

# Shaping access to formal dementia care: the perspective of policy and political decision makers

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## Background

As part of the **ActifCare project**<sup>1</sup>, a EU Joint Programme – Neurodegenerative Disease Research (JPND), we conducted **expert interviews**<sup>2</sup> in **eight European countries** with policy and political decision makers to determine their perspectives on access to formal care for people with dementia and their carers. In the ActifCare context, the concept of **formal care refers to home nursing care, day care services and community or long-term medical, nursing, and social care structures and processes**, and excludes domestic home help, housekeepers, volunteers, support groups, transport services, and meal programmes. The project specifically focuses on the **“middle” stage of dementia**, in contrast to early stages with informal care or later stages with institutionalisation. Selected persons who are influential in politics and decision making were interviewed on innovative ideas, strategies or suggestions concerning how to structure and shape dementia care.

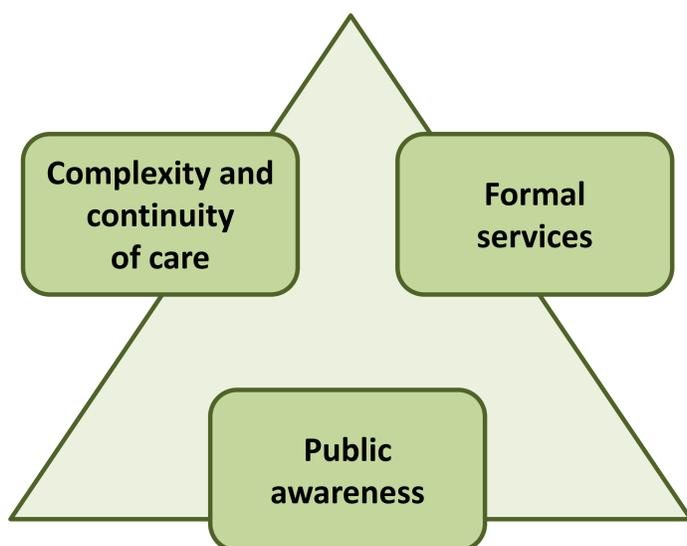
## Methods

### Sample:

- Each ActifCare country (Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Sweden, United Kingdom) interviewed 4-7 experts (total n=38) between 09/2015 and 01/2016.

### Interviews:

- Protocol-driven development and pilot test of semi-structured interview guide, which addressed three topics identified in ActifCare focus group interviews with people with dementia, informal carers, and health and nursing care professionals



### Analysis:

- Country-specific analysis of interview transcripts using inductive qualitative content analysis<sup>3</sup>
- Cross-national synthesis focusing on similarities in themes and categories across the ActifCare countries

## Results

The figure details themes for each interview topic with either direct expert quotations (*italic*) or lists of expert statements (normal)

### Complexity and continuity of care

- Coordinating role
- Information
- Networking
- Funding issues

„The most important thing is to have a single navigation point of a person.“ (UK)  
 „We must find out how to overcome the information deficit that obviously exists.“ (DE)  
 „You need systems where they are talking to each other.“ (IE)  
 „Sometimes a lot of this is about resources, and there just simply aren’t resources.“ (IE)

### Formal services

- Characteristics of services
- Biopsychosocial approach
- Groups with special needs
- Challenges of meeting special needs

Services should:  
 - be client-centred, tailored, responsive, bespoke  
 - operate multidisciplinary, proactively, flexibly  
 - involve voluntary sector, provide 24/7 access  
 „It is important to see the person behind the dementia.“ (NL)  
 migration backgrounds/minorities, under age 65, lower SES, comorbid diagnoses, living in rural areas, dyads where patient and carer are elderly, people without a family carer  
 small numbers in special groups, stigma of dementia, cultural aspects, remoteness of rural areas

### Public awareness

- Inclusion
- Raising awareness

„The aim should not be to have services for people with or without dementia. The aim should be to have services for people in advanced ages... We have to create normality here.“ (DE)  
 - education, even in kindergartens and schools  
 - involving mass media  
 - using campaigns, esp. “Dementia Friends”  
 - involving celebrities  
 - fostering community engagement

## Discussion

For the three topics, the common themes across ActifCare countries reveal keywords such as “Coordination”, “Information”, “Networking”, “Client-centred, multidisciplinary, proactive services”, or “Education, mass media and campaigns to raise public awareness”. These keywords are not new requirements, but are well established. Experts seem to be well aware of barriers and facilitators in their current dementia care systems, and well acquainted with current discussions among both researchers and practitioners of approaches to improve dementia care. Knowledge gained in these expert interviews may be used by national decision makers when they consider reshaping the organisation of dementia care.

### References:

- 1 <http://actifcare.eu/>
- 2 Gläser J, Laudel G. [Expert interviews and qualitative content analysis.] Wiesbaden: VS 2010.
- 3 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today, 2004, 24, 105–112.