

# Functioning, quality of life, and end of life care of patients with Huntington’s disease living in long-term care facilities; the Advanced HD study design

Marina Ekkel<sup>1</sup>, Els Verschuur<sup>2</sup>, Marja Depla<sup>1</sup>, Ruth Veenhuizen<sup>1</sup>, Bregje Onwuteaka-Philipsen<sup>3</sup>, Cees Hertogh<sup>1</sup>

1. Department of General Practice & Elderly Care Medicine, Amsterdam Public Health research institute, Amsterdam UMC, Amsterdam, the Netherlands
2. HAN University of Applied Sciences, Nijmegen, the Netherlands
3. Department of Public and Occupational Health, Amsterdam Public Health research institute, Amsterdam UMC, Amsterdam, the Netherlands

## Background

Huntington’s disease (HD) is an inherited neurodegenerative disease, characterized by movement disorders, psychiatric symptoms, and cognitive decline. Care for HD patients in long-term care facilities (LTCFs) is complex and practice-based.

Little is known about:

- The functional status and quality of life of HD patients in LTCFs.
- End of life care for HD patients.
- Advance care planning (ACP) for HD patients

## Aims

To gain insight in motor, psychiatric, and cognitive symptoms, functional ability and quality of life of HD patients living in a specialized LTCF.

To gain insight in perceptions of HD patients concerning their future and end-of-life, and whether these perceptions change over time.

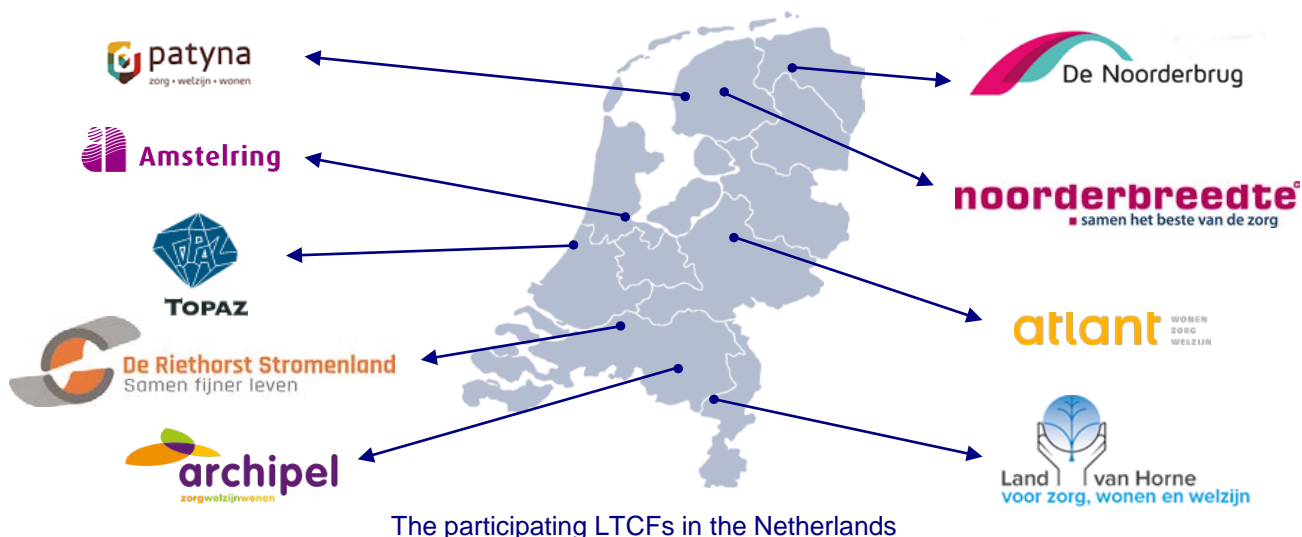
To gain insight in views of elderly care physicians on ACP and end of life care for HD patients.

## Methods

Observation scales and questionnaires. We aim to include all HD patients living in a specialized LTCF in the Netherlands in the period 2017-2019 (n=250).

Multiple in-depth interviews with HD outpatients or day care visitors, every six months for a period of 2,5 years (n=10-15).

In-depth interview with all elderly care physicians working in a specialized LTCF in the Netherlands (n=18)



## Results

Results are expected in 2021.

## Conclusions

This study will provide valuable information on the functional status, quality of life and end-of-life care of HD patients living in LTCFs. Results may provide elements for developing evidence based guidelines for care of institutionalized HD patients.

Contact: [m.ekkel@vumc.nl](mailto:m.ekkel@vumc.nl)