

#### Value meets CRISPR

from value regimes of actions-in-context to TA diplomacy

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Karen Kastenhofer





#### **CRISPR** as action-in-context

- no generic appraisal of gene editing technologies (such as "interfering in nature is *per se* bad")
- appraisal in the context of concrete applications within technology assessment
- in media couverage debates in the context of a distinct event, such as the publication of the birth of "the CRISPR/Cas9-babies"





#### Hwang Woo-suk and human cloning in 2004

In 2004 and 2005, Hwang Woo-suk, a professor at Seoul National University, published two separate articles in the journal *Science* claiming to have successfully harvested pluripotent, embryonic stem cells from a cloned human blastocyst using SCNT techniques.

Hwang claimed to have created eleven different patent-specific stem cell lines. This would have been the first major breakthrough in human cloning.

However, in 2006 *Science* retracted both of his articles on clear evidence that much of his data from the experiments was fabricated.

(Wikipedia)



#### Hwang Woo-suk and human cloning in 2004





Healthy culture: Koreans support stem-cell research, say Shin Yong Moon (left) and Woo Suk Hwang.

#### **Cloning success marks Asian nations as scientific tigers**

While lauding the advance, some at the AAAS meeting said that the pace of human therapeutic cloning research in Asia and elsewhere threatens to leave US scientists stranded, as they cannot get federal funds to derive stem cells from human embryos.

But some US biologists say that they can contribute to the field by collaborating with researchers in South Korea, Britain and other countries where the work is supported. "We should behave in a complementary manner," says Gerald Schatten, who studies primate cloning at the University of Pittsburgh. "We don't have to do everything in every country."

#### Pearson (2004) Nature 427, 664

# THE LEGAL LANDSCAPE

A 2016 survey in *Science* examined existing laws (legislation) and documented policies (regulation) that explicitly govern gene editing or might be applied to such activities. The survey labelled countries as restrictive, permissive or something in between. But specialists disagree over whether rules in some nations might be intepreted to permit gene editing.



R. Isasi et al. Science 351, 337-339 (2016)



### He Jiankui and human genome editing in 2018





A Chinese scientist claims that twin girls have been born whose genomes were edited at the embryo stage.

GENOMICS

# International outcry over genome-edited baby claim

The revelation from a Chinese scientist represents a controversial leap in genome editing.

Scientists are shocked and outraged by reports that a Chinese scientist claims to have helped make the world's first genome-edited babies — twin girls, who were born this month.

He Jiankui, a genome-editing researcher at the Southern University of Science and Technology of China in Shenzhen, says that he impregnated a woman with embryos that had been edited to disable the genetic pathway HIV uses to infect cells.





#### He Jiankui and human genome editing in 2018

"As representatives of the Committee of Genome Editing of the Genetics Society of China and of the Chinese Society for Stem Cell Research, we were shocked by He Jiankui's claims last month that twin girls were born from embryos that were gene-edited for HIV resistance (*Nature* 563, 607–608; 2018). Such work would violate the current code of conduct from China's ministry of health, as well as internationally accepted ethical guidelines.

The consensus of **the international scientific community**, including Chinese researchers in genome editing, is that engineering the human germline for reproductive purposes should be forbidden until the scientific issues have been resolved and there is broad social agreement. **China has clear regulations** specifying that human embryos with genetic modifications cannot be implanted, in agreement with **regulations adopted worldwide**."

(Wensheng Wei, 2018, Nature 564, 345)





**Southern University of Science and Technology** said in a statement on 26 November that it was unaware of **He's experiments**, that the work was not performed at the university and that He has been on leave since February.

"The Southern University of Science and Technology requires scientific research to abide by **national laws and regulations** and to respect and comply with **international academic ethics and academic standards**," the statement said. The university says it will set up an independent committee to investigate the matter.

More than **100 Chinese biomedical researchers** have posted a strongly worded statement online condemning **He's claims**. "Directly jumping into human experiments can only be described as crazy," the statement reads. The scientists call on **Chinese authorities** to investigate the case and introduce strict regulations on this procedure.

"This is a huge blow to the international reputation and the development of **Chinese** science, especially in the field of biomedical research," the statement says. "It is extremely unfair to the large majority of diligent and conscientious scientists in China who are pursuing research and innovation while strictly adhering to ethical limits."

(Cyranoski & Ledford, 2018, Nature **563**, 607-608)





# CRISPR germline engineering—the community speaks

Katrine S Bosley, Michael Botchan, Annelien L Bredenoord, Dana Carroll, R Alta Charo, Emmanuelle Charpentier, Ron Cohen, Jacob Corn, Jennifer Doudna, Guoping Feng, Henry T Greely, Rosario Isasi, Weihzi Ji, Jin-Soo Kim, Bartha Knoppers, Edward Lanphier, Jinsong Li, Robin Lovell-Badge, G Steven Martin, Jonathan Moreno, Luigi Naldini, Martin Pera, Anthony CF Perry, J Craig Venter, Feng Zhang & Qi Zhou

*Nature Biotechnology* asks selected members of the international community to comment on the ethical issues raised by the prospect of CRISPR-Cas9 engineering of the human germline.

Bosley et al. (2015) Nature Biotechnology 33, 478–486





# **Science diplomacy**

"the use of scientific collaborations among nations to address the common problems facing 21<sup>st</sup> century humanity and to build constructive international partnership" (Fedoroff 2009)

Royal Society / American Association for the Advancement of Science (2010):

- Science in diplomacy
- Diplomacy for science
- Science for diplomacy

**'polylateral diplomacy':** state + nonstate institutions (Kaltofen & Acuto 2018)

'para-diplomacy': conduct of international relations between subnational entities (ibid.)

"empirical inquiries on the practices of relating science, politics, and other forms of knowledge, actors and practices to each other" (Buerger 2014)

science: neutral, flexible, faster





**CRISPR as distinct case**: use of a scientific community across nations to address common / local problems raised by technoscience itself

- reflexive constellation (Beck / reflexive modernity)
- involved parties:
  - the international scientific community, international academic ethics and academic standards
  - national laws and regulations, 'Chinese science', Chinese authorities
  - individual gung-ho scientists, individual scientific institutions





#### Blurred boundaries, shifting paradigms, fluid and hybrid constellations

- merger of science and technology (technoscience)
- orientation towards innovation and international competition (triple helix)
- shifting centre of action in technoscience: Europe -> US -> Asia
- doing boundaries, identities and paradigms gains importance and adds to 'constitutional' models of modern differentiation

(fluid modernity, Bauman)





Doing boundaries, identities and paradigms via an ,international scientific community' (Bosley et al. 2015)

- letter to Science with 18 signers (query for an "open discourse", "unparalleled potential for modifying human and non-h genomes", "unknown risks to human health and well-being")
- **50 researchers, ethicists and business leaders** in the "global community" contacted by *Nature Biotechnology* to comment on issues raised by CRISPR (the scientific community "sees the implications", "has a stake in getting this right", "has a responsibility both to find the right way to realize the potential of this powerful technology and also to do it in a way that is highly ethical"





- CRISPR as powerful technology with potential (& science-fiction scenarios)
- technical barriers (unsolvable / solvable soon or late), knowledge (vast/incomplete)
- ethical, health, environmental concerns, soft and hard impacts
- Asia as an economic and scientific powerhouse
- (dis)trust in science, openness, transparency, technological culture
- the self-correcting quality of science and open society
- a behind-the-scenes race
- garage biology and "responsible (and educated) scientists", scientific societies
- the wholly voluntary nature of the handling of the ongoing controversy
- regulation & control (impossible / necessary)
- an Asilomar-type conference (yes / no)
- some countries leading the way, "isolated national initiatives"
- temporary moratorium, public discussion, develop clear guidelines
- European Convention for the Protection of Human Rights and Dignity of the Human Being, UK Human Fertilization and Embryology Act, UNESCO's International Bioethics Commission
- the ominous ,we' and ,I' ("I, and perhaps society at large")





# Science diplomacy & CRISPR: what's new?

- (P)TA traditionally oriented towards technology (within a given national context)
- Science and technology studies traditionally focus on technoscientific systems
- Science diplomacy as reference point allows for
  - an additional focus on nation states and international relations
  - treating technoscientific and diplomatic practices as equally important
  - acknowledging hybrid (technoscientific-diplomatic) practices





#### Thank you for your attention!

Contact:

Dr. Karen Kastenhofer A-1030 Vienna, Strohgasse 45/5 Tel: +43 (1) 51581 6580 Fax: +43 (1) 7109883 Email: <u>kkast@oeaw.ac.at</u> WWW: <u>www.oeaw.ac.at/ita</u>