

Narratives in Public Deliberation: Empowering Gene-Editing Debate with Storytelling

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Gene-editing in the environment is a wicked problem with high uncertainty whether there is sufficient potential for benefit to justify risks, as well as disagreement about harms and benefits for different populations and under different condition.^{1,2} How people assess appropriate risks, benefits and their fair distribution is strongly affected by their life experiences. In the case of gene editing for release into the environment or to be used on agriculture, there are often broader benefits, whether conserving a threatened species (albeit a modified version), eliminating pests, increasing yields, or reducing the need for pesticides and fertilizers. The potential harms are also broad and uncertain. The long-term effect of gene editing in humans is indeterminate, and at least some believe that the issue is not wholly resolvable without evidence post-gene editing. Ecosystem effects may be very difficult to predict and reach beyond the community or ecosystem that were the intended beneficiaries of the gene editing. Making wide-reaching decisions when outcomes have considerable uncertainty is particularly challenging. To address these wicked problems, scholars have long been advocating for a deliberative and community-led approach^{3,4,5} to co-create the solutions and explore a wider range of perspectives on the relationship of humans to nature, and global considerations of the kind of society we all want to live in. Deliberation must find a way to be inclusive, and many community and stakeholder perspectives reject the tendency of dominant policy, expert and industry actors to value immediate economic and health benefits over long terms risks and economic dependency. Arguments that attempt to provide widely generalizable justification based on quantified or monetized units of benefit and risk are at odds with considerations of human responsibility or ethics in relation to the environment that often have both international and unique local expressions.

Narratives are one of the most important elements of public deliberation, as human beings are storytelling animals, and as such there are arguments that narratives ought to be incorporated into the policymaking process, as detailed in the narrative policy framework.⁶ Narratives play an important, if often underappreciated role in deliberation, that is particularly poignant in the context of decisions about the release of genetically modified organisms into the environment.⁷ Broadly, public deliberative provides a context in which narratives are particularly important. The key functions of narrative include: 1) enabling the articulation of nuanced perspectives (including people's values, and "how" they come to their current positions), 2) diversifying how perspectives are communicated (e.g., different from "logical reasoning"), 3) encouraging participating by people who are less familiar with the use of formal reasons, 4) opening to challenge the presumptions made by policymakers/experts/industry actors in the more general context or framing of the deliberation issues and 5) inviting participants to listen carefully and think through issues from the perspective of the speaker, and to consider what is appropriate empathy in collective positions or outcomes

These key functions are supplementary to other forms of reasoning and enable a more inclusive form of deliberation. Narratives can be an alternative form of warranting, provided the understanding of warranting is not restricted to trying to justify universal or abstracted

conclusions, but rather to consider the range of embodied knowledge that diverse persons narrate so that their knowledge and perspectives can be respected.

These functions are particularly important for broad deliberation about genetically modified organisms to be released into the environment. Narratives can introduce novel views into deliberation and policy considerations regarding the relationship between nature and humans. Narratives enable a richer notion of the futures under consideration than those that are often restricted by an insistence on narrow views of reason and argument. These narrow views are often related to the cost and benefit analysis of gene-editing policy. Narratives allow policymakers as well as the lay public to consider how to integrate personal, social, cultural and spiritual perspectives into policy and advice about the genetically modified organisms. Narratives also provide a context for the extent and limit of expert and situated perspectives that the deliberative group is willing to support in collective positions or policy recommendations.

This paper is organized in the following order. We first discuss the meaning of narratives, especially its *storytelling* nature, to explain their communicative and performative functions in public deliberation. Sociolinguists, narrative theorists, critical scholars, sociologists of illness⁸ and many others have produced a significant, and often disconnected body of scholarship about narratives and the roles of narrative in various social contexts, including specific to bioethics.⁹ We will then discuss whose narratives are necessary in controversial science policymaking, with an emphasis on hearing stories from the under-represented populations. Finally, we will provide suggestions about how we can design effective environments to warrant storytelling in public deliberation to collectively govern emerging technologies, such as gene-editing in the environment.

Narratives defined and illustrated

Our use of “narrative” is distinct from narrative as an analytic tool to characterize broad analytic categories, such as ideologies or cultural narratives. We acknowledge that these other narratives are helpful ways of characterizing broad ideologies or cultural orientations that have important explanatory roles in surfacing implicit assumptions that may frame issues brought to deliberation, or characterize participants’ approach to deliberation. “Narratives” can also refer to the use of crafted stories to manipulate public opinions.¹⁰

We want to draw attention to storytelling as situated accounts that are in the first instance individual accounts that reflect a person’s life experience, albeit with recognition that all life stories have a history and a context, and are often extrapolations from what is familiar to new situations. These accounts might surface local knowledge or suggest framing assumptions that are different from the way issues are framed by organizers or by expert and stakeholder accounts. Fundamentally these stories capture a personal orientation and express how one’s lifeworld influences perceptions and responses to issues raised in the context of deliberation. These stories simultaneously articulate a situated personal account, whether historical or speculative, while inviting listeners to think, feel and live through the story to build empathy for the speaker’s perspective. Stories may be told as responses to other stories, whether other participants or the accounts of experts and stakeholders. In these stories we come to understand more “how” a

person comes to a view or perspective. This is in contrast to reasoning as arguments that provide a basis for us to be convinced that a position is right or wrong. The epistemology behind the acceptance of stories as important forms of knowledge is rich, but beyond the scope of this paper. Suffice it to say that whatever epistemological basis, decisions require an assessment of *how important* various considerations are to the decision, and that is not merely a function of the scientific measurement of the probability and magnitude of effects. Stories can draw our attention to why scientific accounts are viewed as incomplete, and to the social and historical basis for distrust, or trust.

Stories are normally conceived of as a sequence of events that lead to a meaning, and stories with the same historical reference may be told in different ways to make different points, or in response to the perceived audience. Stories can also be creative efforts where individuals or groups “try on” a perspective to work out its implications and as a way to articulate their concerns. For example, Heather Walmsley explains how a small group within a deliberation on biobanks presented their report in the form of a skit that acted out issues raised by biobanks in a world where some scientists are rogue in the sense of “mad” or “bad.”¹¹ Walmsley argues that such approaches are important for the legitimacy and accountability of the deliberative process, in terms of both its outcomes and its process.

Walmsley’s account also illustrates how stories can fulfill all the purposes listed in the introduction. The use of stories enabled articulation of nuanced and more diverse perspectives than was reflected in the introductory materials and the conception of the challenges of biobanks by the organizers. Participants struggled to express their concerns in formal reasoning, yet utilized a story to challenge dominant assumptions and enabled the listeners to think through issues from their perspective.

Creating time and legitimate space for story telling is an important component of providing an opportunity for diverse perspectives to be articulated into the deliberation, that is, made available for the participants to consider. The diversity of participants in a deliberation is an important issue that is beyond the scope of this paper, and has been considered elsewhere.¹² However, achieving diversity in the constitution of the deliberating mini-public will be inadequate without processes that enable the full diversity to be articulated for consideration in the deliberation.

Marginalized perspectives are often most readily presented in stories, whether personal or as accounts of the history of communities. Stories about nomadic life and how community life was importantly connected to the land was crucial in the *Delgamuuk v. the Crown*, a Supreme Court of Canada trial related to Indigenous land claims.¹³ Discussing the use of stories in the case, Angelina Means explains that “narrative frames do not just provide the form for argumentative content; the two are so richly interwoven that if we bracket narrative forms we will simply never hear some “arguments.” In particular, we will be unable to hear the reasonable arguments of various cultural strangers.”¹⁴

Storytelling can also capture a perspective that has evolved through the deliberation. In one deliberation on mandatory vaccination for children attending public school, there was considerable challenge in presenting the perspectives of parents who opposed vaccination without seeming to endorse those perspectives.¹⁵ Participants thought that the background

material and speakers failed to provide adequate understanding of these parents' views, so the organizers located and provided access to online accounts. While the participants came to recommendations in strong support of mandatory vaccination, the online accounts had the effect of increasing empathy for parents refusing vaccination. Despite this convergence, in a discussion of penalties for parent who refused to vaccinate their children one participant explained that he now understood that parents who refuse to vaccinate their children sincerely believe that they are acting in their children's best interests. Paraphrasing for brevity, he told a brief story based on this new insight.

Since I came to Canada, I have been impressed by the inclusiveness, the way different people are accepted. So, I wonder whether we can find a way to achieve herd immunity without punishing parents who sincerely believe that they are acting in their children's best interests.

Following this intervention, several participants reconsidered their support of penalties for parents who refuse to vaccinate their children. Stories of unfamiliar and opposed perspectives influenced the participant, who in turn articulated in narrative form how his understanding of these unfamiliar perspectives increased his empathy. The participant's story brought home to some of the other participants the relevance of the online parents' stories with regard to empathy in policy recommendations, even though it did not undermine strength of the recommendation in support of mandatory childhood vaccination policy.

Whose narratives are necessary

There is a sense in which more formal reasoning such as statistical or scientific explanations, or arguments in support of a particular conclusion, are part of the larger category of narratives. Experts draw on contextual and cultural assumptions just as any story teller does. Expert and stakeholder accounts generally depict outcomes of an action or policy effect as benefits and risks. Deciding that an outcome is a benefit or a risk depends on the value assigned to each, and that value depends on judgments made within particular contexts. These contexts are usually assumed rather than stated explicitly. Perhaps the most obvious example is the outcome of death, typically assigned a negative value as an outcome, and any reduction in probability of death as an outcome as good. But as considerations of assisted suicide illustrate, under some conditions of suffering and irreversible deterioration, death and the probability of death can reasonably be assigned less negative value, or even be seen as a benefit. Another example is the framing of organ shortage either as a problem of scarcity, to be remediated by increasing supply, or allocation, with an emphasis on equity of allocation. Schicktanz and Schweda have argued that this rhetoric has an economic subtext with implicit normative premises that have far reaching ethical and social consequences.¹⁶

The role of storytelling in deliberation is to emphasize that the assessments of the moral importance of any set of consequences or changes in relationships are necessarily made in particular contexts. While public participation in decisions and policy making is the most obvious objective, public deliberation is also about exploring as many moral perspectives as possible before making policy recommendations about how we live together.¹⁷ While

stratification or wide sampling are attempts to ensure that marginalized perspectives are included in a deliberation, merely getting a diversity into the deliberation does not produce a clear path to having that diversity articulated into the deliberation. Stories from people whose life experiences have put them in situations where dominant assumptions hold less influence are important for several reasons. The stories open participants to broader consideration of how to assess the issues. Stories may also encourage participants to consider the role of empathy in their recommendations, and have the potential to disrupt the assumptions that are implicit in expert and mainstream accounts. Storytelling may bring the broader narratives into stark relief, making them visible and open to question.

Storytelling does not in itself tell us what life experiences are important to include in deliberation, but as a feature of deliberation it better enables wider participation and opens assumptions of expert and stakeholder presentations for examination. Certain traditions practice storytelling as part of their culture, but as the example of the story from the mandatory childhood vaccination illustrates, any participant might shift perspective by telling a story about how aspects of policy recommendations affect others toward whom we might consider more empathetic responses, despite rejecting their knowledge claims. As the example from organ donation illustrates, experts' identification of dominant assumptions or narratives can also open up alternative accounts for consideration. But since experts and stakeholders participate in a deliberations as privileged knowledge keepers, the real power of storytelling is in the unanticipated reflections and tentative "trying-on" of positions by participants.

Deliberations on gene editing on organisms to be released into the environment might benefit from hearing from a range of perspectives, some of which might be identified ahead of time as important to include because they operate from a different set of assumptions than some experts or other stakeholders. In deliberations on data and biobanks, there was good reason to ensure that Indigenous perspectives are included, not merely to make the case for different management of data and biospecimens when working with Indigenous communities, but because their different relationships to data and biospecimens are important alternative perspectives for participants to consider.¹⁸ It is inadequate to merely recruit Indigenous participants in the hope that they will articulate perspectives that organizers can identify in advance as important for a well-informed deliberation. Merely inviting participants from diverse backgrounds and supporting storytelling as a valid input to deliberation fails to give the perspectives adequate respect when expert views are given a more authoritative presence through formal presentations. Further, there are too many influences in deliberative activity that might mitigate the articulation of their perspective. One approach is to invite Indigenous presentations while being clear that this is to get the participants to consider a range of approaches for recommendations about civic society, but not to assess any aspect of Indigenous self-governance or culture. In deliberations on gene edited organisms and their release into the environment, it may be that particular perspectives can be identified that must be considered for the deliberation to have engaged the range of relevant views. This argues for these perspectives to be brought in alongside scientific experts as authoritative knowledge keepers of a different kind of knowledge and context. This may, of course, support participants in the deliberation to raise the perspectives that they share with the stakeholder knowledge keepers, or even to contest them when local knowledge suggests that the more general approach also needs to be reconsidered as participants formulate their recommendations.¹⁹

Even sincere attempts to introduce alternative, marginalized or cultural perspectives in deliberations can be problematic. Scholars and activists working in the area of culture have long been critical of the tendency to essentialize culture.²⁰ Rubinstein usefully characterizes the generalization of cultural elements as static as the “fallacy of detachable cultural description.”²¹ Non-scientific or expert views are sometimes contrasted with “cultural” views and viewed as optional or less urgent in policies.²² Yet the importance of alternative ways of representing these alternative ways of understanding has gained wider recognition in deliberative theory.²³ The introduction of diverse perspectives into deliberations on gene editing on organisms to be released into the environment are best managed by the invitation of appropriate speakers, the provision of written materials, and possibly other forms of communication to reflect know perspectives. The role of storytelling is to follow-up these different perspectives in deliberation and enable participants to tell their own stories and “try on” perspectives as they work through the issues.²⁴

Discussion: how to structure storytelling on gene-editing in the environment

Storytelling plays a vital role in deliberation to inform policy on the release of genetically edited organisms. Gene editing is associated with considerable uncertainty about the risks. As highlighted in NASEM’s 2016 report on gene drives, “the appropriate language for identifying, expressing, and weighing these value considerations is unclear.”²⁵ Gene-drive modified organisms might benefit human beings, but could at the same time cause risks to the environment such as affecting biodiversity, resilience of ecosystem, and the rights of nature itself.²⁶ The benefits and risks discussions are also closely intertwined with social justice issues such as who is affected and who make decisions.²⁷ Further complicating the matter is that a policy on gene editing defies jurisdictional boundaries. This is not unique; biological innovation in humans, agriculture or the environment are often difficult to contain given such phenomena as health tourism, wind and current drift and other natural forms of natural dissemination. Policies that govern gene editing must consider how much uncertainty is tolerable, and under what conditions of governance. This tolerance cannot be determined by ethical, legal or scientific expertise without deciding what constitutes relevant benefits and risks, whether the benefits justify the risks, and how the fairness of the distribution of those risks are determined.

A public engagement approach is necessary to explore and identify “what constitutes beneficial and harmful outcomes, how to deal with uncertainty about those outcomes, what level of precaution to endorse, and how to understand the human relation- ship to nature.”²⁸ With few exceptional cases of limited releases, gene editing of organisms to be released into the environment carry implications that cross traditional jurisdictional boundaries. The range of relevant public input is wider than for many other technologies or policies, and most “public” consultation have been deficient.²⁹ Bio- and databanks can have different governance regimes and work out how to collaborate and whether to share data. Policies on access to health services, whether abortion or cancer care, can and do vary across provinces and states as well as nations. But in the case of gene editing the obligation of wide inclusiveness and representation is a strong argument for paying explicit and careful attention to the role of storytelling in public deliberation.

So, how could we structure the deliberation to enable storytelling and thus to ensure adequate representation and diversity in discussing gene-editing in the environment? Aligning with what is proposed in the essay “Decision Phases Framework” in this special report,³⁰ we stress that, foremost, these structured deliberation elements should be implemented throughout the technology development process, from research and development, to regulatory review, and to the deployment, management and monitoring stage. Detailed discussion of the design elements of deliberation can be found in the essay “Deliberative Public Consultation: Criteria and Methods”³¹ in this special issue, but we highlighted two important considerations.

1. Participant recruitment to ensure diversity. Getting diversity of perspectives into the deliberation and avoiding the unreflective assumption of dominant and elite-driven perspectives directs attention to the recruitment, stratification and support of participants. In the Deliberative Poll, scientific random sampling method is used to ensure that participants are representative in both demographics and attitudes toward the issues to be discussed and the sample size is large enough to evaluate participant representativeness.³² Another important design in recruitment is to include diverse discursive styles and experiences that are likely to include arguments and narratives.³³ Overrepresentation, targeted recruitment, support for expenses and payment for time may be required. Deliberations on gene editing will need to take care to understand diversity of life experiences to decide who needs to be recruited. This may require considering recruitment strategy that moves from a deliberating body that reflects the demographic of the population to overrepresent people living in communities most likely to be affected by benefits of the release, or those less likely to realize benefits, but who may still be exposed to the risks.³⁴

2. Facilitation of deliberation to enable storytelling. Storytelling requires time and two-way engagement to ensure consideration about the role of empathy in what participants are willing to support collectively. It is important that in designing for public deliberation events, there is adequate time, in small and large group formats, for participants to work through various aspects of the proposals and to hear and respond to different storytelling. While participants must consider the role and importance of each story for them in the deliberation, it is also important for researchers and policymakers to conduct transcript analysis to identify and articulate the role of stories, not only for the deliberation, but to extend the benefit of the deliberation to policy makers and wider publics.³⁵ It is possible that an outcome from deliberations can be supportive or creative in terms of social movements. In the case of gene editing policy options, these pre-designed options are likely to be focused on particular examples, in the perspective from experts and policymakers, but participants may want to raise very broad concerns about the uncertainty, global effects, and unease with making permanent genetic changes that may have far reaching and unknowable effects on their lifeworld and values. Many of the challenges to such framing effects will come in the form of stories that discount or alter limitations in the initial examples. Deliberative designs that enable storytelling allow the expression and consideration of the concerns without requiring that they be articulated in scientifically precise terms.

As illustrated in the reframing of the issue around biobanks in the “mad scientist” skit, it does not take long for deliberation participants to begin to question the narrow framing of policy and scientific reasoning. Participants blend an acute sense of their own position and perspective with an awareness that all large-scale actors are driven by interests that need to be scrutinized and often constrained in the interest of wider publics. Global discussions tend to be dominated by experts, industry and well-organized stakeholders. It is therefore critical that broad deliberation

be another source of input into decisions, and that such deliberation enable the consideration of non-dominant and situated perspective through the use of storytelling.

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