CUHK Centre for Bioethics
The Chinese University of Hong Kong
香港中文大學生命倫理學中心

HUMAN GENOME EDITING AT THE INTERSECTION OF PREVENTION AND ENHANCEMENT

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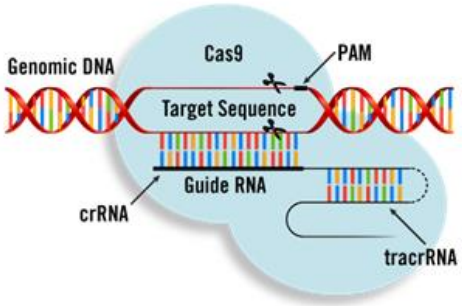
Plan of the talk

- (1) Human genome editing (HGE) and the treatment-enhancement-distinction (TED)
- (2) Challenges to the TED as a guide for regulating HGE
- (3) Policy implications

1. HUMAN GENOME EDITING (HGE) AND THE TREATMENT-ENHANCEMENT DISTINCTION (TED)

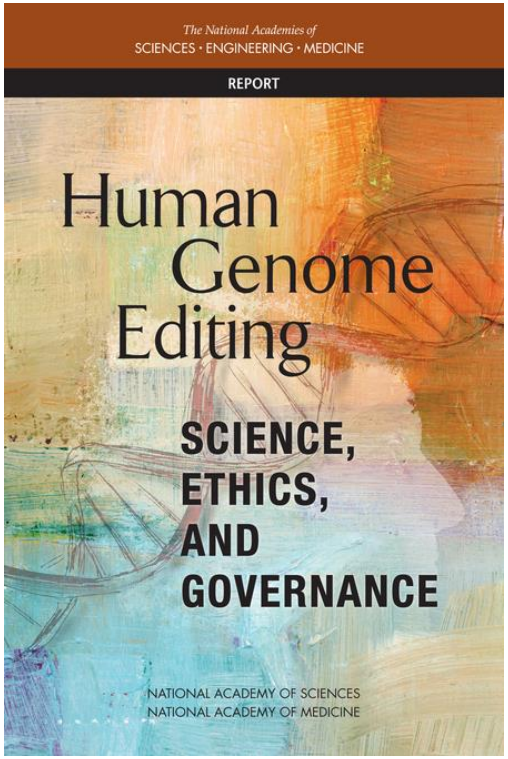
The TED as an ethical line for regulation



- Possible uses of HGE:
  - Somatic vs germline
  - Therapy vs enhancement
- Common assumptions about therapies vs enhancements:
  - Enhancement interventions ethically more problematic than therapeutic ones
  - Risk-benefit ratio (RBR) of enhancements worse than that of treatments
  - Social benefits of enhancements less clear

The TED as an ethical line for regulation: a recent example

- **"RECOMMENDATION 6-1. Regulatory agencies should not at this time authorize clinical trials of somatic or germline genome editing for purposes other than treatment or prevention of disease or disability"** (National Academies of Sciences and Medicine, 2017, p. 123)



The many formulations of the TED

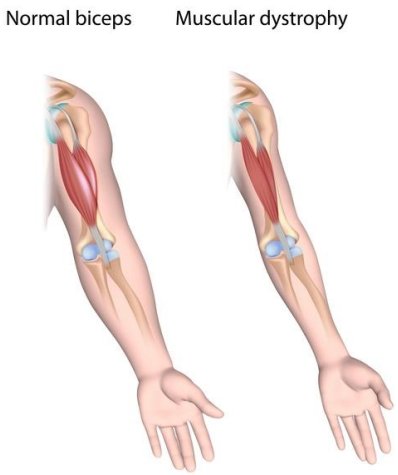
- Too many to mention them all here
- My personal favorite:
- Therapies: biomedical interventions that improve human traits or performance in way that (a) achieves/restores health (treatment) or (b) preserves health (prevention)
- Enhancements: improvements of healthy or “normal” human traits/performance (cf. Daniels, 2000)

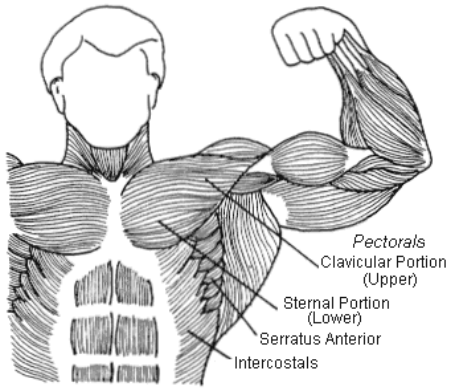
2. CHALLENGES TO THE TED AS A GUIDE FOR REGULATING HGE

Using somatic HGE (CRISPR/Cas9) to reverse human aging

- George Church: animal trials already under way, human trials coming soon
- Procedure would arguably involve *both* treatment and enhancement (Erler, 2017)
- How does TED-centred policy deal with such cases?
- 1st possibility: “purpose” = enhancement, so trials impermissible
- 2nd possibility: “purpose” = therapy (prevention), so trials are ok

Does therapeutic purpose = green light?





- Consider f. ex:
- Replacing genetic variant predisposing to muscular dystrophy with “optimal” one for muscle growth
- Other, structurally similar examples possible
- “Therapeutic defense” risks opening floodgates to enhancement uses of HGE
- Distinguish between uses where enhancement necessary counterpart of therapy, and those where it’s not?

3. POLICY IMPLICATIONS

What should we conclude?

- Either:
- (1) Rule out all forms of HGE (including therapeutic ones) with enhancing effects
- (2) Clinical trials of somatic HGE with enhancement effects can be ok now if these effects are necessary counterpart of therapeutic benefits; otherwise not
- (2) is preferable to (1)
- Ultimately, desirable to judge each instance of HGE with enhancing effects on its own merits, based on expected benefits & risks

What about risk?

- Main concern about enhancement uses of HGE might relate to risk
- But research projects like Church's suggest RBR of such uses need not be poor
- More discussion needed about what constitutes acceptable RBR when it comes to such uses:
  - US report recommends only editing in "versions that are prevalent in the population and are known to be associated with ordinary health"
  - Seems to err on side of caution – but too much caution

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THANK YOU!

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