NUS National University of Singapore
Centre for Biomedical Ethics
Yong Loo Lin School of Medicine

2nd International Genome Summit on Human Genome Editing

Governmental Actions and Advisory Opinions Regarding Human Genome Editing

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Genome editing in Singapore

- **Scientific research**
  - Limited applications in food/crop science
  - Disease modelling with iPSCs
  - Synthetic biology
  - Autologous GE-HSC therapy

CRISPR – Embryo Research?

Genome editing in Singapore

- **Genetic Modification Advisory Committee (GMAC)**
  - **Non-binding guidance**
    - Biosafety Guidelines for Research on GMOs
      - Experiments involving the construction and/or propagation of biological entities which have been made by genetic manipulation and are of a novel genotype and which are unlikely to occur naturally or which could cause public health or environmental hazards.
      - Importation of GMOs and/or GMO-derived products for research purposes.
    - Guidelines on the Release of Agriculture-related GMOs
      - Assessment of risks of agriculture-related GMOs to human health and the environment;
      - Approval mechanisms for their release in Singapore
  - **No specific guidance for CRISPR-Cas9**
    - Necessary?

Genome editing in Singapore

- **Centre for Biomedical Ethics, National University of Singapore**
  - **Ethical Framework for Genome Modifying Technologies (GMTs)**
    - Science, Health and Policy-relevant Ethics in Singapore (SHAPES)
      - National Medical Research Council Funding Initiative
    - Convening a Working Group of local and international experts
      - Identity substantive and procedural values that should guide GMTs
      - Symposium in April 2019
      - Framework released in 2020

SHAPES

An NUS Centre for Biomedical Ethics initiative supported by the Singapore Ministry of Health's National Medical Research Council

Human Genome Organisation (HUGO)

- **Committee for Ethics, Law and Society (CELS)**
  - Benjamin Capps (Chair)
  - Tamra Lysaght (Vice-Chair)
  - Yann Joly
  - Catherine Mills
  - John Mulvihill
  - Hub Swart
  - Edison T. Liu (Ex-officio)
  - Ruth Chadwick (Ex-officio)

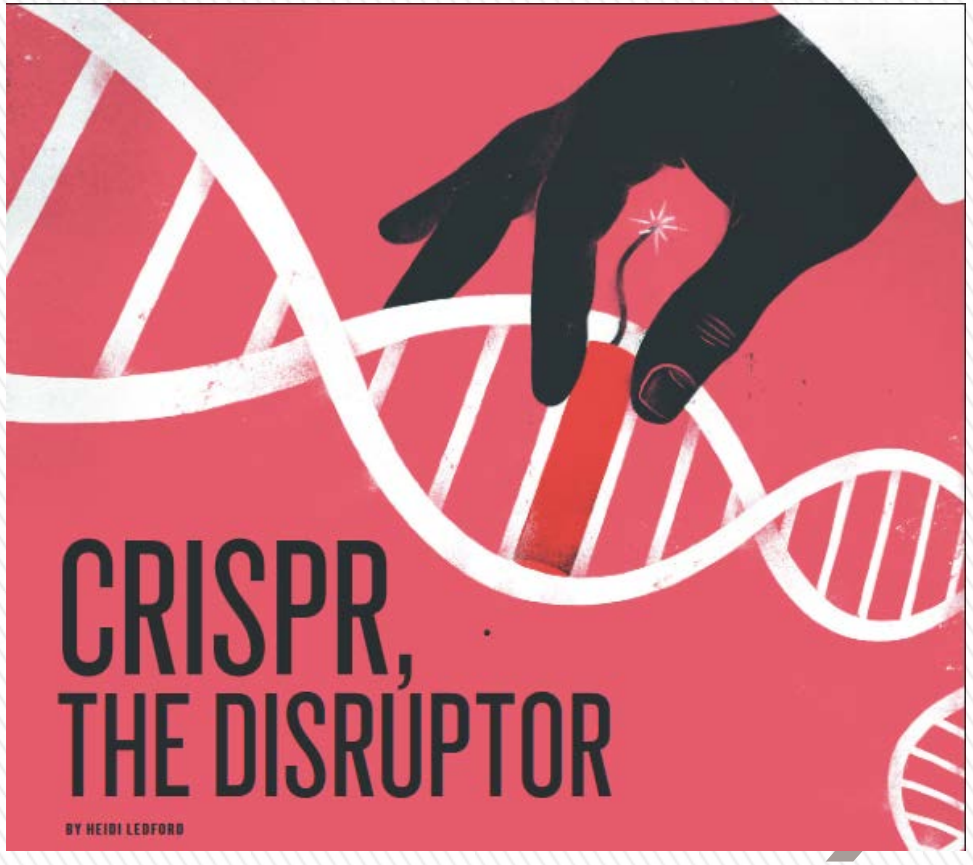
Ethical values in GMTs

- **Ethical issues of CRISPR technology and Gene Editing**
  - **International Summit on Human Genome Editing 2015**
    - Agrees with summary statement
      - *It would be irresponsible to proceed with any clinical use of germline editing until:*
        - *the relevant safety and efficacy issues have been resolved, based on appropriate understanding and balancing of risks, potential benefits, and alternatives, and*
        - *there is broad societal consensus about the appropriateness of the proposed application.*
    - Supports a moratorium on experiments aimed toward germ cell mutations
      - Not just safety; misuses of technology (e.g. eugenics)
      - Sharing the benefits widely, not just to a few

Mulvihill et al. (2017) British Medical Bulletin 122(1):17-29

Ethical values in GMTs

- **If CRISPR will change the world..**
  - **Align the technology with our values**
- **Fairness & Equality**
  - **Sharing the benefits with all**
    - Ensuring everyone has access to health benefits, not just the wealthy who can afford it
    - Affordable and widely accessible applications
  - **Avoid making existing inequalities and injustices worse**



Ledford 2015, Nature 522: 20-24

Responsible genome editing

- **Anticipatory governance of gene editing technologies**
  - **Responsible research and innovation (RRI)**
    - Aimed at shaping emergent science-based technologies to deliver outcomes that are socially acceptable and morally justifiable while it is still possible to do so
  - **Opportunities to shape outcomes from GMTs are narrowing**
    - Need to reflect on the world we want to create for future generations
      - Carrying the benefits and burdens of decisions made in the present
    - Need for normative principles and values to guide futures with GMTs
      - Informed by deliberative democratic processes of participation, inclusion & reflexivity

Acknowledgements

- **References**
  - Ledford, H. (2015). "CRISPR, the disruptor." Nature 522(7554): 20-24.
  - Mulvihill, J. J., B. Capps, Y. Joly, T. Lysaght, H. A. E. Zwart and R. Chadwick (2017). "Ethical issues of CRISPR technology and gene editing through the lens of solidarity." British Medical Bulletin 122(1): 17-29.

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