

# **Governance, Regulation, and Control:** **Of Which People, By Which People,** **For Which People?**

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# Consensus on Human Germline Editing?

- **Yes** perspectives I heard, from most to least permissive:
  - Edit the human germline genome if it is no more risky than “natural” sexual reproduction and you want to get rid of disease
  - Edit the human germline genome if it is likely to be safe, effective and make a big difference, e.g. for monogenic / oligogenic serious conditions
  - Edit the human germline genome only if there are no other alternatives such as PGD to avoid a serious condition, e.g. both genetic parents homozygous for same serious condition
  - Editing the human germline genome likely to happen because it fits pronatalist, genetic screening friendly, pro-medicine ethos and subsidies of nation (Israel)

# Consensus on Human Germline Editing?

- **No** perspectives I heard, from most to least permissive:
  - Hold off (moratorium) on editing human germline genome for implantation while we work out technical issues of safety, efficacy, delivery, etc
  - Hold off (moratorium) on editing human germline genome for implantation at least until we (re)frame vital debates and learn to listen to and incorporate ideas of other stakeholders and non-stakeholders, future generations, vulnerable, other species etc
  - Ban editing of human germline genome because it is a reasonable line to draw against hubris, eugenics, possible ecological and other harms
  - Ban editing of human germline genome because of the moral status of the embryo / human dignity

# In the interests of understanding, 1: Metaphors

*Does the central metaphor matter?*

Gene/genome editing?

Genetic modification/GMOs?

Recombinant DNA?

Gene surgery?

Gene therapy?

What's the difference and what are the stakes?

Don't pick one over the other just to avoid  
critique: risk of the “adult stem cell” phenomenon

# In the interests of understanding, 2:

## What genome editing is germline?

- If embryos are edited but not implanted, not germline editing (e.g. non-viable or deselected embryos from ARTS), so one position draws line at implantation
- If gametes or gamete precursor cells are edited then used for reproduction, it is germline, even if embryo not edited
- If pluripotent stem cells were derived, edited and then used for reproduction, it would be germline
- etc

# Some missing Debates + Constituencies, 1

Nb organizers worked hard on all the matters that follow; they reflect underlying social problems not lack of desire or will

- **Disability perspectives:** Gregor Wolbring (nb was unfortunately not able to attend, though invited) and Tom Shakespeare in this week's *Nature*
- *Nothing About Us Without Us* is a great place to start all conversations about deselection / cures / medical model
- **Critical race perspectives:** scholars have shown that modern science has been imbricated with race and racializations from science's inception to the present day
- E.g. in the United States, a conversation about how to govern a threshold technology that will effect us all should not be able to proceed without indigenous voices, African American voices, Latino, and other migrant voices, especially this year, right now #BlackLivesMatter #NativeLivesMatter

# Missing Debates + Constituencies, 2

- **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 every speaker has been great)
- But actually, #AllGendersWanttogotoPluto let's get this done
- **Queer bioethics:** question whether or not what we currently think is a medical condition that needs curing really is; experiment to see whether human (somatic) gene editing could be used for creative, non-normative purposes outside biomedical frame

# Missing Debates + Constituencies, 3

- **Health disparities:** what kind of health care system a country has and who has access to the fruits of what research should frame debate
- **Commercialization:** what impact does the intellectual property and investment landscape have on the field and our views of what is acceptable?
- **Cross-border care, medical tourism:** we know from our work on reproductive technologies and stem cell therapies that new reprogenetic technologies with pricing and ethical-regulatory differentials set up all kinds of sending and receiving pressures that can become problems in themselves



# Missing Debates + Constituencies, 2

- **Bioart and biohacking:** what are the creative and democratic potentials of these techniques, given genome editing is now relatively affordable and efficient? Are the biosecurity risks exaggerated? Will they bring us high street healthcare or community empowerment?
- **Other species:** what can we learn from genome editing that happens “naturally”, within and between other species, including ourselves and our microbiomes? Should this make us worry less about germline editing in humans? Is gene editing the right threshold for moving to in-vivo-ized in vitro models, and away from animal models for human health research?

# How much variation in practice and regulation is ok?

- Empirical STS, 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, characteristic ways that reflect the very nature of their governance, history, and biopolitics
- We learned again the last 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 "bioconstitutions"
- How much does consensus matter, at which levels?

# What do we already know is needed as this NAS initiative goes forward?

- Bring in missing conversations
- Look beyond stakeholders so as to see broader distributive justice and downstream effects
- Be explicit and purposive about things we care about that might be at stake with these technologies, like inclusion or selection of traits, and set up regular points and mechanisms to assess how the field is doing
- When the charismatic megafauna (important people) of the field assemble, what jobs can that group do alone and when do they need others for the job at hand?

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