HUMAN GENOME EDITING: SCIENCE, ETHICS, AND GOVERNANCE

OVERSIGHT AND USE OF HUMAN GENE EDITING

SUMMARY OF RECOMMENDATIONS

Global Principles for Research and Clinical Use

Consider and apply the global processes in governance of human gene editing (2.1)

- Promoting Well-Being
- Transparency
- Due Care
- Responsible Science
- Respect for Persons
- Fairness
- Transnational Cooperation

Basic Laboratory Research

Use existing regulatory processes to oversee human genome editing laboratory research (3.1)

Somatic Genome Editing

Use existing regulatory processes for human gene therapy to oversee somatic human genome editing research and uses (4.1)

Limit clinical trials or therapies to treatment and prevention of disease or disability at this time (4.2) Evaluate safety and efficacy in the context of risks and benefits of intended use (4.3) Require broad public input prior to extending uses (4.4)

Germline (Heritable) Genome Editing

Permit clinical research trials only for compelling purposes of treating or preventing serious disease or disabilities, and only if there is a stringent oversight system able to limit uses to specified criteria (5.1)

Enhancement

Do not proceed at this time with human genome editing for purposes other than treatment or prevention of disease and disability (6.1)

Encourage public discussion and policy debate with respect to somatic human genome editing for uses other than treatment or prevention of disease and disability (6.2)

Public Engagement

Public input should precede any clinical trials for an extension of human genome editing beyond disease treatment and prevention (7.1)

Ongoing reassessment and public participation should precede any clinical trials of heritable germline editing (7.2)

Incorporate public participation into the human genome editing policy process about "enhancement" (7.3)

When funding genome editing research, consider including research on strategies to improve public engagement (7.4) and for long-term assessment of ethical, legal and social implications of HGE (7.5)

Learn more and download the full report at: nationalacademies.org/gene-editing

