

Imperatives of Governance:

Pathways for Democratic Deliberation and
the Global Observatory Project

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Some (false) imperatives

I.

Science first,
ethics second

(if its not already too late...)

“the unthinkable has become conceivable...Now we must face the questions that arise: how, if at all, do we as a society want to use this capability?”

- David Baltimore, December, 2015

Science → Technology → Society

“There has been a line drawn by many that says...you should refrain. That was mostly because there was no way of considering how to do that at all...so nobody was arguing that it should be done.”

--Richard Hynes, NASEM *Human Genome Editing* committee co-chair, February, 2017

“new era of fundamental danger triggered by the rapid growth of genetic engineering...[raises the question of] the fundamental nature of human life and the dignity and worth of the individual human being.”

(Letter to Carter Administration, General Secretaries of the National Council of Churches, the Synagogue Council of America, and the United States Catholic Conference, 1980)



COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

Convention on Human Rights and Biomedicine (1997) ("Oviedo Convention")

Article 13 – Interventions on the human genome

An intervention seeking to modify the human genome may only be undertaken...if its aim is not to introduce any modification in the genome of any descendants.

Article 18.2 – Research on embryos *in vitro*

The creation of human embryos for research purposes is prohibited.

“germline editing is going to happen, and to think otherwise is naïve...”

-- 2015 statement made by a member of the *International Commission on the Clinical Use of Human Germline Genome Editing*

II.

Science races ahead, society lags behind

Rogue Scientist Says Another Crispr Pregnancy Is Underway

Chinese researcher He Jiankui, who earlier claimed to have gene-edited twin baby girls, now says there's another pregnancy with a Crispr'd embryo.



Responsible	Rogue
The Community	Outlaw Science
Us	Them





Ät dem som har gjort
mänskligheten den största nytta
Nobels testamente

Nobel församlingen
Karolinska Institutet
har beslutat att 2010 års

NOBELPRIS

i fysiologi eller medicin
skall tillerkännas

Robert G. Edwards

för utvecklingen av
in vitro-fertilisering

ÅRSPÅRSEDNINGEN 10 DECEMBER 2010

Robert G. Edwards



Ulla Löfdahl

“...as is always the case, the speed at which the science is advancing outpaces society’s ability to grasp its implications.”

--Marcia McNutt,
President, National Academy of Sciences,
February, 2017

“If we are waiting for society to reach a consensus...its never going to happen...But once one or a couple of scientists make first kid, its safe, healthy, then the entire society including science, ethics, law, will be accelerated. Speed up and make new rules...So, I break the glass...”

He Jiankui (Interview with Ben Hurlbut, December 26, 2018)

“[The famous scientist] told me, ‘Don’t worry about the ethics, in five years, ten years, everything will change.’”

He Jiankui (Interview with Ben Hurlbut, December 26, 2018)

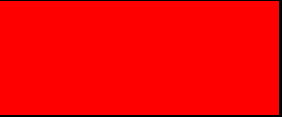
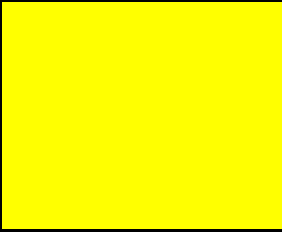
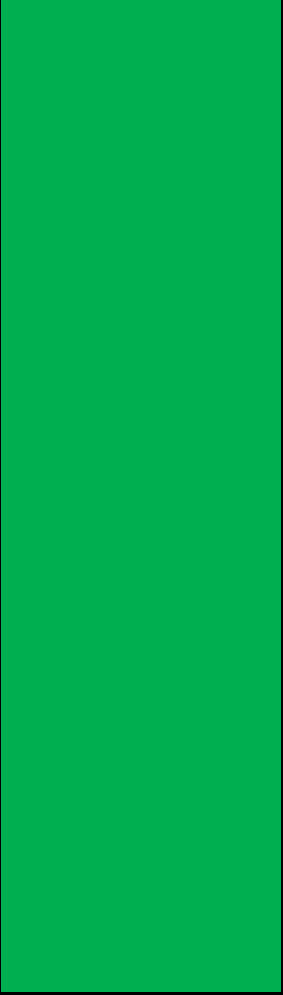


When you see something that is technically sweet, you go ahead and do it, and you argue about what to do about it only after you have had your technical success.

J. Robert Oppenheimer on the Hydrogen bomb, 1954

“defined genetic improvement of man” is a means
“to carry on and consciously perfect” the human
species.

(Robert Sinsheimer 1969)



III.

Once the line has been crossed,
there is no going back...

Wake-up call from Hong Kong

The Second International Summit on Human Genome Editing, held in Hong Kong last month, was rocked by the revelation from a researcher from Shenzhen that twins whose embryonic genomes had been edited to be resistant to HIV. Despite warnings by the summit organizers, scientific academies, and prominent researchers, such research was “deeply undesirable,” and the launch of an international convention by the researcher’s actions, it is apparent that the use of CRISPR-Cas9 to edit the human genome has outpaced nascent efforts by the scientific and medical communities to confront the complex ethical and governance issues that they raise. The current guidelines and principles on human germline genome editing

To maintain the public’s trust that someday genome editing will be able to treat or prevent disease, the research community needs to take steps now to demonstrate that it can be applied with confidence. Unfortunately, it is clear that Hong Kong might not be able to protect human lives as well as



It will not suffice. We must ensure that the system that would enable us to prevent cases of research not conforming to established principles or The Second International Summit organizers called for establishing a global international forum for human genome editing. It should provide such a forum along with other

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“We need...broad agreement on...criteria for human germline genome editing research...”



INTERNATIONAL COMMISSION ON THE
CLINICAL USE OF HUMAN GERMLINE GENOME EDITING

“A translational pathway to germline editing...”

Statement by the Organizing Committee of the
Second International Summit on Human Genome Editing,
November 29, 2018

SPL



Embryos cultured as part of *in vitro* fertilization can be screened for genetic diseases.

Adopt a moratorium on heritable genome editing

Eric Lander, Françoise Baylis, Feng Zhang, Emmanuelle Charpentier, Paul Berg and specialists from seven countries call for an international governance framework.

With a science that's moving forward as rapidly as this science is, you want to be able to adapt to new discoveries, new opportunities and new understandings. **To make rules is probably not a good idea.**

--David Baltimore (Chair, 2015 and 2018 International Summits on Genome Editing), April, 2019.

US science academies take on human-genome editing

National Academy of Sciences and National Academy of Medicine to develop guidelines for rapidly advancing technology to modify human embryos and germ cells.

Sara Reardon

18 May 2015



Print

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The 1975 Asilomar conference helped set rules for research on DNA.



Sen. Ted Kennedy (D-MA)

“The factors under consideration [at Asilomar] extend far beyond [the scientists’] technical competence. In fact they were making public policy. And they were making it in private.”



COUNCIL OF EUROPE CONSEIL DE L'EUROPE

Convention on Human Rights and Biomedicine (1997) ("Oviedo Convention")

Article 28 – Public debate

Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion ...



Imperatives of Governance

- Science is— and must be— in the service of society. (Self-governing science is rogue science.)
- The question of whether research should progress— and what counts as progress— is for We the People to decide.
- We must look beyond the narrow scope of a given technology to imaginations of purpose, progress and perfectibility that animate it.
- At stake are the ways we as a human community guide and govern our technological futures.

The Global Observatory Project



A global observatory for gene editing

Sheila Jasanoff and J. Benjamin Hurlbut call for an international network of scholars and organizations to support a new kind of conversation.

- ***Collect:*** more perspectives
 - Clearinghouse for deliberative and governance activities.
- ***Analyze:*** foundations of thought
 - Not just what is treated differently, but how and why?
- ***Convene:*** excluded and occluded voices
 - Not only science
 - Not only professional ethics
 - Not only “stakeholders”
 - Not only secular perspectives

- *Question progress:* What is going unasked? Who is setting the terms of debate? How are stakes and stakeholders designated, and by whom?
- *Humility in Diversity:* International, interdisciplinary, and cross-sectoral dialogue among communities not normally in a position to encounter each others' perspectives within existing institutions.
- *Consensus through Critique and Dissent:* Global dialogue, expanding cross-cultural awareness, and laying foundations for a cosmopolitan bioethics.

What is the purpose of this technology?

“In selecting this type of experiment we were never misled. It was a form of compromise. The object of the compromise was society, and one could even say with the whole world. As an AIDS sufferer and family member, we firmly and deeply know that it is possible to use a preventative drug to have a healthy child...That drug can cure disease, but it cannot cure prejudice...

For everyone who is listening, please hear this. At a certain level our participation in the experiment was indeed forced, but we weren't coerced by any person in particular. We were coerced by society.”

Thanks!

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