

Ethics in the Genomics Era

Mickey Gjerris

Member of the Ethical Council of Denmark

Associate professor in Bioethics,

University of Copenhagen

- The Danish Council of Ethics
- Three areas of interest
 - Health data
 - Genome testing
 - Changing the human genome

The Danish Council of Ethics

- Established by the Minister of Health in 1988
- 17 members appointed by either Government or Parliament
 - Politically independent – no strings attached
 - Maximum time: 2 x 3 years
 - No paycheck
 - Monthly meetings in Council
 - 3-4 works groups ongoing at any time
 - Monthly meetings
 - Council can respond to political queries or take up issues on own initiative
 - Members appointed for professional expertise in relevant areas
 - Medicine
 - Genomics
 - Climate research
 - Ethics
 - Etc
 - OR – for having a strong voice in public debates on relevant issues



Chairman (2016-): Gorm Greisen,
Clinical Professor, Dr.Med.Sc



Forside - The Danish Council on Ethics

2. DECEMBER 2015



The Danish Council on Ethics

We advise and create debate on biotechnology, which affect human life, our nature, the environment, and food. We also work with ethical issues related to the health care sector.

We are busy updating our new website, and we are in the process of migrating our English content.

Please use the links below to find our publications, and information about us:

- [Publications](#) (translated to English)
- [Members](#)
- [Mandate](#)

Tasks

- Advisory body to Parliament on ethical issues within the mandate
 - Reports
 - Statements
 - Legislative consulting
- Stimulate and qualify public debate on ethical issues within the mandate
 - Hearings
 - Public meetings
 - Participation in debates
 - Individual members can write columns etc.
 - Develop learning materials for schools and high-schools



Mandate

1. (2) The Council's sphere of activity is the ethical issues associated with the researching and application of biotechnologies and genetic engineering pertaining to human beings, nature, the environment and foodstuffs. The Council's sphere of activity also includes other ethical issues associated with health services and biomedical research relating to human beings.

Issues



DET
ETISKE
RÅD

[Annual Report 2014 \(2015\)](#)

[Research with health data and biological material in Denmark \(2015\)](#)

[Annual Report 2013 \(2014\)](#)

[The Danish Council of Ethics' statement on the use of antibiotics \(2014\)](#)

[International trade in human eggs, surrogacy and organs \(2013\)](#)

[Annual Report 2012 \(2013\)](#)

[Genome Testing. Ethical dilemmas in relation to diagnostics, research and direct-to-consumer testing \(2012/2015\)](#)

[Genome Testing – summary \(2012\)](#)

[Bioenergy, food and ethics in a globalized world – summary \(2012\)](#)

[Report on bioenergy, food production, and ethics in a globalised world \(2012\)](#)

[Statement on coercion in psychiatry \(2012\)](#)

[Medical enhancement – summary \(2011\)](#)

[Synthetic Biology – a discussion paper \(2011\)](#)

[The Future of Prenatal Diagnosis \(2009\)](#)

[Organ Donation – Ethical Deliberations and Recommendations \(2008\)](#)

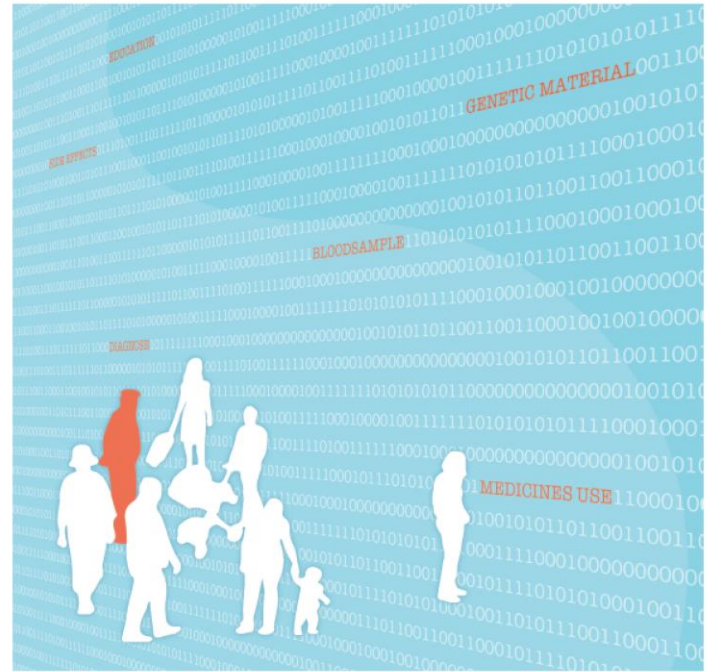
[Man or Mouse? \(2008\)](#)

[Utility, Ethics and Belief in connection with the release of genetically modified plants \(2007\)](#)

[End of Life – Ethical Challenges and Problems \(2006\)](#)

[Ethical Forum for Young People \(2005\)](#)

Health data



Benefits

- Better research
- Better treatments
- Better public health
- Economic potential

Risks

- Loss of privacy
- Misuse of information
- Informed or assumed consent
- Loss of trust in patient/doctor relationship

Genome testing



Genome testing

*Ethical dilemmas in diagnosis, in research
and direct-to-consumer*

Background report



Benefits

- Earlier diagnosis of disease
- Personalized medicine
- Prevention rather than treatment
- Knowledge

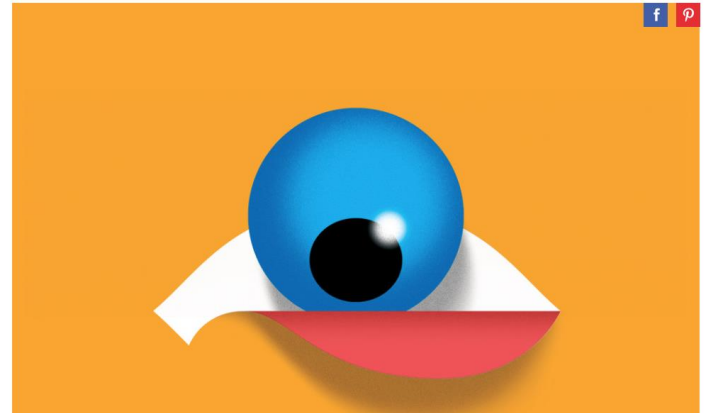
Risks

- Scientific uncertainty
 - False hopes and worries
- Private companies make the money
 - Health sector provides genetic counselling
- Living with an open or closed future

Changing the human genome

SARAH ZHANG SCIENCE 12.01.15 9:40 AM

**CRISPR IS GETTING BETTER.
NOW IT'S TIME TO ASK THE
HARD ETHICAL QUESTIONS**



Benefits

- Helping couples to have healthy children
- Curing diseases through genetic intervention
 - Somatic cells
- Improving "normal" human traits
 - Intelligence, memory etc.

Risks

- Long term effects on children by editing the genome
- Loss of human diversity
- Genetic doping
 - Problem of distinguishing clearly between treatment and improvement
- Unnaturalness

Fundamental issues

Special issues

Genome testing

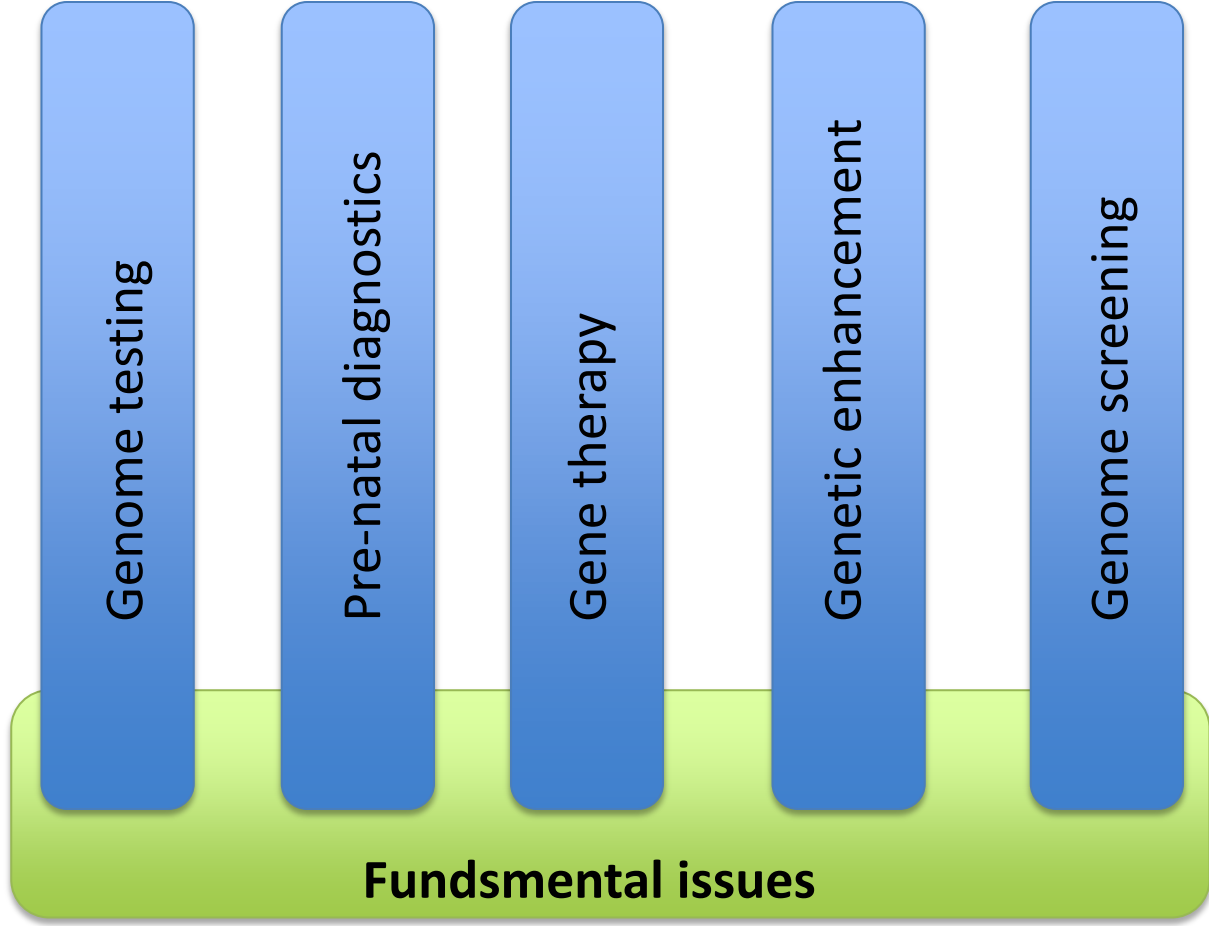
Pre-natal diagnostics

Gene therapy

Genetic enhancement

Genome screening

Fundamental issues



- Genetic determinism?
- What is sickness and health?
- What is the right way to prioritize?
- Should we change human nature?
 - "Playing God?"
 - "Hubris!"