



# Human Genome Editing: The way forward?

2<sup>nd</sup> International Human Genome Editing Summit  
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# What are principles for?

- How do we make meaningful use of principles?
- How to go from principles to actions / decisions?
- Do we need (& can we define) a universal set of principles?
- Can we have common principles but different regulatory outcomes?
- Less about substantive principles, more about process?



# Engagement into governance?

“active engagement with a wide range of stakeholders...” (UK funders’ statement, 2015)

“meaningful and substantial public engagement... [Decisions] should be made through inclusive, deliberative processes...” (Hinxton, 2015)

“a comparison of the different visions of desirable future states of affairs and narratives... feeding back into a public discourse informing governance” (Nuffield, 2016)

“... transparent and inclusive public policy debates... [and] broad participation and input by the public... are particularly critical conditions...” (NASEM, 2017)

“broad, inclusive societal debate” (Nuffield, 2018)

- *How* should publics participate in policy discourses? *What* constitutes meaningful engagement?
- From local to global engagement:
  - Different social, cultural, political contexts; expectations
  - What assumptions are we embedding?

# Ethics into policy

- How are ethically salient concepts negotiated?
- Risk
  - Moral vs physical risk?
  - Who / what is harmed & how?
    - e.g. heritable human genome editing; gene drives & species integrity
  - How should risks be distributed?
    - Somatic vs germline
    - Individual vs population
- Choice
  - “... no alternatives”
  - What constitutes an “alternative”?
    - Context-dependent
    - Reproduction; health; ‘good life’
- Agency & responsibility
  - E.g. informed consent

# Principles into action

- What do we do ~~when~~ ...NOW...?
  - The next steps are crucial
  - How should scientific *communities* respond?
- Multiple ‘publics’; multiple ‘scientific communities’
  - Global politics
  - Local contexts and values
  - Differences of scientific and ethical opinion (e.g. acceptable risk)
- Disruption to traditional modes of knowledge production and innovation
  - What counts as ‘(good) science’?
  - Who is allowed to be a knowledge producer?
  - Modes of action with respect to science: participants, patients, ... consumers?



# Thank you!



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