

**DC13:** The ethics of gene therapy in lung transplantation research: the perspective of the donor

**Host institution:** UMC Utrecht

**Country:** Netherlands

**Supervisory team:** Dr. Rieke van der Graaf (PhD promoter, UMC Utrecht), Prof. dr. Pascal Borry (KU Leuven)

**Project description:**

The objectives are: 1. to consider to what extent would lung transplant donors make genuinely informed decisions in both first-in-human clinical research and clinical contexts. 2. to consider how should donor consent be structured to address the ethical challenges posed by the postmortem application of gene therapy to donated lungs?

DC13 (UCMU) and DC14 (KUL) will investigate social and ethical aspects related to ex vivo gene therapy on lungs, especially those related to first-in-human trials, and anticipate the ethical aspects related to implementation in clinical practice. DC13, focusing on lung donors will perform an ethical-legal analysis of the opt-out systems within Eurotransplant countries, and then conduct a cross-sectional survey to investigate the acceptability of genetic lung modification among prospective and living lung donors. Follow-up qualitative research will be performed with living lung donors in the Netherlands (30-40 interviews, prospective and those who have already donated), using interpretive qualitative methods. Finally, DC13 will perform an ethical conceptual analysis on the moral status of the genetically modified lung and consider the role of human enhancement in the context of genetic lung modification.

A successful project will result in: Results of ethical-legal analysis, cross sectional survey and qualitative research interviews with (living) lung donors. Insight into (living) lung donor perspectives on the research questions and the moral implications of the genetically modified lung.

**Enrolment in Doctoral School:** University of Utrecht Graduate School of Life Sciences

**Planned secondments:**

- Eurotransplant, Netherlands: familiarisation with regulations around organ donation (month 9)
- KU Leuven, Belgium: work with DC14 on conceptual paper (Month 26-27)

**Essential requirements of a successful candidate**

- You hold a Master's degree (no PhD) a Master's degree in Philosophy, Law, Biomedical Sciences, Medicine, Bioethics, Social Sciences, another relevant degree (Master's level) with a pronounced interest in area of research.
- You have experience with ethical conceptual thinking and with social scientific methods, such as qualitative methods.
- You are enthusiastic, ambitious, dynamic, flexible, and open to challenges and developments.
- You have good organizational skills and can work independently and make decisions.
- You have excellent social and written communication skills in English.
- You can work in an international multidisciplinary team.
- You are willing to contribute to collective activities of the research group (such as educational services, lab meetings, research proposals, supervision of bachelor and master students, etc.).
- You have not resided or carried out your main activity (e.g. work, studies) in the Netherlands for more than 12 months in the 3 years immediately prior to the start of his/her assignment.
- Willingness to travel

**Skills and expertise that are viewed as an asset:**

- Social and written communication skills in Dutch is desirable