Societal Implications of Emerging Technologies

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The Proposal

1. Continue research on **somatic** gene editing with due oversight and ethical, social, and legal studies

2. Set **Moratorium** on **basic research** for 2 years until end of 2017

The Proposal

3. Secure the internationally existing **ban on germ line gene editing for reproductive purposes** through UN and regional bodies and prepare international binding regulations

PART ONE

Motives of the parties involved in germ line gene editing

Motives of **Researchers**

1. Scientific contribution: TO DO SOMETHING GOOD FOR MANKIND

2. competitive share and/or economic position of research institutes/companies: PATENTS are the currency of scientific value in order to secure the funding for further research

Motives of :
Clinicians

HELP COUPLES TO HAVE AN OWN AND HEALTHY CHILD

INFORMATION AND MEDICAL-ETHICAL COUNCELING

Motives of:
Public Health and Governance Institutions

SET PRIORITIES OF FUNDING; 'PUBLIC/COMMON GOOD'

1. Intrinsic Assessment of goals and methods
2. Extrinsic Assessment of societal needs and public priorities
3. Normative Principles guiding the assessment:
    1. HUMAN RIGHTS (WELLBEING AND FREEDOM) AND
    2. JUSTICE (EQUAL HEALTH RIGHTS OF ALL)

Motives of :
Future Parents

COUPLES ------- Goal: to have an OWN and HEALTHY child

Based on PERSONAL GOALS; LIFE DECISIONS

Motives of:
Social Science & Society

ANALYZE SOCIAL TRANSFORMATIONS

1. Transformations of the Concept of parenthood
2. Contexts of gene editing Research (Science and Economics)
3. Society & Science dialogue

PART TWO: Role of Ethics

Development of a Concept of responsible gene editing research

Role of Ethics

- Assessing the goals and means of gene editing research
- In view of values and normative claims

- To be deliberated publically, in a society & science dialogue

Ethical Reasoning about

Responsible **science**

Responsible **medicine**

Responsible **Governance**

Responsible **Parenthood**

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Social responsibility

Assessing **Goals and Means**

Knowing: Goal to know more drives science
by gene editing – YES, with a price

Healing: goal to heal drives medical research
by gene editing --- YES/NO

Promoting the public/common Good: goal to provide the best possible means to wellbeing and freedom AND to promote justice drives governance
by gene editing --- YES/NO

Assessing Goals and Means

Couples aiming for Procreation: goal to have a genetically related healthy child drives future parents;

by germ line gene editing --- NO

Overall social goal: Living a good life in dignity: Goal of society: to promote a better life for all; to ensure that everybody can live a life in dignity and freedom

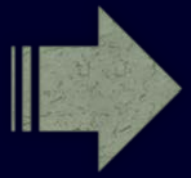
by gene editing -- NO

Consequences and Rights

Consequential assessment

- Safety risks or predictable harms for all affected are bigger than potential benefit
- Unpredictable side-effects cannot be studied in lab

there are better alternatives



for couples; unpredictable risks for future children

Rights and Obligations

Consequences and Rights

Consequential assessment

Rights and Obligations

- There is no *right* to a genetically related child (but: high value for parents and children) but an obligation to
- respect the human dignity – or at least respect some morally relevant status of the human embryo
  - Germ line editing neutralizes the moral status

- Respect future children's health AND freedom rights

Rights and Justice

Justice

- Whose and which reproductive rights are priorities of research?
- Ensure rights of all (not only equal access but also: health and freedom rights)

- Reproductive needs must take precedence in research funding priority decisions over reproductive desires & interests
  - Benefit/harm analysis is crucial

Social Values and Imageries

Transformation of social imageries of parenthood

- Parents are *not* responsible for the genetic condition of their child
- Assisted reproduction is not the *more* responsible act ro secure the health of future children
- The biological concept of reproduction reduces the social concept of parenthood to the transmission of ‘good’ or ‘bad’ genes

Social Values and Imageries

The assisted reproduction market fuels a wrong social imagery:

- Human embryos are either neutralized or considered property & goods
- Future children resemble chosen 'products' of 'design' rather than chosen/given counterparts to parents
- Prospective parents are consumers, not patients
- Ethical deliberations are individualized as choices of medical services

Social Values and Political Ideologies

Non-Coercive Eugenics and Abuse by targeting particular groups

- Governance vs. regulation:
  - It is impossible to determine WHO modifies WHAT for WHICH purposes unless strict regulations are in place that prohibit any germ line gene editing for reproductive purposes
- The political 'dream' to "design human beings" is not unprecedented in recent history!

Conclusion of ethical reasoning

1. Reproductive Germ line gene editing exposes women and future children to **non-justifiable health risks, and it violates the freedom rights of future children,** especially with respect to a life of monitoring and their own reproductive decisions.

Conclusion of ethical reasoning

2. Reproductive germ line gene editing **disregards *any* moral status a human embryo** has. It implicitly de-humanizes and de-grades human embryos and neutralizes the moral respect towards them in the isolated treatment in the lab, which reduces embryos to experimental human material.

3. Reproductive germ line gene editing violates medical ethical norms, because it disregards the second patient, i.e. the future child, in the considerations. **There are alternatives, which the physician can offer prospective parents!**

Conclusion of ethical reasoning

4. Reproductive germ line gene editing violates medical ethical norms, because it disregards the second patient, i.e. the future child, in the considerations. **There are alternatives, which the physician can offer prospective parents!**

5. It risks to estrange the scientific community from society, especially the **trust** that science aims to serve the public/common good. And **it will not be possible to obtain patents from the procedure – at least not in Europe**, because patenting involving the destruction of embryos is considered **'contra the public order'**.

Conclusion of ethical reasoning

6. It violates any consideration of **justice** and will **widen rather than narrow the gap** between the reproductive rights of underserved women and groups and reproductive interests of affluent women and groups.

7. Reproductive germ line gene editing adds to an ethically **unjustified shift of responsibility** in the understanding of parenthood, morally favoring assisted reproduction for some couples over sexual reproduction.

Conclusion of ethical reasoning

8. Reproductive germ line editing **cannot be restricted to 'some' genetic diseases**. Already now, genetic enhancement is proposed, separating gene editing from any medical concern. It requires a complete ban in order to exclude the adverse effects on future generations and the ever-more degradation of human embryos in medical research.

The Moral Path Forward

- Secure the internationally existing **ban on germ line gene editing for reproductive purposes** through UN and regional bodies and prepare international binding regulations.

The Moral Path Forward

Set a Moratorium on basic research for 2 years

- Develop international ethical standards for basic research and
- Regulations to exclude that basic research is used to pave the way for reproductive gene editing
  - Public & private research must be regulated by laws and/or effective forms of governance.

- **No public funding should be granted** for basic research involving germ line gene editing during the time of the moratorium.

The Moral Path Forward

- Set an agenda and timeline for public discourses on gene editing, in order to find out whether the moratorium is good to be lifted or should be maintained.

The Moral Path Forward

- Secure public funding for social, ethical, and legal research accompanying somatic gene editing

- Secure public funding for social, ethical, and legal research on basic research involving germ line editing during the time of the moratorium.

Thank you!