving forward with the technology.<sup>55</sup>

In framing human genome editing as an issue “not for science alone,” the summit asserted that publics, broadly construed, have legitimate political and social standing to participate in decision-making for human genome editing. In so doing, the summit set the stakes for human genome editing to be issues of inclusion of wider publics in decision-making and good democratic governance. If the shared stakes collectively implicated society at-large, then, how would those decisions be made, by whom, and on whose behalf? Baltimore made those stakes explicit during the closing panel of the summit when he referred to the summit as “the way that decisions get made in a democracy. And we may not be representative of all...but it’s a beginning process.”<sup>56</sup>

Baltimore’s appeal to democracy, however, left questions of who exactly constituted the public only vaguely answered. The summit constructed a public that was incredibly broad and non-specific. Summit organizers and panelists obliquely gestured

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<sup>49</sup> Ibid: 37.

<sup>50</sup> Baltimore et al., “A Prudent Path Forward”, 37.

<sup>51</sup> Ibid: 36.

<sup>52</sup> Committee on Science, Technology, and Law, Policy and Global Affairs and the National Academies of Sciences, Engineering, and Medicine. “Meeting in Brief,” 6.

<sup>53</sup> Ralph Cicerone, Presentation at the International Summit on Human Gene Editing: A Global Discussion, Washington, D.C., December 1-3, 2015.

<sup>54</sup> David Baltimore, Presentation at the International Summit on Human Gene Editing: A Global Discussion, Washington, D.C., December 1-3, 2015.

<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

toward “the public” or “society” without significant detail, using “the public” as a broad term for those non-experts who were not present at the meeting. Not that more specific groups were not recognized as populating that broader notion of “the public,” but such identifications were in long lists of various other stakeholders—scientists, ethicists, health care providers, patients, people with disabilities, policymakers, regulators, research funders, faith leaders, public interest advocates, industry representatives, and, as a final catch-all, members of the general public.<sup>57</sup> The organizers of the summit imagined relevant publics both as abstract, international citizens, without specific identifying features—to be universally generalizable and contextually flexible—as well as a distinct individuals with features like genetic diseases or conditions needing genetic alteration—to motivate morally laden action with a recognizable stakeholder group. The portrayal of the public as a flexibly interpretable and versatile stakeholder as well as a relevant and necessary party also underwrote the decision-making discussion about heritable human genome editing as democratic and representative of broader society.

The summit’s framing of germline gene editing decision-making as “not for science alone” also set up the public as the source of societal and moral authorization for the development and application of heritable human genome editing. Summit discussions were fraught with ethical, legal, and social concerns about heritable human genome editing, including misgivings about violating human dignity, the specter of eugenics, the uncertainty of possible long-term, heritable effects across generations, and the inability of those affected future generations to consent to such alterations.

One summit speaker, George Q. Daley of Harvard Medical School expressed the need for public engagement about such controversial aspects of the technology saying, “There needs to be an attempt...to define when, if ever, there would be enough assurance of safety and efficacy and enough public consensus about the permissible medical application [of human germline editing] that we would allow certain use.”<sup>58</sup> The identified prerequisite for moving forward with heritable human genome editing was a “broad societal consensus” on whether particular applications were ethically and socially acceptable or not.

Alongside considerations of risk and benefits, societal controversy about its acceptable uses was also among the barriers to clinical applications of heritable human genome editing. Summit speakers framed the resolution of societal controversy as an issue of social permissibility in which public consensus authorized the development heritable human genome editing applications. Implicit in the approaches to resolve societal controversy around heritable human genome editing was the notion that, like health and safety risks, societal controversy is a challenge to overcome. The development of germline editing, however, they nevertheless took to be the presumptive, desired end result. Broader ethical and social concerns were not reasons to abandon technological development altogether, but as guardrails to ensure a more prudent path forward. Public engagement, therefore, was a means of resolving societal controversy in a way that facilitated and authorized scientific experts to move forward with developing clinical applications of heritable human genome editing.

The summit’s focus on public engagement to resolve societal uncertainty around heritable human genome editing circumscribed the public as an object of analysis and a source for legitimacy for expert decision-making. Rather than promoting public participation in deciding whether to move forward or not, public engagement prepared

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<sup>57</sup> Committee on Science, Technology, and Law, Policy and Global Affairs and the National Academies of Sciences, Engineering, and Medicine. “Meeting in Brief,” 7.

<sup>58</sup> George Q. Daley, Presentation at the International Summit on Human Gene Editing: A Global Discussion, Washington, D.C., December 1-3, 2015.

the way for heritable human genome editing by smoothing out points of possible dissent or opposition. The framings of public engagement as tool for controversy resolution also stabilized a distinction and critical distance between scientific experts and the public. Setting up societal consensus as an ostensible prerequisite to following a scientifically prudent path forward maintained a boundary that separated scientific experts as “outside” of the public. In so doing, the summit characterized the public as an obstacle to be overcome along the prudent path forward for developing the technology and the associated promises of social benefit. By contrast, scientific experts were elevated and reinforced as responsible actors working on behalf of the public good, demonstrated not only by their pursuit of the social benefits of heritable human genome editing, but also through first eliciting “broad societal consensus.”

### Responsible and Rogue Scientists

In the years following the International Summit in Washington, D.C., heritable human genome editing research continued to gain momentum. The US National Academies of Science, Engineering, and Medicine published a report on human genome editing in 2017,<sup>59</sup> and incremental research advances in heritable human genome editing continued toward possible clinical uses.<sup>60</sup> The potential applications and broader implications of heritable human genome editing also remained prominent in international scientific discussions.<sup>61</sup>

In November of 2018, a Second International Summit on Human Genome Editing convened in Hong Kong. The summit was an opportunity to revisit the discussion from the first summit, taking into consideration the technical and societal developments around genome editing during the three years preceding. Days before the Second International Summit on Human Genome Editing began, He Jiankui, a scientist working at Southern University of Science and Technology in Shenzhen, China, announced that he had successfully performed what he claimed to be the first germline genome editing of humans in a pair of twin girls, born in China one month prior with genetic modifications intended to increase resistance to HIV infection.<sup>62</sup>

International scientific communities, including by those at the Hong Kong summit, quickly and strongly condemned He’s actions as premature and against international norms for research conduct and labeled him an irresponsible, rogue scientist.<sup>63</sup> Those

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<sup>59</sup> National Academies of Science, Engineering, and Medicine, “Human Genome Editing.”

<sup>60</sup> Puping Liang, Yanwen Xu, Xiya Zhang, Chenhui Ding, Rui Huang, Zhen Zhang, Jie Lv et al., “CRISPR/Cas9-Mediated Gene Editing in Human Triploid Zygotes,” *Protein & Cell* 6, no. 5 (2015): 363-372; Hong Ma, Nuria Marti-Gutierrez, Sang-Wook Park, Jun Wu, Yeonmi Lee, Keiichiro Suzuki, Amy Koski et al., “Correction of a Pathogenic Gene Mutation in Human Embryos,” *Nature* 548, no. 7668 (2017): 413.

<sup>61</sup> Sara Reardon, “First CRISPR Clinical Trial Gets Green Light from US Panel,” *Nature News*. June 22, 2016; Heidi Ledford, Heidi, “CRISPR: Gene Editing is Just the Beginning,” *Nature News* 531, no. 7593 (2016): 156; Kelly E. Ormond, Douglas P. Mortlock, Derek T. Scholes, Yvonne Bombard, Lawrence C. Brody, W. Andrew Faucett, Garrison Nanibaa’A et al., “Human Germline Genome Editing,” *The American Journal of Human Genetics* 101, no. 2 (2017): 167-176.

<sup>62</sup> Cyranoski and Ledford. “Genome-edited baby claim,” 607-608.

<sup>63</sup> Zhang et al. “Open letter from Chinese HIV professionals,” 26-27; National Academies of Sciences, Engineering, and Medicine, “Second International Summit on Human Genome Editing.” He Jiankui may not have himself thought that he was violating those principles (See Baylis,

who decried He's actions cited numerous problematic and ethically troubling aspects of the genetic editing he had done. In the first place, many scientists doubted whether the intended edits were successful incorporated into the individuals' genomes.<sup>64</sup> Moreover, even if the editing of the gene associated with HIV resistance was successful, it may also have had other deleterious health effects, including increased susceptibility to other more common infections with significant health risks, like West Nile Virus.<sup>65</sup>

Furthermore, based the recommendations of the prior international summit in Washington, D.C., and the subsequent US National Academies of Science report in 2017, the genetic edits that He made were precisely of the sort that had been identified as inappropriate candidate targets for initial germline genome editing. That is, genetic editing to increase HIV-resistance was not a medically necessary procedure. The twins were not at significant risk of contracting HIV in the first place, and HIV prevention had other viable medical and non-medical alternatives already. Rather than addressing a medical need or providing a scientifically useful trial case, the genetic alteration was more likely motivated by aversion to social stigma associated with HIV.<sup>66</sup> Instead of being a therapeutic when no viable alternatives were available, He's editing enlisted a medicalized solution to a perceived social problem.

Moreover, He carried out the editing work largely in secret. Though He did share his plans with some scientists and bioethicists who knew about his intentions beforehand, that controversial "circle of trust" was a relatively small and insular group.<sup>67</sup> As a result, his announcement ahead of the Hong Kong summit evoked surprise and outrage for violating scientific norms of openness about one's research. Moreover, critics indicted He's work as having scant clinical ethical protocols that failed to maintain a critical distance between researcher and subject. Ultimately, it was those breaches in medical and research ethics that Chinese courts cited in He's conviction in 2019 and subsequent sentencing to three years imprisonment and a fine of three million yuan.<sup>68</sup>

He's experimental work was also a significant departure from the guidelines laid out at the first summit three years prior.<sup>69</sup> The first summit had recommended international, public dialog and achieving a "broad societal consensus" about germline genome editing before attempts to move to clinical applications of heritable human genome editing would be acceptable. In light of He's actions, the Hong Kong summit in 2018 was an opportunity for scientists and the summit's organizers to reaffirm commitments to public engagement and societal consensus in the governance of heritable human genome editing.

But that is not what happened. The summit leaders condemned He for his ethically

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"Questioning the proposed translational pathway," 200). Moreover, the narrative of He's motivations are more complicated than one of He merely as a rogue scientist in defiance of scientific norms, which calls attention toward the ways that norms of responsible science are (and are not) articulated, invoked, and enforced in-practice (See Benjamin J. Hurlbut, "Imperatives of Governance: Human Genome Editing and the Problem of Progress," *Perspectives in Biology and Medicine* 63, no. 1 (2020): 177-194).

<sup>64</sup> Antonio Regalado, "China's CRISPR Babies: Read Exclusive Excerpts from the Unseen Original Research," *MIT Technology Review*. December 3, 2019.

<sup>65</sup> Regalado, "China's CRISPR Babies."

<sup>66</sup> Zhang et al., "Open letter from Chinese HIV professionals," 26-27.

<sup>67</sup> Cohen, "Inside the Circle of Trust," 431-432.

<sup>68</sup> Normille, "Chinese Scientist Sentenced."

<sup>69</sup> Committee on Science, Technology, and Law, Policy and Global Affairs and the National Academies of Sciences, Engineering, and Medicine, "Meeting in Brief," 7.

compromising consent process, for the ineffective design of the actual edits, and for the secrecy with which he conducted the procedures. But failure to engage with publics or to develop societal consensus was not on the list of objectionable offenses that He had committed. The problem with what He did was not that there was not yet societal consensus about whether or not attempt heritable human genome editing or how to best do so. He's scientific sin was not that he failed to do public engagement, but that he had "failed to conform with international norms" of scientific communities.<sup>70</sup> As one summit speaker later put it, "In effect, what [the summit organizers] said was that He did the right work the wrong way."<sup>71</sup> In doing so, the response at the summit and the ensuing narrative of He as a rogue scientist shifted the responsibility and authority for governing heritable human genome editing. Questions of whether to move forward at all with the technology, and, if so, how, were the purview of scientific communities acting on behalf of the public interest.

Importantly, though those decisions were for the interests of broader society, they were not ultimately for publics to regulate as responsible or not. The framing of He's actions as a violation of international, scientific norms and not of a failure of public engagement or "broad societal consensus" about heritable human genome editing effectively closed down the role of publics determining its governance. He's critics charged him with violating the norms of the international scientific community rather than violating than that of broader society, which was in tension with prior commitments to any decision about human genome editing as being "not one for scientists to make alone."<sup>72</sup> Instead of reasserting commitments to public engagement and open, inclusive dialog as prerequisites, the organizers closed the second summit discussing the need for a "rigorous, responsible translational pathway"<sup>73</sup> for human germline editing to move from the experimental to clinical applications. The question of whether or not to proceed with heritable human genome editing was subtly, but definitively, no longer on the table.

When asked explicitly about the departure from the "broad societal consensus" previously articulated, organizers referred to the development of a "translational pathway" specific to various regional contexts as a sufficiently similar standard for moving forward with heritable human genome editing.<sup>74</sup> The summit organizing committee did not specify further at that time what that translational pathway in various regional contexts might entail in concrete terms. Their appeal to distinct regional contexts and variability, though, was consonant with persistent ideas that Western nations have more bioethically stringent research requirements, oversight, and norms compared to a so-called "wild east," and China in particular,<sup>75</sup> in which more lax ethical standards allow for a "lawless frontier" to thrive for biomedical research.<sup>76</sup>

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<sup>70</sup> National Academies of Sciences, Engineering, and Medicine, "Second International Summit on Human Genome Editing."

<sup>71</sup> Benjamin J. Hurlbut, "On Crossing and Ethical Line in Human Genome Editing," *Chemical and Engineering News* (2018).

<sup>72</sup> Baltimore, Presentation at the International Summit on Human Gene Editing.

<sup>73</sup> National Academies of Sciences, Engineering, and Medicine, "Second International Summit on Human Genome Editing," 7.

<sup>74</sup> *Ibid*: 7.

<sup>75</sup> Douglas Sipp and Duanqing Pei, "Bioethics in China: No Wild East," *Nature* 534, no. 7608 (2016): 465-468.

<sup>76</sup> Lijing Jiang and Hallam Stevens, "Chinese Biotech Versus International Ethics? Accounting for the China–America CRISPR Ethical Divide," *BioSocieties* 10, no. 4 (2015): 484.

Numerous scientists and ethics scholars have strongly objected to such claims and deny that the alleged differences in ethical and research norms exist in practice, particularly between research taking place in the US and China.<sup>77</sup>

When summit speakers did mention public engagement, they framed it in ways that implicitly reinforced scientific experts as the appropriate authorities for heritable human genome editing governance. During the one summit panel specifically on public engagement, social scientist Joy Zhang from the University of Kent suggested that “it is precisely the lack of public engagement that has turned scientific debates into highly political ones.”<sup>78</sup> Zhang argued that failure to engage publics had enabled issues that should have remained within the purview of scientific judgement to become broadly disputed politically and socially. Past public engagement efforts about heritable human genome editing were showcased as success stories in which lay publics were invited to participate in discussions with the caveat that they “stick to the empirical” and refrain from “value judgements,” effectively screening off any points of ethical or social dissent or contestation.<sup>79</sup> The summit, again, presented public engagement, as an important process by virtue of its ability to resolve the political and societal uncertainty around genome editing, and thereby enable decision-making about human genome editing to remain in the remit of scientific experts. It was the jeopardizing of the decision-making authority of scientists that underpinned their insistence on public engagement, not the lack of meaningful, public participation per se.

#### Scientizing Governance

In the aftermath of He’s genome editing work, one might expect that such a censuring international response would dissuade similar violations of ethical norms around human genome editing. But only a few months after the sweeping international condemnation of He, another scientist in Russia, Denis Rebrikov, announced his plans to pursue similar clinical heritable human genome editing aspirations by implanted edited embryos in women with the intent to carry them to term,<sup>80</sup> plans on which he followed through later in 2019.<sup>81</sup> Following such announcements, many scientists and other experts called for a voluntary global moratorium on heritable human genome editing.<sup>82</sup> The purpose of a moratorium, in part, was to facilitate international public deliberation on if and how heritable human genome editing ought to proceed and with what sort of international standards and policies to guide it. The discussion of a moratorium, though, was similar to much of what transpired shortly after the advent of

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<sup>77</sup> Jiang and Stevens “Chinese biotech versus,” 484-488; Xiaomei Zhai, Vincent Ng, and Reidar Lie, “No Ethical Divide Between China and the West in Human Embryo Research,” *Developing World Bioethics* 16, no. 2 (2016): 116-120; Di Zhang and Reidar K. Lie, “Ethical Issues in Human Germline Gene Editing: A Perspective from China,” *Monash Bioethics Review* 36, no. 1-4 (2018): 23-35.

<sup>78</sup> Joy Zhang, Presentation at the Second International Summit on Human Genome Editing: Continuing the Global Discussion, Hong Kong, November 27-29, 2018.

<sup>79</sup> Zhang, Presentation at the Second International Summit on Human Genome Editing.

<sup>80</sup> Cyranoski, “Russian Biologist Plans More CRISPR-Edited Babies,” 145-146.

<sup>81</sup> David Cyranoski, “Russian ‘CRISPR-baby’ Scientist has Started Editing Genes in Human Eggs with Goal of Altering Deaf Gene,” *Nature* 574, no. 7779 (2019): 465-467.

<sup>82</sup> Lander et al., “Adopt a Moratorium on Heritable Genome Editing,” 165-168; Kevin Davies, “Walk the Line: Debating a Germline Editing Moratorium,” *The CRISPR Journal* 100 (2019):74-76.

CRISPR gene editing technology in the first place.<sup>83</sup> Similar imperatives were given even prior to the first summit in 2015 and yet did not inspire such broad, international dialog of substantial scale ahead of He's human genome editing work. However, it is unclear if being on the other side of a red line of genetically edited humans has made a difference for the renewed calls for public engagement.

The reopening of discussions of moratorium was also a call for scientists to assume tacit responsibility for and leadership of public engagement about the applications of the technology.<sup>84</sup> In doing so, scientific experts—their perspectives, interests, and values—inherently shape the aims, means, and framings of decision-making about heritable human genome editing. Such situating of the governance of heritable human genome editing as firmly within the purview scientists reinforces their position as the politically legitimate and normatively appropriate decision makers, despite the purported purpose of public engagement to promote inclusive participation of diverse publics.

Shortly after the news of He's genome edited twins, the World Health Organization announced its intention to form a multi-disciplinary advisory committee to developing guidelines for international governance of heritable human genome editing with heavy attention to the scientific, ethical, legal, and social challenges.<sup>85</sup> Likewise, in 2019 the US National Academies of Sciences and Medicine and the Royal Society of the United Kingdom established a new international commission that would hold multiple public meetings during the year to develop a report with more detailed and explicit frameworks for possible pathways for clinical human germline editing.<sup>86</sup> In each case, the committees had to decide *how* to move forward with heritable human genome editing, not *whether* doing so required public consensus.

At the same time, those expert committees attempted to establish a disinterested, neutral position for experts in decision-making about heritable human genome editing. In particular, the 2020 report resulting from the collaboration between the US National Academies of Sciences and Medicine and the Royal Society focused their report on detailing a “responsible translational pathway toward potential clinical uses of heritable human genome editing”<sup>87</sup> in which “broad public engagement” as being “as important as the clinical pathway components.”<sup>88</sup> The authors of the report left questions of whether any particular use would be permissible as matters for engagement with specific, relevant publics to decide and noted that “questions of precisely how such discussions should proceed was beyond [their] charge.”<sup>89</sup>

However, in striving for neutrality the expert committee functionally offloaded

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<sup>83</sup> Katrine S. Bosley, Michael Botchan, Annelien L. Bredenoord, Dana Carroll, R. Alta Charo, Emmanuelle Charpentier, Ron Cohen et al., “CRISPR Germline Engineering—The Community Speaks,” *Nature Biotechnology* 33 (2015): 478; Lanphier et al., “Don't Edit the Human Germ Line,” 410; Nature Editors, “Germline Gene-Editing Research Needs Rules,” 145.

<sup>84</sup> George Q. Daley, Robin Lovell-Badge, and Julie Steffann, “After the Storm—A Responsible Path for Genome Editing,” *The New England Journal of Medicine* 380 (2019): 897-899.

<sup>85</sup> World Health Organization, “WHO-RUSH,” 1-11.

<sup>86</sup> National Academy of Medicine, National Academy of Sciences, and the Royal Society of the United Kingdom, “International Commission on the Clinical Use of Human Germline Genome Editing.”

<sup>87</sup> National Academy of Medicine, National Academy of Sciences, and the Royal Society, “Heritable Human Genome Editing,” 145.

<sup>88</sup> *Ibid*: 28.

<sup>89</sup> *Ibid*: 146.

ultimate responsibility for the development and use of heritable human genome editing to publics and broader society. Reactions to the report from scientists and other experts, many of whom had participated in previous summits, further highlighted that whether and how heritable human genome editing might proceed was a social matter that required further public debate and discussion.<sup>90</sup> It was the responsibility of society to deal with those questions, not experts. Scientific experts were responsible to *pursue* public engagement to cultivate societal consensus prior to applications of heritable human genome editing, but the responsibility for the ethical outcomes of its use lay with publics. In doing so, the report set scientific experts up as trustworthy and moral actors eligible to shape heritable human genome editing decision-making in significant ways. In that way, public engagement functioned to absolve scientists of accountability for the outcomes of the technology while simultaneously also underwriting scientific experts' epistemic and normative authority in heritable human genome editing decision-making.

### Conclusion

Public engagement—what it entails, who it involves, empowers, and marginalizes—is fundamentally intertwined with how the issues of heritable human genome editing governance are themselves framed. Expert discussions about human genome editing governance framed public engagement as a means of facilitating a procession along a prudent or translational path forward for the technology by resolving societal controversy through collecting data on public attitudes. Likewise, their constructions of public engagement as an act of data collection simultaneously centers the discussion on having salient, sufficient knowledge, thereby reinforcing the ability of scientific experts as knowledge specialists to preside over the agenda setting and ultimate decisions making for governing emerging technologies.

Despite experts' invocation of public engagement as an important part of navigating to find a prudent path forward for heritable human genome editing, their treatment of public engagement in those discussions functionally undermines meaningful participation in democratic deliberations. When public engagement is actually present in such discussions, scientific experts have largely framed it as fundamentally about getting the right knowledge about publics to avoid, minimize, or resolve societal uncertainties. Doing so constrains public input as a form of data collection to supplement the assumed decision-making authority of experts if it is not quietly sidelined entirely.

Instead, scientific experts leverage appeals to public engagement to situate the broader social implications of heritable human genome editing as being fundamentally issues that fall within the jurisdiction of science. Such re-categorizations of the stakes and nature of the challenges prompted by heritable human genome editing reinforce scientific experts as the primary wielders of adjudicative power and proper custodians of governance.

This discursive pattern of scientific commitments to public engagement echoes aspects of Ruha Benjamin's work examining stem cell research debates in California,<sup>91</sup> in which similar framings of public engagement with science as a way of addressing societal controversy to enable continued technological development. Benjamin argues

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<sup>90</sup> Misha Angrist, Rodolphe Barrangou, Françoise Baylis, Carolyn Brokowski, Gaetan Burgio, Arthur Caplan, Carolyn Riley Chapman et al., "Reactions to the National Academies/Royal Society Report on Heritable Human Genome Editing," *The CRISPR Journal* 3, no. 5 (2020): 332-349.

<sup>91</sup> Benjamin, "People's Science," 27-54.

that “it is upon...fractured ground, and not upon any firm authority and hegemony on the part of science or overwhelming trust or consent on the part of society, that public engagement with science [takes] place.”<sup>92</sup> Rather, public engagement takes place in the midst of those social contestations about the rightful place of scientific expertise and public engagement in the governance of emerging technologies and collective imaginations of social goods.

It is precisely upon that fractured social ground that scientific experts reasserted their authority regarding human genome editing. By making commitments to greater public engagement, scientific framed the stakes for the development of heritable human genome editing as a demonstration of their responsible character and normative authority. Simultaneously, the also framed public engagement in way that deflected moral accountability for the outcomes of heritable human genome editing development and further stabilized their position of guiding influence over heritable human genome editing decision-making.

For whom, then, is public engagement? Ostensibly, public engagement is for all of us, for some notion of a shared society and common good. But examining closely heritable human genome editing discussions, it is not clear that is always necessarily the case. Though publics are not explicitly barred form discussions, they also are not included in the same capacity as experts, and the stratification of decision-making authority and inclusion, especially when it goes on unrecognized, is antithetical to democratic principles.

At stake in public engagement are fundamentally issues of who ought to be included in the democratic governance of science and technology. Insofar as scientific experts leverage public engagement to prepare a translatable, prudent path forward for emerging technologies, greater engagement does not curb the influence of scientific experts. Rather, it empowers them as the presumptive and rightful epistemic and normative authorities in technoscience decision-making. Such engagement does not so much increase the range of voices included in discussions as it does expand on whose behalf experts lay claim to make decisions. Insistence on public engagement leverages the rhetoric of democracy and inclusion to authorize the expansion of oversight of public interests to scientific experts. Commitments to public engagement without commensurate commitments to making explicit who engagement includes, excludes, and whose interests it serves muddy the waters of good democratic governance. Public engagement alone, therefore, serves not as a check on governance by scientific experts, but as an enabling handservant of technocracy.

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<sup>92</sup> Ibid: 7.

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