

# Ethics and implementation

Dr. Simone van der Burg

Senior researcher philosophy and ethics of  
medical technology



**ZonMw**

**IQ** Scientific Institute for  
Quality of Healthcare

# Implementation

‘Implementation research is the scientific study of methods to promote the systematic uptake of clinical research findings into routine clinical practice, and hence to reduce inappropriate care.’ (p. 2, Hutton, Eccles, Grimshaw 2008. In: Implementation science)

## Purpose of implementation science

‘(..) implementation research, which endeavours to translate improvements in clinical research into improvements in health care, is ethically commendable.’ (p. 8, Hutton, Eccles, Grimshaw 2008)

## Purpose of implementation science

‘It should be ethically troubling that research on how best to ensure that biomedical discoveries and effective public health strategies make a difference in people’s lives has received only a tiny portion of our national science budget and remains a virtually invisible field within the biomedical research establishment. Bioethicists can articulate the harm done by not investing in implementation science (..).’(p. 32, Solomon, 2010. The American Journal of Bioethics)

## Ethics and implementation

- Q Implementation itself is ethical (Hutton et al 2008; Solomon 2010)
- Q Ethical regulation for research obstructs effective implementation research (Hutton et al. 2008)
- Q Morals of health care workers partly explains their resistance against the implementation of new technologies, public health interventions or skills. (Lamiani et al. 2009)
- Q Morality itself needs implementation (Jones et al. 2009; Ten Have 2010; Obora et al. 2009; Verpeet et al 2006)

## Ethics and implementation

- Q Implementation science should be subjected to the approval of an ethics committee, because it exposes research subjects to risks (Eccles et al. 2011; Chanaud 2010)
- Q In implementation science we deal with ethical decisions about equity and (global) justice: for whom and where are we making something available? (Rennie et al. 2006)
- Q Equity, justice, patient centredness: are the medical and scientific models of disease implied in implementation strategies also shared by patients? (Hepworth et al. 1997)



## Q Ethics on the laboratory floor

- Goal: co-shaping (medical) technology in (hopefully!) more favorable ways
- Focus on the technology
- Starts from the supposition that research does not always lead to instruments that are worth implementing

## Engagement with technology

Starts from three suppositions:

Technology matters to morality, for technology and morality co-evolve (Swierstra and Rip 2007)

Technology is not a neutral instrument, but changes human experience and actions in profound ways (Ihde 1999; Latour 1994; Verbeek 2005)

Research/development and use of a technology is a social matter (Lynch and Kline 2000; Johnson 2007)

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## Newborn screening

2007: 17 diseases: thyroid disorders, disorders of the adrenal gland, blood diseases, metabolic diseases

2010: 18 diseases (17 hereditary)

# Tandem Mass Spectrometry/ High-performance liquid chromatography (HPLC)



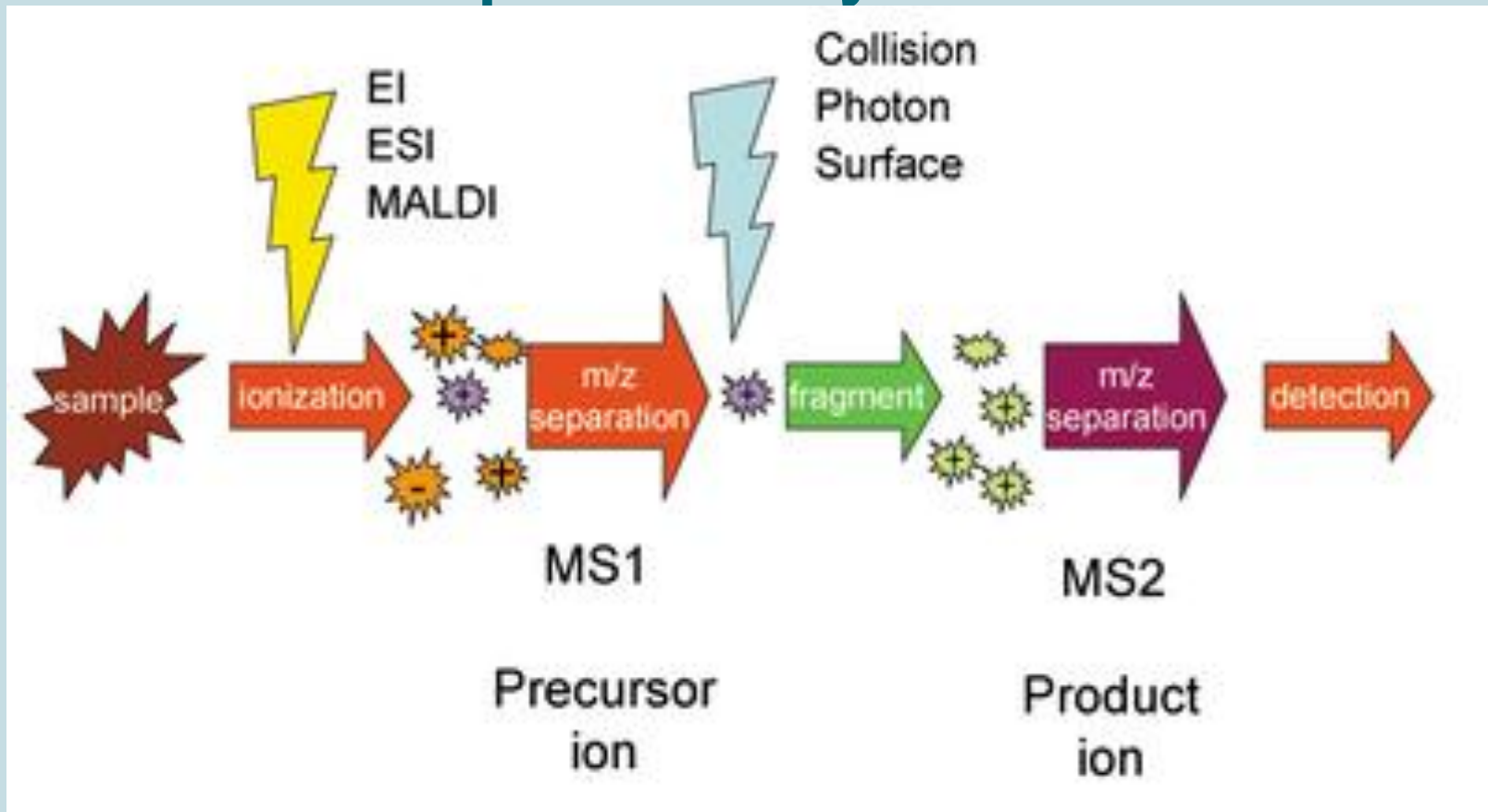
## Criteria

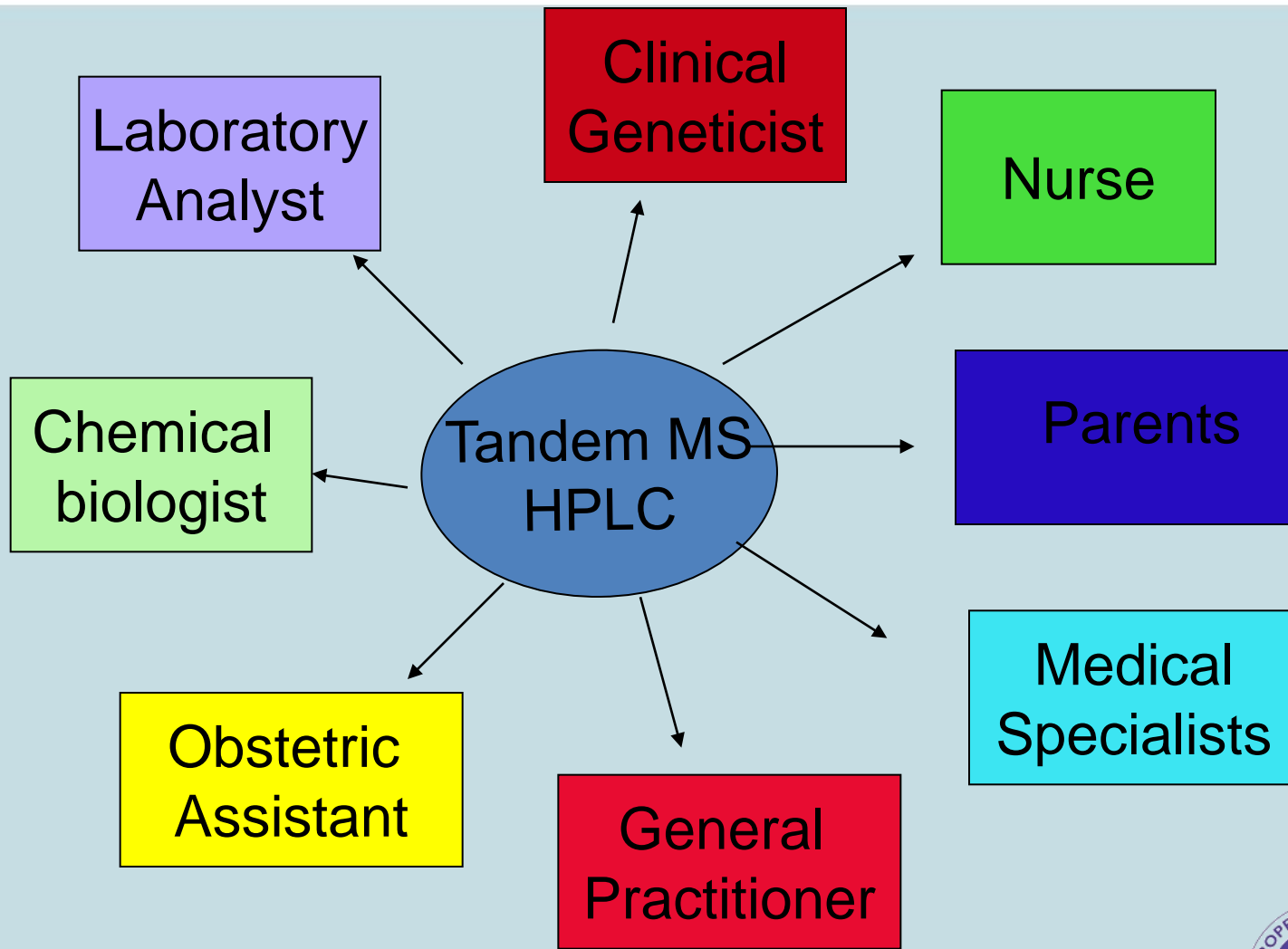
There should be an adequate detection method for the diseases in the program

Diseases should be treatable and the treatment should be accessible

Participation is voluntary, and this requires that parents are informed

# Tandem Mass Spectrometry





## Difficulties

False positives

Uncertain results; findings about other diseases than are included in the program

Information on carrier status

Rare diseases, little knowledge about natural biological development and effect of treatment

Overtreatment/undertreatment

Hereditary diseases

## Ethical questions relevant to implementation

How do professionals interact with the technology?

How do (the distributions of) responsibilities of professionals change?

Do dependencies change too (and how)?

How should professionals accommodate their new responsibilities into their profession?

What is needed to sustain or restore trust?

## Ethics and implementation: what it *could* do too

- Q Assist the evolution of morality
- Q Analyze how a new technology changes responsibilities
- Q Identify new responsibilities
- Q Enhance reflection about these new responsibilities

Thank you!