



INTERDEM MEMBERS – BRIEF CURRICULUM VITAE



NAME: Janne Papma
TITLE: Dr.
PROFESIONAL GROUPING:
WORK ADDRESS: Alzheimer Center Erasmus MC, Erasmus MC, Dr. Molewaterplein 40; 3015 GD Rotterdam
TEL. WORK/WORK MOBILE: +31107043828
EMAIL ADDRESS: j.papma@erasmusmc.nl
WEBLINK: www.linkedin.com/in/jannepapma
PRESENT POSITION: Head of Alzheimer Center Erasmus MC, Senior researcher
HIGHEST ACADEMIC QUALIFICATION (e.g. PhD, MD etc.): PhD
PROFILE OF MEMBER: MSc Neuropsychology, MSc Neuroscience
AREAS OF EXPERTISE: Person-centered dementia diagnostics and care; Culture-sensitive diagnostics and care; Care pathways people with young onset dementia; Neuropsychiatric symptoms in Alzheimer's disease

KEY PUBLICATIONS (Max. 5):

1. To generalize safety and efficacy findings of Alzheimer's disease drug trials it is essential that diverse populations are well-presented. In this review we show that certain eligibility criteria may have led to a disproportionate exclusion of underrepresented groups for medication trials for Alzheimer's disease.

Franzen s, et al., Papma JM (sept 2021) Diversity in Alzheimer's disease drug trials: the importance of eligibility criteria. *Alzheimer's & Dementia* Number of citations: 6, IF 21.6

2. Dementia diagnostics in people with a diverse background in terms of culture, education, and language, requires culture-sensitive adaptations. Dementia diagnostics heavily rely on cognitive or neuropsychological testing in order to examine the cognitive profile. In a systematic review, we have examined the state of the art of neuropsychological tests and their adaptations to a diverse population. This study was the basis of a large number of the TULIPA projects, which focused on the development of evidence based culture-sensitive cognitive and behavioral diagnostic instruments.

Franzen S., et al. Papma JM A systematic review of neuropsychological tests for the assessment of dementia in non-Western low-educated or illiterate populations. *Journal of the International Neuropsychological Society* Number of citations: 26, IF 3.1

3. Investigating the presymptomatic stage of familial frontotemporal dementia (FTD) aids our understanding of the disease process, improves early stage diagnosis, and offers treatment options. In the past years I have led the neuroimaging research line within a study focused on presymptomatic FTD, and thereby have worked on the characterization of the presymptomatic stage of FTD. Together with my PhD students, I have discovered genetic and phenotypic specific patterns of neuroanatomical and clinical changes. These findings support the development of a personalized approach for both diagnostics and treatment.

Papma J.M., et al., Van Swieten J.C. (2019) Cognition and gray and white matter characteristics of presymptomatic C9orf72 repeat expansion. *Neurology*, Number of citations: 57, IF 8.7

4. Despite the fact that neuropsychiatric symptoms (NPS) are highly prevalent in Alzheimer's disease (AD), these symptoms are under recognized and subsequently undertreated in the early stages of Alzheimer's disease. In this study we have used data from the Amsterdam Dementia cohort and examined the prevalence and association between neuropsychiatric and cognitive symptoms. This great research is a good example of a good collaboration that I have managed to establish with national dementia researchers.

Eikelboom W.S., et al., Papma J.M. (sept 2021) Neuropsychiatric and cognitive symptoms across the Alzheimer disease clinical spectrum: cross-sectional and longitudinal associations. *Neurology*, Number of citations: 11, IF: 8.7

5. Within the PRECODE national scientific collaboration it is our goal to perform an estimate of the number of young-onset dementia patients, in order to adapt the clinical care for this vulnerable patient group. This review and meta-analysis performs an estimate from the prevalence numbers in scientific literature, an important step towards personalized care for young-onset dementia patients:

Hendriks S, Papma J.M. ... Kohler S. (sept 2021) Global prevalence of young-onset dementia: a systematic review and meta-analysis. *JAMA Neurology* Number of citations: 28, IF 18.3

RELEVANT RESEARCH ACTIVITY:

Please indicate for past 5 years only (i) Grants Awarded: Names of investigators; Years; Title of Project; name of awarding agency (ii) PhD and other projects: Title, start or completed date.

Over the last 5 years I have supervised several projects either as PI or work package leader and was the daily supervisor of 6 PhD students, 2 post docs and 6 research assistants. In the latter half of 2022 I received the news that I will be involved in several of the National Dementia Strategy consortia, i.e. YOD-included (lead Prof.dr. Raymond Koopmans), a consortium that focuses on optimizing diagnostics, care and support for people with young onset dementia; SPREAD+ (lead Prof.dr. Marjolein de Vugt), a consortium focusing on timely and effective psychosocial and technological innovations for people with dementia, NDPI (lead dr. Sebastian Kohler), a consortium focusing on inclusive dementia prevention initiatives.

Overview of the projects in which I worked as PI or WP leader, and was daily supervisor:

Project (awarding agency)	Topic	Supervision	Period
Post-diagnostic care and support (Erasmus MC Foundation)	Person-centered post-diagnostic care and support from a memory clinic perspective	Post doc (Jackie Poos)	2022-2024
Young Outstanding Researcher award (Alzheimer Nederland)	Measuring neuropsychiatric symptoms in day to day life (using wearables)	Post doc (Jackie Poos)	2022-2024

ABOARD consortium (ZonMw & Health Holland)	Culture-sensitive dementia diagnostics and care	Datamanager (Romy de Haan), PhD student (Najoua Lazaar), post doc (Sanne Franzen)	2021-2025
Social cognition testing in diverse populations (University of Paris)	Culture-sensitive dementia diagnostics	PhD student (Renelle Bourdage)	2021-2024
Klein maar Fijn project (gemeente Rotterdam)	Reaching hard-to-reach populations for health interventions in the municipality of Rotterdam	2 Research Assistants (Lisa van Son, Berfin Yurdakul)	2021-2022
Pilot project post-diagnostic care and support (Achmea & CZ)	Person-centered post-diagnostic care and support	Research assistant (Marijn van Ham)	2021
TIP project [thuis in probleemgedrag] (ZonMw & V&VN)	A bottleneck analysis on person-centered home care for dementia patients with neuropsychiatric symptoms	Research assistant (Hanna Bodde)	2020-2022
PRECODE consortium (Alzheimer Nederland & Gieskes Strijbesfonds)	Prevalence of young onset dementia in the Netherlands – related to existing care networks	2 Research assistants (Hanna Bodde & Guy Kolman)	2018-2022
TULIPA project (ZonMw Memorabel)	Culture-sensitive diagnostics and care	PhD student (Sanne Franzen), Research assistant (Yuled Kalkisim)	2017-2022
BEAT-IT study (ZonMw Memorabel)	Managing neuropsychiatric symptoms in Alzheimer's disease – person-centered care and support (an intervention study)	2 PhD students (Willem Eikelboom, Ellen Singleton)	2017-2022
FTD-RisC study (o.a. ZonMw Memorabel)	Presymptomatic behavioral and cognitive changes in frontotemporal dementia	3 PhD students (Lize Jiskoot, Jessica Panman, Jackie Poos)	2014-2021

CURRENT RESEARCH INTERESTS/ONGOING PROJECT TITLE:

Person-centered dementia diagnostics and care

I aim to improve dementia diagnostics and care by performing research into tailoring the patient journey to patient characteristics, such as cultural background, age (specifically young onset dementia), symptom profiles, and preferences. I thereby focus on the care pathway, examining and eliminating important hurdles for case-finding, early and person-centered diagnostics, and post-diagnostic support, as well as the care transitions in between. Through my research I aim to have important impact on the lives of people with dementia and caregivers. To achieve this, I perform translational research that is closely linked with the clinical work performed at the Alzheimer Center Erasmus MC (expert center dementia diagnostics). The topic of my research is **person-centered dementia diagnostics and care**. In my projects I focus on tailoring generic dementia diagnostics to patient characteristics and needs in terms of cultural background (culture-sensitive care), age (specialized care for young onset dementia patients), and symptoms (outpatient clinic treatment of underdiagnosed behavioural symptoms). The latter is the basis for new research into optimization of post-diagnostic support in order to empower community-dwelling people with dementia and their caregivers during an otherwise neglected phase within the patient journey.

HOW DO YOU INTEND TO CONTRIBUTE TO INTERDEM:

- I would like to be involved in gathering information and setting up a working group considering research on/and care in people with young onset dementia.
- I would like to share my knowledge on inclusive dementia research, diagnostics, care and support with Interdem (existing collaboration with Pharos on educating on inclusive research).