

March 14-18 2016

Nijmegen, the Netherlands

Keynote speaker:

Prof. dr. Peter Paul Verbeek

professor of Philosophy of Technology and co-director of the
DesignLab of the University of Twente

Advanced European Bioethics Course

Ethical Issues in Human Genomics and Big Data: the need for Responsible Research and Innovation

INTRODUCTION

Human life is increasingly entangled with medical technology. Between conception and grave, virtually all medical problems and concerns receive a technological response.

Innovative medical technologies, while they may contribute to improving health and prolonging life, may also shift our understandings of health and disease, elicit new clinical practices and routines and shift responsibilities for health care providers and patients in preventing, diagnosing, monitoring and treating disease. As debates over medical technologies indicate, these shifts have ambiguous value.

In this course we will explore the nature of human-technology relations, as well as their value. The focus will be on ethical dimensions of developments in medical technology and genomics.

Debates about new technologies reveal a need to balance their pro's and con's, preferably at an early stage of their development. At that point it is still possible to alter the technology, or choose an intelligent implementation strategy that helps to realize its most attractive aspects and diminish the influence of the less attractive aspects. Such early ethical engagement contributes to responsible innovation. The rationale behind responsible innovation is that it contributes to realizing better technologies, which actually foster human health and wellbeing, because their up- and downsides are considered early on.

The lectures will introduce basic philosophical and ethical concepts related to responsible innovation and genomics. Small group discussions and working groups are devoted to in-depth discussions of particular contemporary ethical issues.

SUBJECTS AND METHODS

In the first half of this course the primary focus will be on developments in genomics and genetic modification and its consequences for public health interventions, curative medicine, patients and citizens. Ethical questions will be addressed by different stakeholders. Debates will be analyzed according to moral frameworks provided during the course. Socratic reasoning and discourse analysis will be part of these days.

During the second half of this course we aim to provide an insight into the philosophy and ethics of responsible innovation. We will study the meaning of 'responsibility' in responsible research and innovation, explore the role of imagination in moral reflection about technologies that still have to come about, and become acquainted with tools to conduct responsible innovation.

SCIENTIFIC COMMITTEE

Evert van Leeuwen PhD, Professor of Medical Ethics. In the field of medical research prof. van Leeuwen is interested in questions concerning ethical conditions relating to the application and evaluation of technology and the active participation of patients.

Simone van der Burg PhD, senior researcher ethics and philosophy of medical technology. Dr. van der Burg's projects are primarily aimed at developing a cooperative and constructive ethics, which will coach researchers and professionals in their ethical reflection on the medical technologies they are developing and using.

INFORMATION & REGISTRATION

Simone Naber: Simone.Naber@Radboudumc.nl,

www.masterbioethics.org, [intensive courses](#)

Telephone: +31 (0)24 361 33 59

Peter Paul Verbeek is professor of Philosophy of Technology and co-director of the DesignLab of the University of Twente. Verbeek's research focuses on the social and cultural roles of technology and the ethical and anthropological aspects of human-technology relations.

Helger Yntema, PhD, Radboudumc, clinical molecular geneticist

Wout Feitz PhD, Radboudumc, professor of regenerative medicine and pediatric urology

Ineke van der Burgt MD, Radboudumc, geneticist

Jasper Bovenberg JD, LL.M., PhD, (invited) attorney-at-law specialized in medical law, data protection, biotechnology transfer

Peggy Manders Radboudumc, biobank manager

Wilma Steegenga PhD (invited), Wageningen University and Research centre, assistant professor human nutrition

Carla van El, PhD (invited), VU University Medical Centre, Amsterdam, senior researcher, associate professor,

Stef Groenwoud PhD, Radboudumc, senior project leader IQ healthcare

Andre Krom PhD, Project leader Future Panel on Public Health Genomics (FP7)

Vincent Blok PhD, Wageningen University and Research centre, Radboud University Nijmegen, assistant professor in Responsible Innovation and Sustainable Entrepreneurship

Steven Dorrestijn PhD, senior researcher Ethics and Technology Saxion University of Applied Sciences

Hub Zwart PhD, (invited) Radboud University Nijmegen, professor of philosophy, Faculty of Science,

Marianne Boenink PhD, University of Twente, assistant professor Department of Philosophy

PARTICIPANTS

This course is designed with participants from various backgrounds in mind: researchers and physicians in the field of human genetics and genomics, biomedical sciences, biomedical engineering, life sciences, genetics and biology but also for professionals from other areas in healthcare such as physicians and nurses, administrators, bioethics committee members, professionals working in the pharmaceutical industry, professionals in the areas of ethics, philosophy and theology, and PhD students undertaking courses of study in any of these areas.

Participants are reminded that they may apply for continuing education credit hours through their professional association.

COURSE FEES and PAYMENTS

The course fee is € 690 for registration before or on 31-1-2016, € 790 for registration after 31-1-2016. PhD students are eligible for a discount of € 230. This price includes tuition and course materials, as well as refreshments, four lunches and a dinner. For cancellation after 15-2-2016 a banking and administrative fee of € 91,- will be charged. Fees are non-refundable for cancellation after 1-3-2016.

ERASMUS MUNDUS MASTER OF BIOETHICS

This course is part of the post initial Erasmus Mundus Master of Bioethics Program, a one-year master program for students from European and non-European countries. This program is organized by the Universities of Leuven (Belgium), Nijmegen (the Netherlands) and Padova (Italy). Because of this combination, participants in the course will be part of a diverse, international audience, which adds to the discussions in a unique way.

Mon 14-3

WELCOME

Registration and welcome

Keynote lecture

Social program

Tue 15-3

DYNAMIC MORALITIES IN HUMAN GENOMICS

Introduction: four moral discourses of person related genomic practice

Reflective discussion with representatives of these four discourses: patient, personal medicine and risk management, genetic variation, enhancement

Working groups: defining key elements of the moral discourse of best practices

Lecture: How do ethical and legal discourse interrelate in genomics

Case discussion: cases from the four discourses

Working groups: develop a patient centered model

Wed 16-3

POPULATION & SOCIETAL HEALTH PERSPECTIVE

Introduction: Genomic knowledge, social science and morality: the new area of public health genomics

Reflective discussion with representatives from ethics and genomics in bio-banking, nutrition, the healthcare system and prevention

Working groups: defining key elements of the moral discourse of best practices

Lecture: The intertwining of social and personal interests in the development of genomics

Case discussion: Cases from the four areas in public health genomics

Working groups: define the main issues that will have to be dealt with from a personal, national and global perspective

Evening program

Pizza and movie

Thu 17-3

RESPONSIBILITY IN RESPONSIBLE INNOVATION

Introduction of the day-theme: what is responsible innovation?

Lecture and discussion: Individual versus social approaches to responsibility

Lecture and discussion: How does a technology steer the behavior of the user?

Workshop: Ethical assessment of technology

Closing session

Fri 18-3

THE ROLE OF IMAGINATION IN MORAL REFLECTION

Introduction of the day-theme: imagination and technology

Lecture and discussion: metaphors and genomics

Lecture and discussion: scenarios in public engagement debates

Workshop: write a scenario