

Research to Assess Policies and Strategies for Dementia in the Young (RHAPSODY) : a European Initiative

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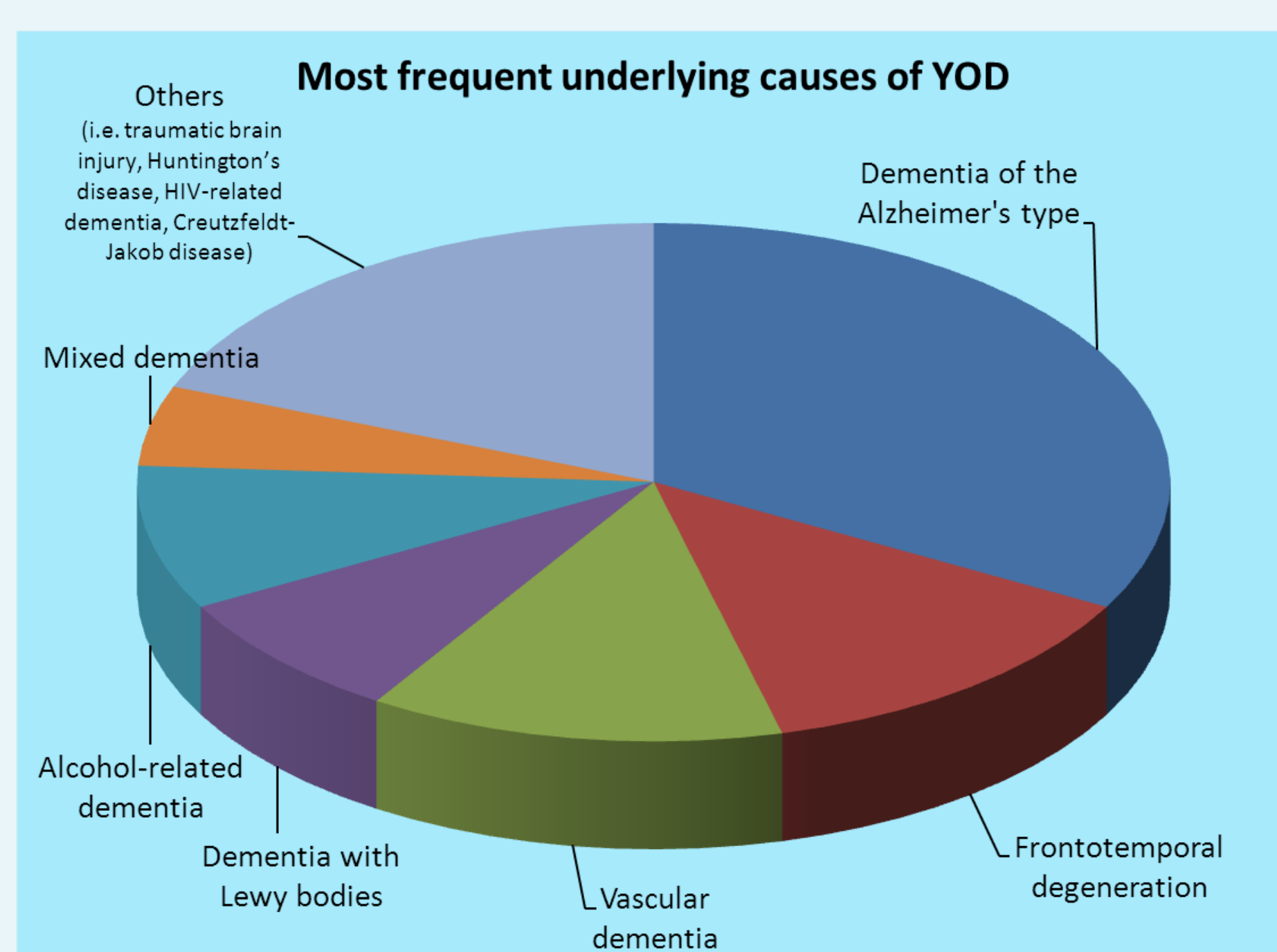
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Background

The RHAPSODY project brings together a multi-disciplinary consortium of eight partner institutions from six countries, with the goal of improving care for people with young onset dementia and their families.

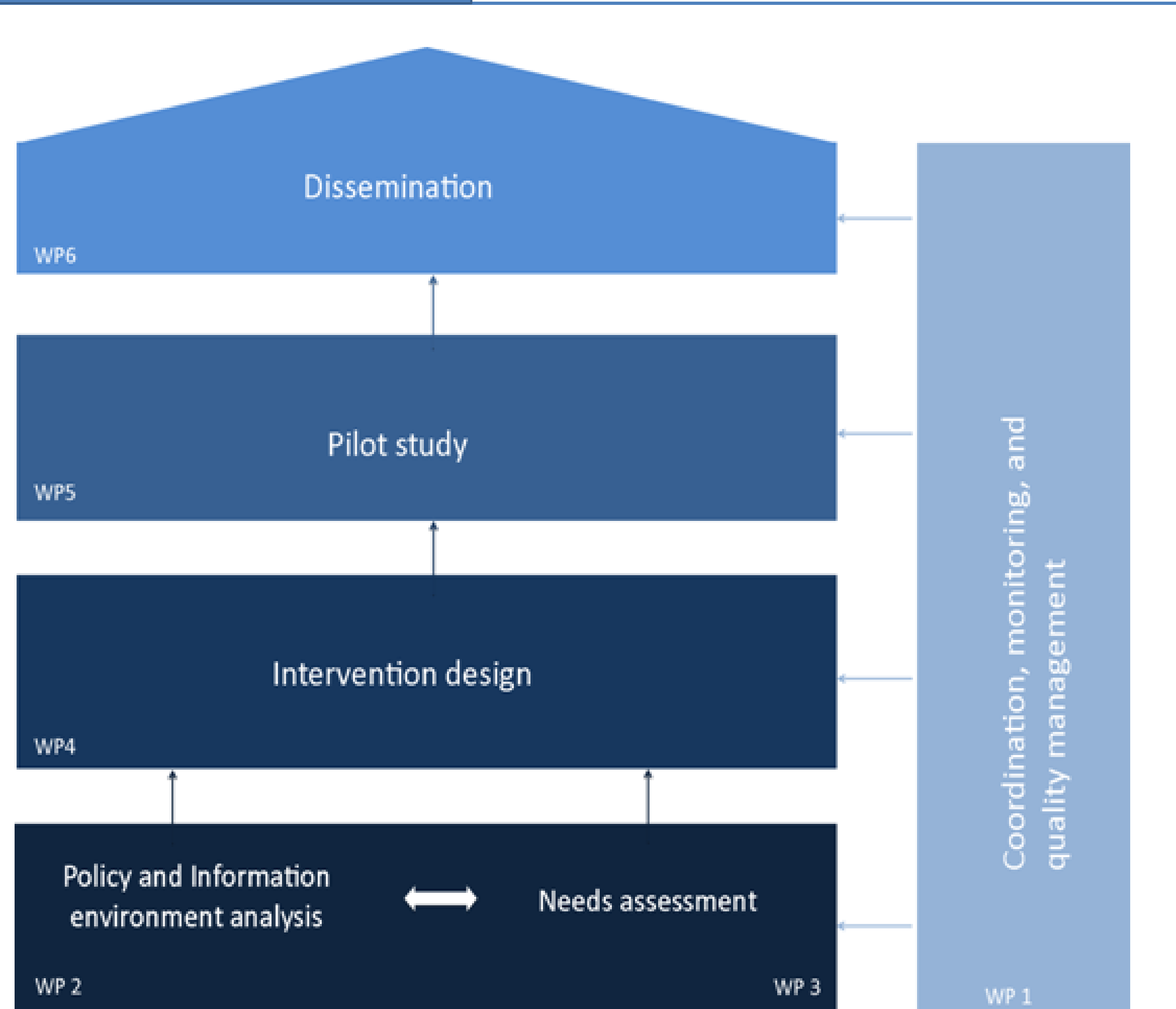
Young onset dementia (YOD) is defined by an onset of symptoms before the age of 65 years. Its prevalence is estimated at 1 per 1,000 in the population aged 45-65 years.

Dementia at a relatively young age is associated with specific and particularly severe challenges for patients, family carers, and healthcare professionals. These include delays in obtaining diagnosis and treatment, a lack of age-appropriate services and resources, reduced household income and significant impact on family relationships.



Source: Vieira et al.: Clin Pract Epidemiol Ment Health 9: 88-95, 2013.

Project Design



Preliminary Results

Policy and Information environment analysis (WP2)

Research Questions

- How is healthcare organized, financed and delivered in participating countries?
- How do system differences affect pathways to diagnosis, treatment and care for people with YOD and their family carers?
- What policies and guidance exists for health professionals, and what information is nationally provided for patients and carers?
- Is any national health and social system particularly suited to meet the needs of this population?

Method

In each country, open and structured internet searches were carried out targeting relevant government, professional and third sector organizations. Identified resources were reviewed and synthesized for cross-country analysis.

Initial Results

- Differences between countries exist concerning: access to specialists and multidisciplinary teams, choice of doctor, waiting times, prescribing, and the nature and frequency of follow ups
- Guidance for health professionals is rarely specific to YOD
- Except in the Netherlands, information for patients and carers is scarce and dispersed.

Needs assessment (WP3)

Research Questions

- What are the individual needs of people with YOD and of their family carers?
- What access do they have to existing services and care in the 6 participating European countries?

Method

- Literature review on the needs of people with YOD and their carers
- 12 focus groups with informal carers in 5 countries (France, Germany, Portugal, Sweden, UK).

Initial Results

- Families living with YOD face several challenges including premature retirement and reduced family income, difficulties for children to adapting to the parent's illness, care required for a longer period of time
- Information on behavioral management and practical advice on day to day living was most important for carers
- There were many similarities regarding carers' needs, across the different countries.

Status of ongoing research tasks

Intervention design & product development (WP4)

- Design of a **web-based educational and skill-building program** for family carers of people with YOD based on findings of WP2 and 3 and on existing programs
- Intervention will incorporate an **interactive learning design** and multimedia resources
- A prototype will be available in 3 languages (English, French and German)

Pilot Study (WP5)

- The **prototype** will be tested in a pilot study, in England, France and Germany
- A **randomized controlled trial design** will evaluate participants' use of and satisfaction with the program. Feasibility of the intervention will be assessed, including an economic analysis and a review of internal processes.

Dissemination and Implementation (WP6)

- **Communication** of results of the project via websites, newsletters of relevant organizations and press releases across Europe
- Production of a range of **educational materials** in various forms, for health-care professionals and service providers
- Design of a **sustainability model**

Project Partners : France, Germany, The Netherlands, Portugal, Sweden, United Kingdom