DEM-CAPS

DEMentia CAre and Psychosocial Support interventions estimating health-economic impact to support access and implementation in practice

More than 90% of persons with dementia and their informal caregivers reported three or more unmet care needs. Fortunately, several psychosocial support interventions have been proven effective in addressing these unmet needs, improving symptoms and relieving informal caregiver burden. However, a lack of implementation and funding limits access to these interventions, and hence, unmet needs remain widely present. A reason for the implementation gap is incomplete knowledge of the resource use implications and cost-effectiveness of psychosocial interventions. To ensure that persons with dementia and their informal caregivers receive better psychosocial support, there is an urgent need for long-term health economic evidence on improving everyday quality of life, or delaying the need for long-term care. Such health-economic estimates can support decision-makers with required evidence for implementing and reimbursing psychosocial support interventions in practice. Aim: Our overall aim is to develop and validate a health-economic modelling framework that demonstrates the value of psychosocial support interventions for non-institutionalized persons with moderate to advanced dementia and their informal caregivers in Europe in collaboration with reimbursement decision-makers and patient organizations.

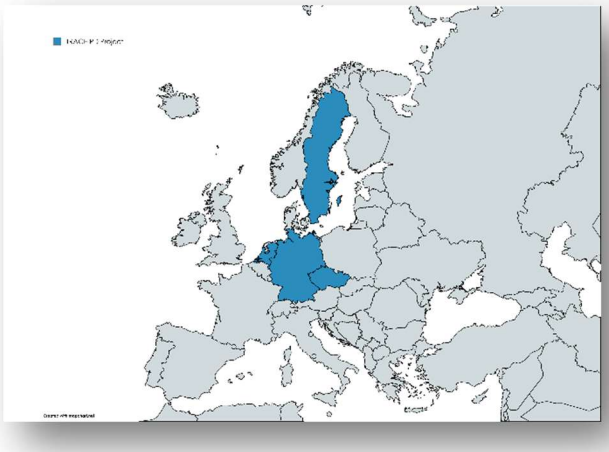
We propose five research questions (RQs) that, when answered, will strongly support the development and validation of a health-economic framework for psychosocial support in dementia care. For RQ1 (stakeholder analysis), we will explore the priorities and preferences of persons with dementia and caregivers through interviews, analysing care plans and assessing the perceived value of psychosocial support interventions. We will also conduct focus groups with payment and reimbursement decision-makers to describe the reimbursement pathway and identify the required health economic evidence needed for translation. In RQ2 (systematic literature review), we will evaluate how psychosocial outcomes have been used as surrogates for health-economic outcomes in existing studies. Additionally, RQ3 (data analysis) will develop and validate psychosocial outcomes as surrogates for health economic outcomes using large European observational datasets. In RQ4 (health-economic model), we will integrate RQ1-3 results into a health-economic modelling framework and apply it to two case studies to set an example of applying our developed framework. Finally, in RQ5 (stakeholder analysis), we will feedback our newly developed framework to the stakeholders in RQ1 for model validation. We will disseminate the model to ensure its application in research and value to reimbursement decision-makers. Dissemination: Open-access scientific publications; Alzheimer Europe conference; 3-day curriculum for psychosocial intervention PhD students (INTERDEM, Alzheimer Europe and its member organizations, and EATRIS network); open-source access to our modelling framework and all its associated materials. Dissemination to payment/reimbursement decision-makers is embedded in RQ1 and RQ5. Patient/public involvement: Alzheimer Europe will involve people living with dementia and their carers throughout the project, coordinating consultations of the European Working Groups of People with Dementia, and Carers.

Total Funding : 1.51 M€

Duration : 3 years

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