



## Joint MD/PhD Fellowships Groningen-Oldenburg

### Outline PhD Project

Working title of project	Towards patient-centered care in clinical genetics: Optimizing efficacy and efficiency of the genetic counseling practice across borders
Promoter/Supervisor UMCG (name, department, e-mail)	Dr. Imke Christiaans, Department of Genetics, Faculty of Medical Sciences i.christiaans@umcg.nl
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Short Summary of PhD project (mx. 500 words), incl. research question(s), methods, approx. schedule (incl. times in Groningen/Oldenburg)

Clinical genetics is the medical profession that diagnoses and counsels people and their relatives who may have a genetic condition. Every professional involved agrees with the primary goal of genetic counseling: improving patient empowerment. Currently, the counseling practice is predominantly standardized within countries, but heterogeneous in content and procedure across Europe. The content and process of counseling sessions are solely depend on the patient group (oncology, perinatal, etc.) and the reason for referral, but not personalized to patients' needs and prior levels of empowerment. Arguably, personalization according to patients' needs would optimize efficacy and efficiency in genetic diagnostics and counselling which is also a European goal (McAllister et al., 2016). Still much needs to be understood about the emergence of patients' empowerment before this goal can be achieved for diverse counselee populations. Thus, we urgently need systematic comparisons of the genetic counseling practices and patients' needs across countries.

In a cross-border context between the Netherlands and Germany, the proposed PhD project will aim for an international effort toward understanding the black box of genetic counseling and by doing so, to subsequently improve its efficacy and efficiency. More specifically, **1)** the proposed PhD project will **adapt and psychometrically evaluate a set of instruments for the genetic counseling** setting that can be used for process- and outcome monitoring among a **diverse population** of counselees, **2) including children.** **3)** We will **monitor** a series of **genetic counselling processes** and assess their outcomes in



Germany and the Netherlands aiming at a **cross-border comparison** and description of similarities and differences at institutional and patient levels. **4) Toward evidence-based and patient-centered counselling, we will further explore counselees' state-trait profiles** and study how these are related with patient-reported outcome measures. **5) Based on the accumulated knowledge, we will deliver a counselling manual for attenuating the counseling to counselee profiles and to achieve optimal care** regarding empowerment and satisfaction. Feasibility tests of the manual guided counseling will be the goal of future collaboration. This systematic effort to open the black box of genetic counselling will inform healthcare systems towards a more effective and efficient advise of about 30 million Europeans currently affected by genetic conditions and their relatives at risk.

The PhD candidate will be supervised by a larger team of PI's from Groningen and Oldenburg. From Groningen supervision will be undertaken by the ELSI (Ethical, Economic, Legal, and (Psycho)Social Issues) in Genetics research group, a multidisciplinary team with expertise in research on genetic counseling and health services including implementation ([ELSI \(umcgresearch.org\)](http://ELSI.umcgresearch.org)). From Oldenburg the multidisciplinary team consists of PI's with expertise in psychology, genetic counseling and modelling of health care data. The supervision team plans to collaborate in a hybrid format and meet once a month with the whole team, especially in critical phases of the project. Times in Oldenburg/Groningen can be adapted to the candidate's needs.

#### PhD Candidate Profile/desired qualifications

- You are a medical graduate with interest in medical genetics and psychology.
- You have good English writing and speaking skills.
- You are a loyal team member and are able to focus on your own interests/productivity and work independently, while also supporting the team.
- You are curious, enthusiastic and sociable.
- You have good social and communication skills.
- Prior experience in research and statistics would be a plus.