



**LUND**  
UNIVERSITY

**RightTime**  
**PlaceCare**

Improving health service for European citizens with dementia

EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

# European health and social care and welfare systems for persons with dementia

Staffan Karlsson, RNT, PhD, Researcher, Senior Lecturer

The Swedish Institute for Health Sciences

The Department of Health Sciences, Faculty of  
Medicine

Lund University, Sweden

# Aim of the project

- Improving health service for European citizens with dementia
- Best practice strategies' development for transition from formal professional home care to institutional long-term nursing care facilities



# Eight countries are involved



EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

- Germany, Witten/Herdecke University, **Prof. Dr. Gabriele Meyer** (coordinator)
- The Netherlands, Maastricht University, **Prof. Jan Hamers**
- Sweden, Lund University, **Prof. Ingalill Rahm Hallberg**
- UK, The University of Manchester, **Prof. David Challis**
- Finland, University of Turku, **Prof. Helena Leino-Kilpi**
- Estonia, University of Tartu, **Prof. Kai Saks**
- France, University of Toulouse, **Prof. Bruno Vellas**
- Spain, Hospital Clinic Provincial de Barcelona, **Dr. Adela Zabalegui**



# Work packages

- WP 1 (Management) coordinate the project, D
- WP 2 (Health Care Structure) will describe and analyse the European care systems, and explore the communication between different care providers and the experiences of patients/consumers, S
- WP 3 (Survey) and WP 4 (Economics) will conduct a survey assessing the factors influencing the institutionalisation of patients/consumers with dementia, NL and D
- WP 5 (Best practice) will develop best practice strategies to improve integrated care in European dementia care systems, and recommendations for best practice models or interventions in long-term care facilities, ES
- WP 6 (Dissemination) will develop and implement dissemination plan to deliver the generated knowledge and best practice strategies to decision makers in dementia care, D



# Methods

- Literature reviews
- Focus groups
- Personal interviews
- Clinical assessments



## Background WP 2

- The care for persons with dementia is involving a diversity of social and health care interventions
- The systems for dementia care and services vary across European countries
- There is a lack of knowledge about the complex system for dementia care on a European level
- A more comprehensive view can serve as a base for the development of best practice in the care of for persons with dementia



# Objective



EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

- The objective the study is to describe and analyse the European health and social care and welfare systems for people with dementia.
- Focus on how data will be collected and how collaboration within the consortium will be performed.



# Terminology and definitions



EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

Agreement for the meaning of relevant terminology to describe the health and social care and welfare system for older people with dementia disease

- Overall description
- Stages in the dementia disease trajectory
- Types of care provided
- Care provider





# Overall description of the care system



EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

- Official statistics
- Laws and regulations
- Policy
- National guidelines
- Structure and organisation
- Financing, related to the elderly and dementia care in each country

Open ended description



# More detailed description of the care System



EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53

- Use of the agreed definitions and terminology
- Stages in the dementia disease trajectory
- Types of care provided
- Care provider

Use of a template to collect data



# Template

Type of care provided	Course of dementia (Moïse, Schwarzingger and Um 2004)/Care providers				
	<b>Diagnosis stage:</b> Marks the entry when the diagnosis of dementia is decided	<b>Early stage/mild Cognitive impairment:</b> When symptoms tend to be mild with a minimal impact on ADL, memory loss and social affairs	<b>Intermediate stage/moderate Cognitive impairment:</b> Marked by an Increased memory loss, and dependency of help in ADL and social affairs	<b>Late stage/severe Cognitive impairment:</b> Severe memory loss and the person is unable to look after her/him selves without continuous assistance in ADL and social affairs	<b>End of life stage:</b> Final stage of life when it is obvious that a person has limited time left to live
Care provided					
<b>Dementia screening program:</b> carried out in primary care with the aim of detecting dementia at early stages. Different tools might be used.	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>
<b>Standard diagnostic procedure for dementia disease:</b> Standard diagnostic procedure decided on a national basis.	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>	<b>A:</b> <b>U:</b> <b>P:</b>

**A= Availability U=Utilization (all, most, few, no one)**

**P= Provider (collected from “Terminology for care providers”)**



## Suggested data sources

- Official documents and descriptions of the system
- Interviews with responsible managers, providers or the like in relevant organizations
- Interviews with persons in consumers/users organizations
- Interviews with staff, professional employees and purchasers in a municipality or other representative for the county
- Validate responses with professionals at managerial levels within relevant organisations
- Official statistics
- Epidemiological studies
- Literature reviews



- This process will obtain an overall agreement for the meaning of relevant terminology for care of older persons with dementia disease
- This will make it possible to describe the health and social care system for older persons with dementia disease in a European perspective



# Thank you

RightTime  
PlaceCare

Improving health service for European citizens with dementia

EU, 7<sup>th</sup> Framework Programme  
Contract number: 24 21 53



<http://www.righttimeplacecare.eu>

