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Title

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Permalink

<https://escholarship.org/uc/item/7tv5624k>

Journal

Environmental Communication, 14(7)

ISSN

1752-4032

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Publication Date

2020-10-02

DOI

10.1080/17524032.2020.1811459

Peer reviewed

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Can the Public Express Their Views or Say No Through Public Engagement?

New technologies often come with calls for public engagement, which presumably brings the views of the public to decision-makers, and the CRISPR genetic modification revolution has led to such calls for a range of applications. Who interprets the results of such a consultation will structure the interpretation. In this essay I compare interpretation from elected officials and bioethics commissions. Interpretation will most likely be by a bioethics commission, and I argue that the structure of decision-making in those commissions means that the public is unlikely to have its values properly portrayed and, more problematically, the public cannot be portrayed as saying "no." If this is correct, it throws the very premise of public consultation into question.

Genetics was actually one of the first scientific issues that was brought to the public. In the first modern debate about human genetic engineering in the 1950s and 1960s, scientists were debating amongst themselves the goals we should set for the human species that could be advanced through genetic engineering. (Evans 2002) At one of those meetings, in 1965, microbiologist and later Nobelist Salvador Luria stated that the public should be consulted because for scientists to "claim the right to decide alone" about the direction of scientific efforts would be "to advocate technocracy" (Luria 1965:3, 17). (Technocracy means non-democratic governance by experts.)

In genetics, this impulse to consult the public has emerged again, after a multi-decade hiatus, with the recent reports by the National Academies about both human gene editing (National Academies of Sciences 2017) and gene drives (National Academies of Sciences 2016) calling for public engagement. The central question for me here is, for decisions above a local level, and particularly for decisions that impact a pluralistic nation, who would run such a consultation? More critically, who would interpret the

policy implications of the findings of the consultation? The answers are ambiguous enough that the title of a recent article on public engagement has the subtitle: “who is in charge?” (Boete 2017)

An accurate depiction of the public’s view will depend on the entity that is doing the interpretation. More problematically, the entity that will probably be in charge of interpretation is unlikely to depict the public as saying “no,” no matter what the public actually thinks.

To understand my claims, let us return to the late 1960s and examine the possible entities that could interpret the views of the public. In contrast to Luria, most scientists and physicians of the time who were involved with the genetic and related debates were not keen on losing control of deciding which technology should be developed. But, the public had begun paying attention to these debates, and thus so were elected officials.

In the late 1960s Congress began to hold hearings on setting up a government commission that would oversee research on topics such as genetic engineering, behavior control, human experimentation and organ transplantation. The influential scientists who testified about this idea were largely hostile to a commission, with the senator who organized the hearing even complaining that one of the scientists “seemed reluctant ‘to have persons other than the people in your laboratory look at the social implications’” (Jonsen 1998:91). A professor of medicine, when asked if other professionals might help scientists with the ethics of their work, replied that “if you are thinking of theologians, lawyers, philosophers and others to give some direction . . . I cannot see how they could help . . . the fellow who holds the apple can peel it best” (Jonsen 1998:93).

Scientists lost exclusive control over whether their research would be allowed to proceed. However, their worst fears did not come to pass. Congress could have interpreted the values of their constituents and regulated or even banned certain technologies from being developed. That is, to foreshadow where I am going in this short essay, Congress could have become the interpreter of the public’s views. But, they did not.

Instead, scientists settled for a buffer between the scientists’ actions and the public’s elected officials – the bioethics commission that would recommend ethical policy to the government. These commissions are designed to install expertise between public demands and government actions, and to forestall action by our elected officials. For example, according to its Chair, a government bioethics commission called the Recombinant DNA Advisory Committee and its later Subcommittee on Human Gene Therapy were in both instances created “in part to fill a vacuum and in part to forestall congressional action” (Walters 1991:117).

It is important for my argument that these bioethics commissions have at best a very weak democratic accountability. On the one hand, they have no actual power, but on the other hand they make recommendations for

policy-makers that are often followed – a framing or agenda-setting power of defining which choices are reasonable. That this power circumvents elected officials has been noticed. As one Congress member complained about one of these commissions, “so actually we have a board of people who are quote unquote ‘experts’ . . . and they’re actually making moral decisions . . . but somebody in the place of the legislator.. . . would be making those decisions” (Hurlbut 2017:100).

But, how are the public’s views represented in these commissions and debates about bioethical policy more broadly? Bioethicists have tried over the years to develop various theories for how the views of those on the members of commissions are representative of the public’s values. One could be called “consensus among diverse commissioners” (Moreno 1995). As described by the director of one of the federal bioethics commissions, consensus “encourages the commissioners to seek the common ground that best expresses the moral insights and values of Americans today, in light of our shared, albeit not uniform, religious and philosophical traditions” (Capron 1983:8). However, given what is known about the relationship between values and educational attainment, we can be skeptical that a consensus among commissioners where nearly all have a doctoral degree represents the public’s view.

The most successful mechanism for the democratic accountability of bioethics commissions was created by the first federal bioethics commission, which was that the commission was going to advance principles, values or ends that were consensually held by all of the citizens of the country – what was called the “common morality.” According to Beauchamp and Childress, the “common morality” “comprises all and only those norms that all morally serious persons accept as authoritative” They also argue that it is “an institutional fact about morality, not merely our view of it, that it contains fundamental precepts” that function above the particularity of sub-cultures (Beauchamp and Childress 2001:3, 4). The common morality is very attractive for an unelected group who will be making recommendations to (typically unelected) government officials. With a purportedly common morality the commission is not forwarding its own values, the values of any particular commissioner, of “science,” “the intelligencia” or any other group. It is advancing the values of the citizens.

The first such commission was instructed by Congress to come up with such principles: to “conduct a comprehensive investigation and study to identify the basic ethical principles which should underlie the conduct of biomedical and behavioral research involving human subjects” and “develop guidelines which should be followed in such research to assure that it is conducted in accord with such principles” (Jonsen 1994:xiv).

They came up with three, which were later expanded to four – autonomy, beneficence, non-maleficence and justice (National Commission

for the Protection of Human Subjects of Biomedical and Behavioral Research 1978; Beauchamp and Childress 1979). Roughly, autonomy means making your own decisions, beneficence means doing good, non-maleficence means avoiding harm and justice means equality in allocation. These common morality principles later came to be considered to be applicable to any public policy bioethical issue such as genetics.

A linguistic metaphor is apt for understanding this system, largely called “common morality principlism” or just “principlism.” This is an extremely “thin” version of ethics compared to the “thick” version that different moral communities would espouse, akin to how a stripped down pidgin language cannot express the complexity of the various home languages of its users. Importantly, principlism represents the home language of bioethicists and scientists, while others have to try to translate their claims into this more simple language.

The way bioethics operates in practice is that the “thick” ethical concerns from particularistic moral communities are translated into the four principles of the common morality, with much remainder, or are ignored and only the claims that can be translated are considered. For example, the concerns expressed in an early 1980s letter from religious leaders to President Carter about “playing God” with genetic technology was translated by the bioethics commission of the time as actually being concerned with safety (non-maleficence). While concerned with safety, the religious leaders had other concerns that were not translated and thus not input into the debate (Evans 2002:Ch. 4).

Many scholars have been concerned about what cannot be expressed by the limited moral language of principlism. For example, a recent Hastings Center working group wants to have a debate about genetics beyond concerns about physical harms (beneficence/non-maleficence) that dominate the debate and instead insert theories of what it means for humans to flourish (Parens and Johnston 2019). Of course there are scholars who identify as bioethicists or who participate in bioethical debate who do not use common morality systems, but the closer one is to actual policy recommendations, the greater the odds that this is the default system in use.

TWO DIFFERENT VERSIONS OF DEMOCRATIC ACCOUNTABILITY

I consider public engagement to be a loose form of democratic accountability for science. And, the power of common morality principlism is that, if it is actually true that these principles represent the morality of all of the citizens (which is debatable), it is indeed a fairly democratic and pluralistic approach to difficult value questions and the creation of policy that will be applied to all citizens. No group is more valued than any other, as all that is being advocated is the thinnest of lowest common denominator values. For example, principlism would not allow for a particularistic theological perspective to be imposed on all citizens. There are legitimate reasons why this form of argumentation is so dominant not only in mainstream public policy bioethics, but in ethical decision-making in pluralistic institutions like hospitals.

The other democratic option besides letting bioethics commissions and public bioethical debate frame our decisions about genetics is to return to the option of the early 1970s and let the elected officials decide. They would decide not by the lowest common denominator values, but by majoritarianism. While that sounds bad, that is how all other decisions are made by our elected officials, and decisions by elected officials are considered to be democratically legitimate. We may not like their conclusion, but if our perspective loses we can conclude that people who share our view did not do enough to convince our fellow citizens. I for one recognize that my political positions are unusual, and are never taken up by my elected officials,

but I still think their decisions are legitimate because my fellow citizens have views opposed to mine.

So, if someone is to set up a form of public engagement as input for government decisions about genetic policy, should the interpreter be elected officials or an unelected body that would tend to use a common morality system of ethics? The decision will strongly determine how the public's view will be portrayed. I will identify two tensions that exist in both of our choices: will the public recognize their concerns in the interpretation and can the public be portrayed as saying "no" to any technology.

WILL THE PUBLIC RECOGNIZE THEIR OWN ETHICS IN PRINCIPLISM?

Let us just assume away all of the recognized problems with setting up public engagement, and assume that this is done via some social scientific process which then concludes that the public's values for genetic modification are X, Y and Z. Let us assume that the logic of common morality principlism is not built into the consultation process itself, and that those who are consulted are allowed to use their particularistic moral languages and advocate for values that they know are not universally held.

My hypothetical case is where 70% of the public expresses the value that we should not design "nature" or interfere with "God's creation." Following this value would move us away from creating new life forms. Most of the public would recognize its values in this consultation report, and we can consider the public to have been well consulted. Since the point of the consultation was to allow the public's values to have some say in bioethical policy, the report goes back to an entity for interpretation of what policy the public would want. Which entity?

If we go back to the situation in the early 1970s, before the idea of an ethics commission that would use the common morality, the interpreter of the public consultation would be our elected officials. I start with this entity because it will never happen. (One attempt in the mid 1980s of a bioethical entity directly appointed by Congress was a spectacular failure (Hanna, Cook-Deegan and Nishimi 1993:209-11)). The history of the field of public bioethics also suggests that the scientific community would be strongly opposed to having the unmediated public's view directly influencing our elected officials (Evans 2012).

But, to return to the thought experiment, Congress is used to settling issues "democratically," by which is typically meant, by majority rule. (Unless someone can claim that genetic applications reach the level of a constitutional right, which is unlikely.) Congress says the majority of the public thinks we should preserve nature as it is, the minority disagrees, and we go with the majority.

What if a bioethics commission, or any group that claims to speak for

the collective but is not democratically representative, is the entity that interprets the findings of the public consultation? They cannot accept values that are not universal, so they will try to translate the values expressed by the public into the lowest common denominator language of principlism. In the method used by the early 1980s bioethics commission in similar act of translation, the interpreter would look for the “rational kernel” in the public’s concerns (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983:58).

The most common maneuver is to translate all concerns into risks (non-maleficence) vs. benefits (beneficence). In my hypothetical, most likely it would be to try to re-configure the desire to leave nature as it is into the principle of “avoiding harm.” It will be concluded that future genetics applications should avoid harming nature, which has essentially translated the preservationist environmental view of the intrinsic value of nature into a consequentialist conservationist environmental view. The concerns of 70% of the public are not actually represented, because they have been translated into a universal concern.

CAN A PUBLIC ENGAGEMENT BE DEPICTED AS SAYING “NO”?

The more fundamental problem with having an entity that uses “the common morality” to recommend bioethical policy is that this ethical system cannot be used to say “no” to any technology once it is safe. Let us imagine bioethical policy on germline human gene editing of an embryo to edit a gene that leads to deafness. Let us further say it is safe (e.g. the principle of non-maleficence is satisfied). The principle of autonomy would mean that people would have the ability to gene edit their children should they see fit – in general, advancing autonomy cannot be used to say “no.” As for beneficence, what is beneficent will be in the eye of the autonomous beholder – if you think that editing out deafness in your children is beneficent, then it is beneficent. “Justice” would simply require that the risks and benefits of the advancing technology not be focused on one group.

In sum, if a public engagement process reveals that the applicable values for gene editing applications are not consensual – as I would expect – then which entity such a process reports to will be critical. In the unlikely scenario that such an entity reports to a democratically accountable body, then there will be no problem and the public’s values will be taken to account to the same extent our elected officials ever take them into account. However, if the entity reports to a body that is not democratically accountable, and which therefore makes claims of common morality, then tensions arise. First, when the group translates the values of the public to the thin common morality, or ignores “non-consensual” values, the public will not recognize its views in the report. This would violate the purpose of public

engagement. Second, in the most common rendition of common morality, it is not possible to say no to any technology, unless other values are somehow smuggled in.

I do not mean to imply that the common morality approach is inferior. Indeed, I have advocated a modified version that could be called a “generally common morality” approach as necessary in a nation with diverse religions and values (Evans 2012). My point is rather that advocates of public engagement should be aware of this tension, and think through who does the interpretation of any public engagement and the method they use to do so. We should also remember what the point of public engagement actually is, which I assume is to determine the values of the public. We must ask whether a situation structured so that the public cannot say no is really engagement.

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