

EAS Award Committee:

Prof. Ruth Frikke-Schmidt  
Prof. Željko Reiner  
Prof. Sheila Francis  
Prof. Dagmar Kratky  
Prof. Philippe Moulin  
Prof. Michal Vrablik

Rotterdam, the Netherlands, 31<sup>st</sup> January 2023

Regarding: Young Investigator Awards for outstanding publications during 2022

Dear European Atherosclerosis Society Award Committee,

With great pleasure I would like to nominate my publication.

“Quality of life and coping in Dutch homozygous familial hypercholesterolemia patients: a qualitative study” was published in *Atherosclerosis* in 2022 (<https://doi.org/10.1016/j.atherosclerosis.2022.03.015>).

With this study I investigated the quality of life and coping mechanisms of homozygous familial hypercholesterolemia (HoFH) patients. Remarkably, little had been published on this topic thus far. The few previous studies only included HoFH patients who were receiving apheresis. Hence, these prior findings could not be extrapolated to the entire spectrum of HoFH patients. In our study, Dutch HoFH patients with all types of cholesterol lowering treatment participated and therefore fills this gap in knowledge. In addition, I provided the first conceptual model, representative for all HoFH patients with as central theme the patient’s perception on HoFH.

Remarkably I found that, if dealt with effectively, the objective elevated risk of cardiovascular disease and premature death only slightly affects the subjective quality of (daily) life of HoFH patients. Also, patients showed a wide variety of coping mechanisms that help them deal with their condition in daily life. This is important for HoFH healthcare professionals to be aware of and enables them to further tailor the care they provide. Moreover, patients reported high confidence in treatment by a dedicated HoFH center, which also contributed to less HoFH-related stress. This confirms the importance of specialized lipid clinics from a patient perspective, which fits perfectly in the aim of the EAS Lipid Clinics Network.

**Why is this an outstanding publication?**

Research on patient experience, is relatively new compared to “traditional” field of research such as basic, translational and epidemiological research. However, it is valuable to improve tailored care and support patients in their current treatment. Qualitative research can give a

solid foundation for further investigation in a larger group. In fact, in collaboration with the HoFH International Clinical Collaborators (HICC) registry, we are now developing questionnaires to investigate quality of life in an international HoFH population.

Research into patient reported outcomes provide knowledge on new topics of which researchers and healthcare professionals were not previously aware. For example, we learned that half of the HoFH patients mentioned that they struggled with the issue of family planning. Based on this finding we have planned a follow-up study among the patients and healthcare providers involved in the HICC registry to further investigate this specific item.

Currently qualitative research is often underappreciated in comparison with other forms of research, especially in the cardiovascular domain. Awarding a publication on qualitative research would be an award for the entire qualitative research field.

**Why do I qualify for a young investigator award?**

I was involved in all stages of this study, starting from the development of the topic list, as well as interviewing all patients, analysing the results, developing the conceptual framework and writing the manuscript.

This project provided a great learning curve for me. I experienced that qualitative research can provide a deeper and unique understanding of a topic. At the same time, it gives patients an opportunity to better express themselves and makes them feel involved. This may lead to insights otherwise missed (e.g. concerned family planning).

Our research provides a better understanding of how patients with HoFH experience and cope with their condition in daily life in a diverse phenotypic HoFH population. These insights into current patient experiences of HoFH will result in better care in general for HoFH patients. Moreover, it will concretely lead to more dedicated care in the case of family planning. I feel privileged to be a researcher and this article stimulates me to further grow and develop.

Therefore, I would kindly like to nominate my publication for a Young Investigator Award as an outstanding publication of 2022.

Looking forward to hearing from you.

Yours sincerely,  
Janneke W.C.M. Mulder

## Curriculum Vitae

Name: J.W.C.M. Mulder  
First name: Janneke  
Date of birth: 09-04-1996  
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3015 GD Rotterdam, the Netherlands  
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### EDUCATION

2022-now MASTER - ERASMUS MC, Netherlands Institute for Health Sciences (NIHES), Rotterdam, Netherlands, Erasmus University, Master of Science in Health Sciences (Aug. 2022-now)  
2019-2022 MASTER - ERASMUS MC, Rotterdam, the Netherlands, Erasmus University, Medicine: *internships of choice being Vascular Internal Medicine (12 weeks), Cardiology (3 weeks), Anaesthesiology (3 weeks)*. (February 2019-February 2022)  
2017-2018 PREMASTER - ERASMUS MC, Rotterdam, the Netherlands, Erasmus University, Medicine  
2014-2017 BACHELOR - ERASMUS UNIVERSITY COLLEGE (EUC), Rotterdam, the Netherlands, Erasmus University, *2 Majors: Pre-Med (cum laude) and Economics & Business (cum laude), incl. Statistics, Computer Science & Qualitative Research.*

### RESEARCH

#### Conferences/Presentations

2023 Erasmus MC symposium Implication of sex and gender for cardiovascular disease prevention: What a difference a decade makes (January 10). Oral presentation as young talent speaker on: "Familial hypercholesterolemia: a life course approach".  
2022 Dutch national lipid day ("Nationale lipidendag") (June 14). Oral presentation on "Patient outcomes: very high-risk patient not reaching LDL-C target level"  
2022 European Atherosclerosis Society (EAS) 90<sup>th</sup> congress in Milan, Italy, (May 22-25). Oral presentation in a Science at a glance session on "Efficacy and safety of PCSK9-inhibitors: a systematic review and meta-analysis of real-world data"  
2022 Scandinavian Society for Atherosclerosis Research (SSAR) annual meeting (April 6-9). Poster presentation in session "Other Topics" on "Efficacy and safety of PCSK9-inhibitors: a systematic review and meta-analysis of real-world data"  
2021 EAS 89<sup>th</sup> virtual congress, (May 30 – June 2). Poster on "Quality of life and coping in homozygous familial hypercholesterolemia patients: a qualitative study"  
2021 Dutch national lipid day ("Nationale lipidendag") (May 18). Oral presentation on "Quality of life and coping in homozygous familial hypercholesterolemia patients"  
2021 SSAR annual (virtual due to COVID) meeting (April 8-9). Oral presentation in the session "Other Topics" on "Quality of life and coping in homozygous familial hypercholesterolemia patients: a qualitative study"  
2019 EAS 87<sup>th</sup> Congress in Maastricht, the Netherlands (May 26-29). Oral presentation in a Science at a glance session on "The Development and First Results of a Health-related Outcomes set in Familial Hypercholesterolemia (FH) Patients: Knowledge is Health"  
2019 SSAR annual meeting in Humlebæk, Denmark (April 10-13). Oral presentation in the session "Other Topics" on "Development and First Results of a Health-related Outcomes set in Familial Hypercholesterolemia (FH) Patients: Knowledge is Health"

## Publications

- To be submitted* Mulder, J.W.C.M., Tromp, T.R., Al-Khnifsawi, M., Bertolini<sup>†</sup>, S., Blom, D.J., Chlebus, K., Cuchel, M., Gallo, A., Hovingh, G.K., Kim, N.T., Long, J., Raal, F.J., Truong, T.H., Boersma, E., & Roeters van Lennep, J.E. Diagnosis, treatment, and cardiovascular outcomes in Homozygous Familial Hypercholesterolemia: a sex-specific analysis in the HICC registry.
- Under review* Mulder\*, J.W.C.M., Galema-Boers\*, J.M.H, Steward, K., & Roeters van Lennep, J.E. Sex differences in efficacy and safety of PCSK9 monoclonal antibodies: a real-world registry. \* shared first authorship
- 2022 Burlage, E., Mulder, J.W.C.M., Nellensteijn, J.M., & Zeegers, A.V.C.M. (2022). Infection mimicking skin condition; Pyoderma Gangrenosum. *BMJ Case Reports*, 15(8), e247770.
- 2022 Mulder, J.W.C.M., Kranenburg, L.W., Treling, W.J., Hovingh, G.K., Rutten, J.H., Busschbach, J.J., & Roeters van Lennep, J.E. (2022). Quality of life and coping in Dutch homozygous familial hypercholesterolemia patients: A qualitative study. *Atherosclerosis*, 348, 75-81.
- 2020 Mulder, J.W.C.M., Galema-Boers, J.M., de Jong-Verweij, L.M., Hazelzet, J.A., & Roeters van Lennep, J.E. (2020). The Development and First Results of a Health-related Outcomes set in Familial Hypercholesterolemia (FH) Patients: Knowledge is Health. *Atherosclerosis*, 293, 11- 17.

## Grants

- 2023 Erasmus Trustfonds for 3 months work visit at the University of Oslo, Norway (Sept.-Dec.)
- 2022 Young Investigator Fellowship and Travel grant to the 90<sup>th</sup> EAS Congress (May 22-25)
- 2021 Young Investigator Fellowship to the virtual/online 89<sup>th</sup> EAS Congress (May 30 – June 2)
- 2019 Young Investigator Fellowship to the 87<sup>th</sup> EAS Congress (May 26-29)

## RELEVANT EXPERIENCE

### ERASMUS MC, Rotterdam, the Netherlands

- Febr 2022-now PhD candidate (fulltime) at the vascular internal medicine department
- 2019-2022 Research student (parttime) at the Vascular Internal Medicine Department
- 2018-2019 Research (parttime) at the Internal Medicine and Public Health Department on health-related outcomes in familial hypercholesterolemia patients (Sept. 2018 - Febr. 2019)

## SKILLS

**Technical skills:** R, Excel, SPSS, Matlab, STATA, NVivo.

**Languages:** Dutch (native), English (fluent), Spanish (intermediate), German (basic)

### Courses:

- ZonMw and NWO-SGW joint online course on Intersectionality-based Sex and Gender Analysis (ISGA) in Public Health
- CIHR Institute of Gender and Health Core Competency Modules: for Sex and Gender in Biomedical Research, Primary Data Collection with Human Participants, and Sex and Gender in the Analysis of Secondary Data from Human Participants.

## EXTRA CURRICULAR ACTIVITIES

- 2022-now Executive secretary of the first founding ECHORM board (Early Career network for Health Outcomes Research & Management)
- 2018-2022 Member of the Audit committee horse-riding club Hagmolenuiters
- 2021 Social media ambassador “EAS congress 2021” (May 30-June 2)
- 2016-2017 Chair of the Student Graduation Committee Class of 2017 of EUC
- 2016 Supportive function ICHOM Value-Based Health Care Conference, London, May 16-17
- 2015-2016 Member of the (first) Graduation Committee of EUC.
- 2014-2015 Secretary of the Yearbook Committee of EUC