

Genetics from Laboratory to Society

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Public debates about genetic testing

- Two current types:
 - An exchange of hopes and fears based on science fiction scenarios.
 - Piecemeal approach: case-by-case assessment of medical merits and ethical aspects of tests
 - With the result: Emphasis on professional standards and on 'informed consent'.

A double policy problem

- *Which* genetic tests should be introduced?
- *How* to organize public debates and decision making about genetic testing in such a way that society learns to deal with genetic testing?

Core of the argument

- Study of established practices in genetic testing provide a view on issues that deserve public concern.
- These issues are not obvious. Much about the current practice is still 'unknown'.
 - Time, uncertainties, work and (re-)distribution of responsibilities are to a large extent taken for granted.
- Articulation of these aspects may help society to *learn* to deal with genetic testing.

Case studies include:

- Constructing results in prenatal chromosome diagnostics.
- Genetic diagnostics for hereditary breast cancer.
- Lifestyle, genes and cholesterol - controversies about solidarity and responsibilities.
- Detecting familiar hypercholesterolemia: the role of families.
- Genetic/lifestyle risk assessment in life insurance underwriting departments.
- Work, health and genetics – problems of regulating genetic technology in a changing society.

Testing takes time ..

- and work and comes with many uncertainties.
- Testing involves many judgements about mixed technical and normative issues by various actors.
 - Responsibilities are (re-)distributed during the process among various actors.

Public learning about genetic testing

- requires variation, rather than standardisation.
 - but variation is useless if experiences are not articulated, collected and evaluated.
- *Genetics from laboratory to society* aims to contribute to that goal.