ENSURED

Empowering Needs-based Social Health and inclUsive care for RarEr Dementias in moderate to advanced stages

Dementia is an umbrella term encompassing multiple subtypes, with Alzheimer's disease (AD) being the most prevalent and extensively studied. However, non-AD dementias, such as frontotemporal dementia (FTD), Lewy body dementia (LBD), and vascular dementia (VaD), remain significantly under-researched, particularly in moderate to advanced stages. Perceptions of dementia are largely shaped by AD, reinforcing the notion of memory impairment as the defining symptom, while other subtypes with distinct behavioral, motor, or psychiatric features remain less understood and recognized in care and research. Dementia is also not a static condition; its impact evolves over time, shaped by personal, societal, and structural factors. Even within a specific subtype, individuals experience widely varying trajectories in social participation, independence, and role fulfillment; key dimensions of social health. Despite this diversity, healthcare research and systems often fail to recognize and address their evolving and often unmet needs, leading to disparities in care across regions and populations. This gap in scientific knowledge and clinical practice limits the development of effective, tailored interventions. A critical step in closing this gap is the use of digital monitoring tools to systematically track symptoms and experiences in rarer dementias over time. Guided by insights from Public and Patient Involvement (PPI), these tools will support timely and tailored interventions, enhancing person-centered care and care transitions. Additionally, the further development of the INTENSE self-experience toolkit will deepen understanding among caregivers and healthcare professionals through immersive simulations of impairments and behavioral changes, to improve their ability to adapt care strategies. Central to this effort is inclusive PPI, coordinated by Alzheimer Europe and embedded across all work packages and the full project duration. While PPI plays a critical role in shaping dementia research, perspectives from individuals with AD in earlier stages remain overrepresented. ENSURED will specifically involve people with rarer dementias, particularly in moderate to advanced stages, through European and national activities. This will generate more nuanced insights into care needs and inform evidence-based recommendations, inclusive research strategies, and innovation that reflect the lived experiences of those most affected.

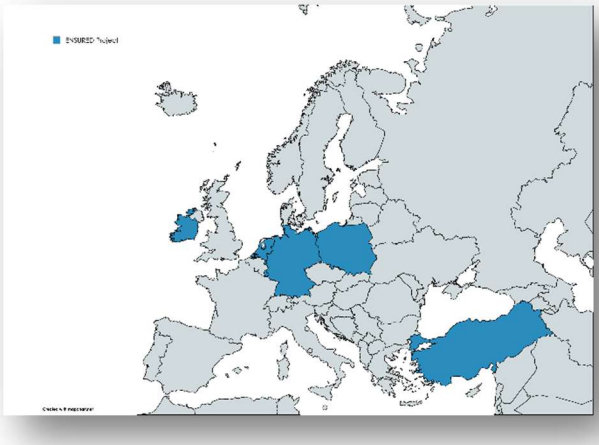
The ENSURED project integrates a social health framework and an intersectional lens to better understand and meet the evolving needs of individuals affected by rarer dementias across the disease process. By focusing on moderate to advanced stages, where individuals increasingly struggle to articulate their needs, we aim to map critical care transitions and identify key intervention points that optimize support across disease stages. The findings will contribute to practical, ethically grounded recommendations for more equitable and tailored dementia care, ensuring that insights from lived experience shape research, care pathways, and policy development. ENSURED will also strengthen capacity and shared learning among researchers, both within the consortium and through international networks such as INTERDEM. Together, these efforts will empower caregivers and professionals, improving social health and inclusive, person-centred support for people with rarer dementias.

Total Funding : 1.56 M€

Duration : 3 years

Coordinator : Prof. Dr. Marjolein de Vugt
✉ : m.devugt@maastrichtuniversity.nl





Consortium Members	
Prof. Dr. Marjolein de Vugt	Maastricht University, The Netherlands
Dr. Louise Hopper	Dublin City University, Ireland
Prof. dr. Martina Roes	German Center for Neurodegenerative Diseases (DZNE), Germany

	Dr. Ana Diaz	Alzheimer Europe, Luxembourg
	Dr. Seda Guney	Koc University, Turkey
	Prof. dr. Dorota Szczesniak	Wroclaw Medical University, Poland