# Charis Thompson

# Governance, regulation, and control: public participation

## Conference paper

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**CHARIS THOMPSON**

**GOVERNANCE, REGULATION, AND CONTROL: PUBLIC PARTICIPATION**

   I'm going to start by looking back on some of the things that we've talked about and seen between the beginning of this summit and now. This is just my take: I'm sure I've got all kinds of things wrong - maybe there's a lesson in that about the limits of communication - but I'm trying to summarize some of the positions that have been expressed.

   **Are we moving toward a consensus on human germline editing or not in this meeting?** We've heard a lot of different positions.

*Figure 1: Text from powerpoint slides accompanying lecture:*

*"Yes" to human germline genome editing, in order from the most to the least permissive:*

1. Edit the human germline genome for reproduction if it is no more risky than "natural" sexual reproduction and is aimed at eliminating serious genetic conditions.

2. Edit the human germline genome for reproduction if it is likely to be safe, effective and make a big difference. (For example, for monogenic/oligogenic serious medical conditions.)

3. Edit the human germline genome for reproduction to avoid having offspring born with a serious condition only if there are no other alternatives, such as in vitro fertilization with pre-implantation diagnosis. (For example, if both genetic parents are homozygous for the same serious medical condition so that none of their embryos would otherwise be free of the condition.)

4. Move toward editing the human germline genome for cultural and religious reasons, such as when a given national culture is pronatalist, has a pro-medicine ethos, and has significant state subsidies for reproductive and screening technologies.

*"No" to human germline genome editing, in order from the most to the least permissive:*

1. Hold off (place a moratorium) on editing the human germline genome for reproduction while we work out the technical issues of safety, off-target effects, efficacy, efficiency of the edit, and the development of a clinical grade delivery mechanism for the editing system.

2. Hold off (place a moratorium) on editing the human germline genome for reproduction at least until we (re)frame and make much more inclusive vital ethical, social, and economic debates around ableism and disability justice, the over medicalization of human variability, racism and sexism in science, local and global health inequality, the views of non-stakeholders as well as stakeholders, and the needs of future generations, the vulnerable, and other species.

3. Ban the editing of the human germline genome for reproduction because it is a reasonable line to draw against hubris and in favor of our human future, against a highly likely slide toward eugenics and the exacerbation of inequality, and against possible ecological and other harms.

4. Ban the editing of the human germline genome because of the moral status of the embryo, human dignity, the freedom rights of the genome-edited child, and/ or religious conviction.

The most permissive (of the 'yes' to human germline genome editing positions) we heard is to edit the human germline genome if it's no more risky than natural sexual reproduction and if you want to get rid of disease.

Second, do it if it's likely to be safe and effective and make a big difference, for example, for serious monogenic and oligogenic conditions.

Moving down the scale, edit the human germline only if there are no other alternatives such as PGD to avoid a serious condition, e.g., both genetic parents are homozygous for the same serious condition. This is essentially the approach advocated by Eric Lander.

Fourth, editing the human germline genome may happen – this was for the Israeli case – in that particular country because it fits a pro-natalist, genetic-screening-friendly, and pro medicine ethos that is subsidized by the nation in question.

These are very different positions but they all basically say that at least under some conditions it would be okay to edit the human germline genome.

Among the 'no' (to editing human germline genomes) positions, the first moratorium position was to hold off on editing the human germline genome for implantation while we work out the technical issues of safety, efficacy, delivery, and so on.

On the less technical and more social side, we heard pro-moratorium positions that recommend holding off on editing the human germline genome, at least for implantation purposes, until we reframe vital debates and learn to listen to and incorporate ideas of other stakeholders—and I would argue, non-stakeholders—future generations, the vulnerable, other species, and so on.

Then we heard a couple of positions that sound more like banning the editing of the human germline genome (rather than imposing a moratorium) because it is a reasonable or important line to draw. I heard a lot of concern that I share about becoming a selecting society.

The first of these positions is that prohibiting human germline genome editing is a reasonable line to draw against hubris, against eugenics, and against possible ecological and other harms.

The most restrictive position we heard at this meeting would be to ban editing of human germline genome because it's against the moral status of the embryo or some universal principle of human dignity.

I'm not going to try to decide among these positions here. I think everybody in the room is good willed on this topic, so I'm going to move on to some things that have also come up to do with possible misunderstandings and then bring it around to what we might do about the fact that there is such a variety of opinions.

**1. First, the metaphors**. There's been a lot of discussion in the corridors, on Twitter, and so on about the metaphors used in this conference. And I think this is very important for the public. We seem to have settled on 'editing' for this summit, and I can't work out why we sometimes say gene and why we sometimes say genome, but I hear both from scientists. We sometimes hear genetic modification, sometimes GMOs, usually in the context of crops. Recombinant DNA, gene surgery, gene therapy, all of these words, all of these expressions are used. What's the difference among them? What are the stakes?

What I would urge is that we don't pick one over the other just to avoid associations with that term. That carries the risk of the adult stem cell phenomenon (think Planned Parenthood) where people were astonished to find out that fetal cells were considered to be adult cells in the context of adult stem cell research, where 'adult' means 'somatic' cells; everyday people, including most social scientists, see 'adult' as being a life course stage.

2. A second critical point is to understand and agree **which kinds of genome editing are germline** (rather than somatic). If embryos are edited but not implanted, it's not

germline editing.  Is that right?  *If so, that would mean that someone opposed to germline editing could still accept editing of human embryos that are not implanted.*

Also, presumably, if gametes or gamete precursor cells are edited and then at any time later used for reproduction, *it is germline gene editing even though there wasn't any editing of any embryos involved*.  This may be completely obvious to all the scientists in the audience, but I think it's really helpful to explain to the rest of us.

If pluripotent stem cells were derived, edited, and then used for reproduction, presumably then it would also be germline editing.  So being clear on the subtleties of somatic versus germline genome editing would be very helpful.

3. Some of the things that I'm about to talk about have come up today, but I wanted to talk next from a social science point of view about some of the **missing debates and constituencies** at this meeting.  I want to start by saying that the organizers worked incredibly hard to a very impressive effect to attend to a lot of these issues, but what ends up happening often reflects underlying social problems, not a lack of desire or will.

**Disability**. As Ruha Benjamin talked about this morning, disability perspectives were largely missing until that point. To be fair, Gregor Wolbring and Tom Shakespeare were invited but were unable to attend; luckily their perspectives were recently published in *Nature*. I'll just echo the disability justice position that "nothing about us without us" is a great place to start for all conversations about deselection, cures, and the medical model of disability.

**Race.** Critical race perspectives again came up this morning with Catherine Bliss's presentation.  Scholars have shown that modern science has been implicated with race and racialization from science's inception to the present day, and at the moment in the United States, for example, any question about how to govern a threshold technology that will affect us all should not be able to proceed without indigenous voices, African American voices, Latino voices, and migrant voices—especially this year.

**Gender.**  At this summit, you'd be forgiven for thinking at times that men are from Mars and women are from Venus despite the amazing women scientists at the heart of genome editing advances and all the excellent speakers we've had.  I hate the expression that men are from Mars and women are from Venus.  All genders want to go to Pluto obviously.  But we really just need to get this done.  We need to pay attention and make sure we don't, for example, have panels on embryos and fertility as we had yesterday—even though every speaker was wonderful—that have no women on them.

**Queer bioethics** is a thriving field that is another site for how to think about things that were considered at one time or another to be medical disorders that needed correcting, needed to be subject to eugenic deselection, that we currently don't think of as medical conditions at all.  Also, it's a wonderful site to think about the use of medicine in creative ways. Presumably somatic gene editing could be used in ways for self-expression, for non-normative purposes, and in ways that are outside of the 'pro-cures' biomedical frame.

**Health disparities.**  What kind of health care system a country has and who has access to the fruits of what research should frame all debates in this area, as it should in all areas of health policy.

**Commercialization**.  It's really important that we do translational science, that we get things to the market, that there's uptake of innovation. But what impact do intellectual property disputes and the investment landscape have on the field and on our views of what's acceptable?

**Cross-border care and medical tourism**.  We know from our work on reproductive technologies and stem cell therapies that new repro-genetic technologies with pricing and ethical regulatory differentials from one country to another set up all kinds of sending and receiving pressures that can become problems in and of themselves.

**Bioart and biohacking**.  What are the creative and democratic potentials of these techniques? I'd like to think for all kinds of reasons to do with gender and other things that it's not just two boys in a garage, but that there are all kinds of spaces where we can do creative work that's artistic and disruptive.

**Biosecurity**. Are the very real national security biosecurity risks of genome editing exaggerated for citizen use of these technologies? Are citizen inventions benign because they're just headed to high street commercialization of these technologies?  Will it be like hair salons for each bit of somatic gene editing?  Or will citizen uses of human genome editing be something more impressive and more important to the cultural archive of our nations?

**Other species.**  What can we learn from genome editing that happens naturally within and between other species including between ourselves and our microbiomes?  The rest of us don't know enough about this.  It would be really helpful to keep reminding us about what happens normally.  What kinds of mutations?  How much exchange between genomes happens 'naturally'?  Should this make us worry less about germline editing in humans?

Is gene editing the right threshold for moving to in vitro models and away from animal models for human health research?  That's a task that also needs to get done and this might be the scientific moment to come together on it.

**Consensus?**  There's a lot of variation in opinions, and to some extent you can predict views by the countries that people come from and the disciplinary perspectives they have. Empirical anthropological, sociological, and historical studies of science and technology have shown us that different countries think about and regulate and tolerate and contest biotech among themselves and with transnational others in different but characteristic ways that reflect the very nature of their governance, their histories, and their biopolitics. We learned again in the past couple of days that one's discipline and life commitments and experiences make a huge difference to one's views even within each of these differing bio-constitutions and jurisdictions.

How much does consensus matter and at which levels?  Is it important for us to convince one another, or is it completely fine for us 'just' to hear one another? How would we

know we had heard one another, and how would that get put in to any kind of resulting legislation and regulation?

**Next steps.** There are a couple of things we already know are needed in this area as this initiative goes forward. *Bring in missing conversations.* I've talked about ones in my neck of the woods. I'm sure there are many others.

I would also argue that we really need to *look beyond the stakeholder model.* Stakeholders have identifiable interests, but all people have genomes and are part of this collective inheritance and are affected by what we do in terms of science policy and health policy. So if we have only stakeholders as citizen representatives on our panels, we miss a massive constituency.

*Be explicit and purposive about things we care about that might be at stake with these technologies, such as inclusion or selection of traits, and set up regular points and mechanisms to assess how the field is doing on these things.* Have a committee of people of disability justice activists who come in as scholars and say where it's going. Are we seeing a drift from clearly medical conditions to things that are much more ambiguous, and is that acceptable? Are we working on discrimination as much as we're working on cures and care?

And finally, when the charismatic megafauna in our field get together—the important people—*what are the jobs that a group of assembled experts can do, and what are the jobs that we need to say, 'hang on, this is something we can't do*; this is something for which we need all kinds of other representation in the room, and we must reconvene with other people at another place, at another time'.