Imperatives of Governance:
Pathways for Democratic Deliberation and the Global Observatory Project

J. Benjamin Hurlbut
School of Life Sciences
Arizona State University
ASGCT Policy Summit
November 6, 2019
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
I understand the concern about where we might go. I’m going to worry about that when I get there.
“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)
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
The Community
Us

Rogue
Outlaw Science
Them
IVF/Louise

LOVELY
LOUISE

BABY OF THE CENTURY

making of Baby Bro...

To Lesley Brown a child is born, safe and sound

A GIRL FOR TEST TUBE MOTHER

Their No. 1 girl is just perfect!

It's the all-British miracle

OVER THE MOON AND BOTH FINE

express

LE BÊBÉ DU SIECLE

Die Retorte der Pandora

The Test-Tube Baby

The miracle miracle

July 25, 1978 — Oldham, Lancs
Nobelpriset
i fysiolologi eller medicin
skall tilldelas...

Robert G. Edwards
för utvecklingen av
in vitro-fertilisering

STOCKHOLM DEN 10 DECEMBER, 2010
“....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 were bryonic genomes had exposure to HIV. Despite the summit organizing scientific academies, prominent such research was “deeply disturbing,” and the launch of an investigation into the researcher’s actions, it is apparent use 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 do not suffice. We must ensure that cases of research not conforming to ethical principles or established for establishing international governance frameworks provide such a framework, along with other.

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

Victor J. Dzau
is the president of the U.S. National Academy of Medicine. vdzau@nas.edu

Marcia McNutt
is president of the U.S. National Academy of Sciences. mmcnutt@nas.edu

Chunli Bai
is president of the Chinese Academy of Sciences. clbai@cas.cn
“A translational pathway to germline editing...”

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

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

Sen. Ted Kennedy (D-MA)
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 mislead. 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!

bhurlbut@asu.edu