Principles for Moving Forward, Lessons from Looking Back

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Which way is forward (and how do we decide)?

“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?”

“the unthinkable has become *actual*…

…Now we must face the questions that arise: how, if at all, do we as a society want to use this capability?”

How did we get here?
(And how can we do better?)

The ways we think and speak about scientific and technological change shapes the ways we guide and govern it.

Self fulfilling prophecy

"germline editing is going to happen,
and to think otherwise is naïve…"

she is...
THE OBSERVER
LOVELY
USE.
BABY OF THE CENTURY
making of Baby Bro
OVER THE MOON
AND BOTH FINE
DAILY EXPRESS
To Lesley Brown
a child is born,
safe and sound
A GIRL FOR TEST TUBE MOTHER
In der Retort gezeugt
TWO MEN WHO BEAT THE WORLD
Their No. 1 girl is just perfect!
Mrs Brown you've got a lovely daughter
It's the all-British miracle
July 25, 1978
Oldham, Lancs
THE TEST-TUBE BABY
The miracle maker
LE BEBE DU SIECLE
Die Retorte der Pandora

Robert Edwards and Patrick Steptoe (1978)

Intra Cytoplasmic Sperm Injection (1991)

Reproduction

World's first baby born from new procedure using DNA of three people

Experts welcome news of successful mitochondrial transfer but caution against operating in countries beyond regulations

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Tuesday 27 September 2016 12.12 EDT

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Save for later

"…where there are no rules…[because] to save lives is the ethical thing to do."

DAILY NEWS 10 October 2016

Exclusive: '3-parent' baby method already used for infertility

Science races ahead,
society [law, ethics] lags behind

"….as is always the case, the speed at which the science is advancing outpaces societies ability to grasp its implications."

“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)

Incremental (Reactive) Bioethics

"I understand the concern about where we might go. I'm going to worry about that when I get there."

Obsolete Norms?

"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."

Governance (of S&T) is a problem of *democratic* governance that depends upon collectively seeing, affirming and regularly revisiting how, why, and to whom *we* delegate authority and responsibility.

…how, if at all, *do we as a society* want to use this capability?”

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.”

"Broad Societal Consensus"

- How broad is broad?
- Who sets the terms of debate?
- Who defines stakes and stakeholders?
- What questions tend to go unasked?

Robust governance requires:

Assessing institutions, not just individual experiments and technologies.

Looking back as well as forward to see patterns, routinized practices, frequently unasked questions.

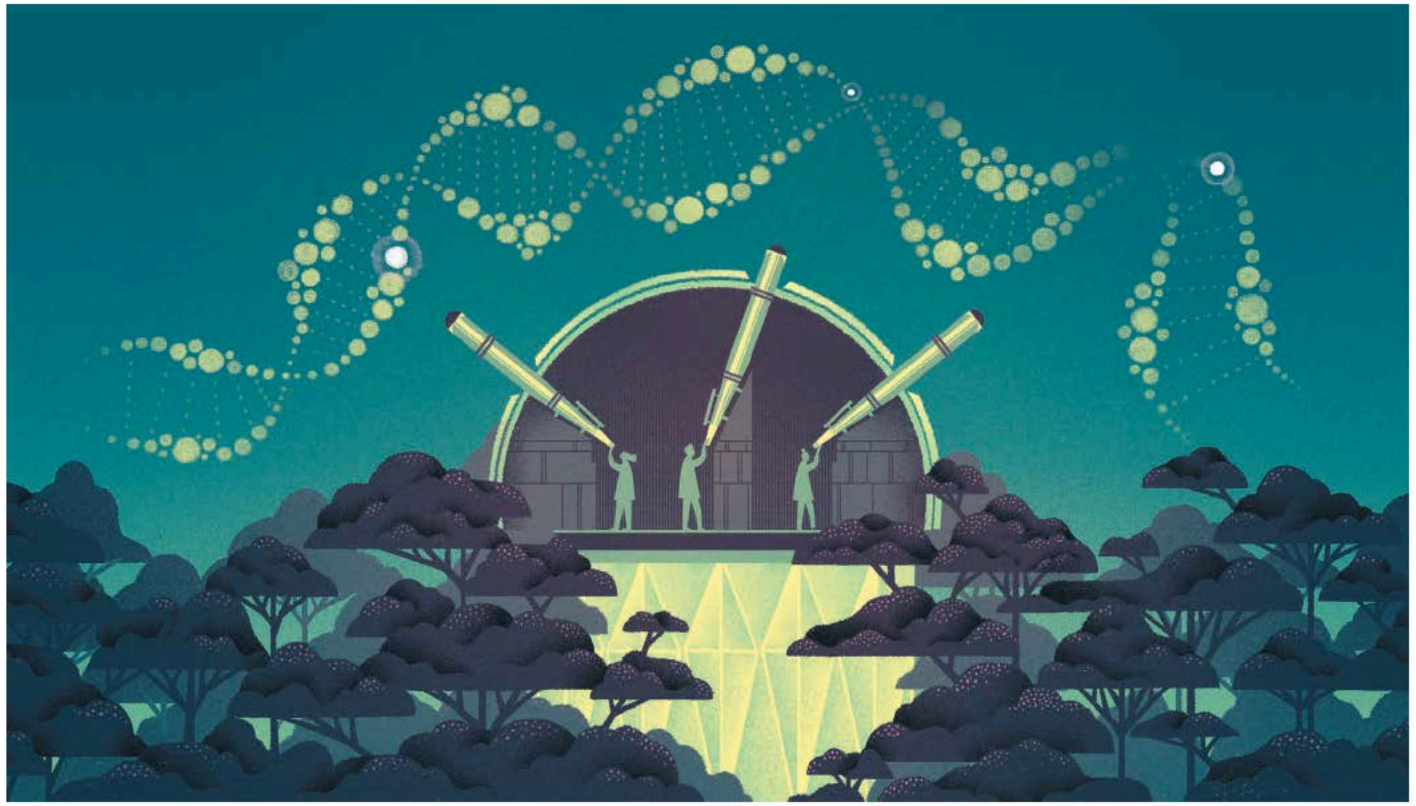
Robust governance requires:

building institutional capacity for inclusive participation, multiple languages, critical reflection, learning, and dissent.
(e.g. by inviting in outsiders to see what insiders cannot)

Ethical responsibility requires asking hard questions *together*, and in ways that inform how science moves forward, rather than merely reacting to where it has gone.

A commitment to ethics must be a commitment to infrastructures of participation and deliberation.

ILLUSTRATION BY MARINA MUUN



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.

Thanks!