



**Maastricht University**

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in Learning!*

**ZonMw Personalised Medicine  
19 April 2018**

**Presentation of the Consortium  
Ethical and Legal Issues of Personalised Medicine**

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## Life sciences & ELSI-research

The relevance of ELSI-research for the life sciences

Precedents:

- HGP: 4% of its budget for ELSI-research
- NGI: 10 yrs support for Centre for Society and Genomics (CSG)

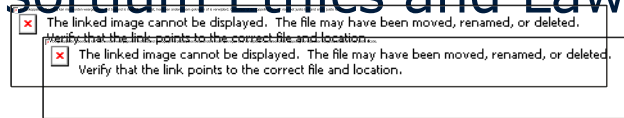
Aim of ELSI-research: contribute to responsible innovation

## The ZonMw-Call and the Consortium ELSI-PM

### ZonMw's focus on PersMed/NGS

The relevance of ELSI → the ZonMw-Call: 2-steps

- Call for a Service Desk (see below)
- Call for a Consortium Ethics and Law of PM →



The 5 Consortium-partners, headed by UM:

- EUR: dr. Eline Bunnik
- UvA/AMC: mr.dr. Corrette Ploem
- VUMC: prof.dr. Martina Cornel
- UMCU: prof.dr. Annelien Bredenoord
- UM: dr. Wybo Dondorp & prof.dr. Guido de Wert

## Aims

### Overall:

Provide an ethical and legal analysis of the most pressing and challenging ethical and legal issues (taking account of the Pre-application Review and the overview of current studies;

Contribute to both an adequate governance of the further development and responsible implementation of PM and a sustainable normative framework and guidance for the field

## Subaims, linked with the 5 WPs/projects

### 1. Models of informed consent

To study the usage and effectiveness of new informed consent models in clinical NGS practice, in order to learn how to fulfill the prerequisite of informed consent

### 2. Opportunistic genomic screening

To scrutinize the ethics of opportunistic genomic screening of both minors and adults

### 3. Responsible innovation

To identify barriers and support opportunities for the implementation of PM in health care practice

Subaims linked with the 5 WPs/projects (cont.)

#### 4. Learning health care system for PM

To study the ethical implications of learning health care system in the context of PM

#### 5. Legal issues

To scrutinize a subset of legal challenges, focusing on privacy issues, the rights of patients and research subjects, and health professionals' duties of care.

## Advisory Board

Prof.dr Inez de Beaufort

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Prof.mr Jaap Sijmons

Dr Annemieke de Vries

Prof.dr Guy Widdershoven

Guaranteeing the Consortiums practical utility

1. Links with other ZonMw/PM projects
2. (Start) Assessing practical needs
3. Continuous cooperation & accomodation with the ELSI-Service Desk