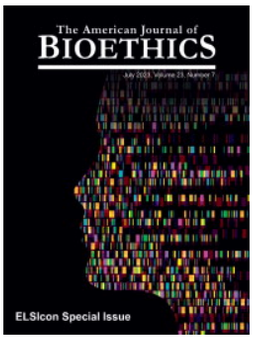

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Imperfect Methods for Imperfect Democracies: Increasing Public Participation in Gene Editing Debates

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Given some of the various possible impacts of clinical germline editing, we can expect robust disagreement about how best to regulate it. One can point to examples of the promise of editing: "roughly 6% of all babies born have a serious birth defect of genetic or partly genetic origin." Germline gene editing may offer a "novel treatment for single gene disorders" and contribute to overcoming polygenic disease (Gyngell et al. 2017, 503), offering some couples the "only way to avoid passing on single gene disorders" (Gyngell et al. 2017, 500) in cases where neither in vitro fertilization nor preimplantation genetic diagnosis is possible (Gyngell et al. 2017, 499). One can just as well point to examples of the possible perils of editing: "Parents could be put under powerful peer and marketing pressure to enhance their children. Children with edited DNA could be affected psychologically in detrimental ways. Many religious groups and others are likely to find the idea of redesigning the fundamental biology of humans morally troubling. Unequal access to the technology could increase inequality. Genetic enhancement could even divide humans into subspecies. Moreover, the introduction of genetic modifications into future generations could have permanent and possibly harmful effects on the species. These mutations cannot be removed from the gene pool unless all carriers agree to forgo having children, or to use genetic procedures to ensure that they do not transmit the mutation to their children" (Lander et al. 2019).

Both examples provide reason enough to include the general public in deliberations on how best to regulate human gene editing. After all, it "could radically alter almost every domain of life, including human health, plant and animal farming practices and the industrial production of drugs and materials" (Burall 2018, 439).

Deliberation can be configured in various ways. Deliberative democracy is one. In its promise, it is particularly attractive. Dryzek et al. (2019) cite examples of deliberative democracy deployed with some success in Ireland, Mongolia, India, Colombia, Belgium, Northern Ireland, Bosnia, Germany and the State of Oregon. Yet none of those examples addressed questions of how best to regulate rapidly developing biotechnologies. None confronted the peculiar difficulties of deliberating on the moral and political dimensions of human genetics.

In this exploratory context, Conley and his coauthors contribute helpfully to the general discussion by identifying the failure of five different projects to realize their shared objective of engaging ordinary citizens in deliberating about—possibly even influencing—the formation of public policy on human genome editing. They find that public engagement "does little more than record already well-known views held by the most vocal groups" and that it remains "unlikely to produce more just or equitable processes or policy outcomes" (Conley et al. 2023, 9).

But identifying failure does not itself illuminate failure, and the authors' recommendation that scholars simply rethink notions of *public* and *engagement* is unhelpful as long as they say nothing about how to re-think them. Worse, they do not address the possibility that popular participation may not be achievable, or not yet, or only rarely and then only marginally. It would be more helpful (a) to identify some of the intractable issues that confront the effort and (b) to contemplate possible alternative models.

(a) Consider six issues. First, much of the populace is unaware of moral issues created by biotechnology.

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Or it is simply disinterested by complex, scientific questions. Second, participation in deliberation on human genetic engineering requires a certain level of genetics and biotechnology literacy to fully understand the implications of genetic engineering. Many citizens will not possess that level. Many may have neither time nor interest in pursuing greater knowledge of a complex and highly technical kind. Third, among individuals and across communities, any public will display significantly diverging perspectives and commitments in light of the profound ethical, cultural, and religious questions raised by gene editing. Further, biotechnological questions can be framed from very different moral standpoints that compete with one another (a deontological standpoint versus a consequentialist one, for example, or a Catholic standpoint in contrast to an atheist one). Because no framing can be value-free, no deliberative exercise can lead to a morally neutral framing. So the framing of possible problems and promises of human genetic engineering is unlikely ever to be consensual (even as efforts might sometimes generate majority viewpoints that could be acted upon). At the same time, any deliberative process (like any regulatory regime) cannot be legitimate unless it includes the perspectives, values, and needs of diverse groups and individuals. The populace may resist guidance in forming or modifying an opinion because it is skeptical of, and does not trust, the various kinds of elites who dominate the conversation: deliberative-science advocates and natural scientists; corporations with financial interests in biotechnologies; policymakers in a climate of populism, political polarization, and disregard for robust scientific evidence (Grove 2017). Further, some citizens may resist deliberation about competing rational arguments due to strong emotional reactions, such as fear and disgust, evoked by the notion of manipulating some of the biological traits of our species. Fourth, groups with vested interests in promoting or preventing genetic engineering exert significant influence on public deliberation processes, either undermining efforts to generate representative views of the populace, or skewing possible outcomes. Fifth, in addition to logistical challenges, engaging the citizenry in deliberation requires significant resources of time, money, and personnel. Sixth, the biotechnology of human genetic engineering easily crosses national borders as well as other kinds of boundaries. Even if broad agreement were achieved within one nation state, there are no multilateral regimes that might transfer it across diverse national and local contexts of application. Yet regulatory efforts will always need to reach beyond those borders—even as those borders frustrate those efforts. Frustrated efforts can only lead to inconsistent, unsystematic, and incomplete regulation (Isasi et al. 2016). Efforts will also see "ethics dumping": researchers, often in high-income regions of the world, avoid local legal and ethical restrictions on research practice by pursuing unethical alternatives in other countries (usually in lower-income regions) marked by persistent legal and regulatory voids (Schroeder et al. 2018). After all, differences in regulatory standards will always disfavor poorer regions, countries, groups, and individuals. One consequence of such inequality is "medical tourism." Another is the inability of some countries to afford extensive and detailed regulatory oversight and enforcement. In a world of maldistributed wealth and uneven development, a global set of cost–benefit calculations is impossible. For these reasons, too, global deliberative publics generating universal standards for the legal regulation of gene editing are unlikely.

(b) The failure of efforts at popular engagement identified by Conley et al. (2023) invites us to consider morally and politically less ambitious alternatives—at least as placeholders until viable forms of deliberative democracy in the gene editing context are achieved. Consider that less than half the world's people are plausible addressees of this effort. The Economist Intelligence Unit Limited (2023) estimates that about 37% of the world's population in 2022 lives in authoritarian states that, as such, are unlikely targets of deliberative democracy and popular involvement in public policy formation. Experiments in developing deliberative democracy should continue full force among the 36% of the world's peoples living in flawed democracies (and the 8% living in full democracies) but, in the meantime, we should also address at least the most yielding of the various inherent weaknesses of democracy. One is a primary concern of deliberative democracy: improving citizen knowledge and the quality of decision-making. But less ambitious means to that end include improving public education and public media; reducing time-consumption and resource-usage by deploying new technologies such as online voting as well as discussion groups via digital communications such as Zoom; and increasing participation by holding elections and referenda on weekends.

An equally significant challenge in political design is the identification of possible less-than-consensual standards for deciding issues of human genetic engineering. All such standards struggle with inadequate inclusivity. Less marginalizing forms of majority rule

may be our best bet. Further, deliberative democratic procedures could be extended to the various elites (above all, scientists, ethicists, biotechnologists, and policy-makers) who always already dominate decision-making—but not yet in democratically deliberated ways. More ambitiously, the proceduralism of expert committees or commissions might be combined with that of deliberative democracy in a hybrid model (Gregg 2022).

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Addressing the Burdens That Newborn Screening Imposes on Underserved Communities

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Newborn screening (NBS) began in the 1960s by testing all newborns for a single condition—phenylketonuria, or PKU—which, when identified and treated early, significantly reduces morbidity. Over the past six decades, NBS has expanded considerably as a public health intervention for newborns born in the United States (US). Currently, the Recommended Uniform Screening Panel (RUSP), a list of conditions which the US Secretary of the Department of Health and Human Services recommends for inclusion in state NBS panels, includes 37 core conditions and 26 secondary conditions (HRSA. Recommended Uniform Screening Panel 2023). While NBS is rightly viewed as a public health success story resulting in an overall

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