



Improving health service for European citizens with dementia



**Improving health services for European citizens with dementia:  
Development of best practice strategies for the transition from  
ambulatory to institutional long-term care facilities**

**SUMMARY OF MAIN FINDINGS FROM**

**RIGHTTIMEPLACECARE**

**November 2013**



This summary is part of the European Union funded project “Improving health services for European citizens with dementia: Development of best practice strategies for the transition from ambulatory to institutional long-term care facilities” - RightTimePlaceCare

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This report reflects the opinions and views of the RightTimePlaceCare Consortium. It does not necessarily reflect the view of the European Commission and does not anticipate future policies in this area.

Gabriele Meyer on behalf of the RightTimePlaceCare Consortium

## **Background and introduction**

Given the increasing number of people with dementia, healthcare services throughout Europe must be prepared to deliver high quality and cost-effective long-term care. At a time of significant financial constraint across Europe, the question of how best to care for people with dementia is of increasing concern. Although institutional long-term care facilities have long formed an important component of care in many countries, current policy guidance is generally focused on reducing the growth of institutional care and on enhancing the provision of home and community services. To date, however, there is considerable variation in the extent to which different countries have achieved this goal. Currently, clinical research data on people with dementia and their informal caregivers are not sufficient to develop best practice strategies for long-term care. The RightTimePlaceCare project aims were to develop such recommendations for transition from formal home care to institutional long-term nursing care facilities. The RightTimePlaceCare Consortium consists of a multidisciplinary group of researchers (nursing scientists, geriatricians, old age psychiatrists, psychologists, economists, biostatisticians) from eight European countries.

The RightTimePlaceCare project comprised six Work Packages (WPs), see Figure 1.

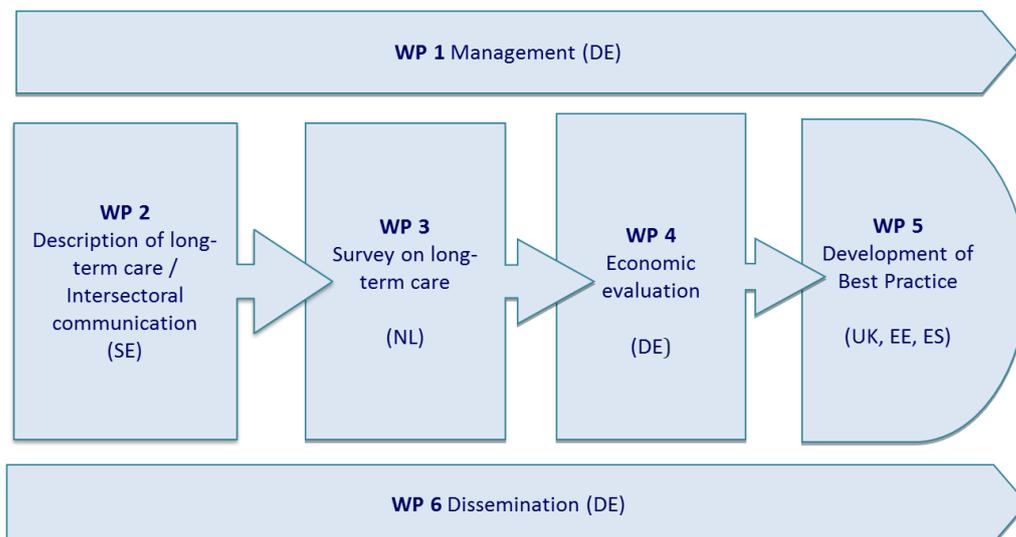


Figure 1: Flow of the RightTimePlaceCare project.

**WP1** (leader: DE) aimed at coordinating and managing the project.

**WP2** (leader: SE) described and analysed the European health, social care and welfare systems, advocacy and informal caregiver support systems for people with dementia and their informal caregivers, and the intersectorial communication using literature review, expert interviews and focus groups.

**WP3** (leader: NL) comprised a survey which a) assesses the factors influencing the institutionalisation of people with dementia and b) investigates the living conditions of people with dementia and their informal caregivers who receive long-term formal professional home care and institutional long-term care.

The related economic impact was investigated in **WP4** (leader: DE). The methods used were personal interviews with people with dementia and their informal caregivers (and formal caregivers in institutional long-term care), and record data extraction.

**WP5** (leaders: UK, EE, ES) aims at generating best practice strategies for intersectorial arrangement needed to improve the effectiveness and efficiency of integrated health care in European dementia care systems, and recommendations for best practice models or interventions in institutional long-term care facilities. Data from the other WPs were interpreted, using the Balance of Care approach.

**WP6** (leader: DE) aims at delivering the knowledge and best practice strategies effectively to politicians and other decision-makers in dementia care and to ensure a maximum general dissemination of the results.

The project period lasted from January 2010 to September 2013 (45 months).

A summary of the main results of **WP 2, WP3, WP4 and WP5** is presented on the following pages. We would like to refer the readers to our already published papers and to further papers which are under preparation or planned. Publication status in November 2013:

### **WP3**

Verbeek H, Meyer G, Leino-Kilpi H, Zabalegui A, Hallberg IR, Saks K, Soto ME, Challis D, Sauerland D, Hamers JP; RightTimePlaceCare Consortium. A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC Public Health* 2012; 12: 68

Beerens HC, Sutcliffe C, Renom-Guiteras A, Soto ME, Suhonen R, Zabalegui A, Bökberg C, Saks K, Hamers JP; on behalf of the RightTimePlaceCare Consortium. Quality of Life of and Quality of Care for People with Dementia Receiving Long Term Institutional Care or Professional Home Care: The European RightTimePlaceCare Study. *J Am Med Dir Assoc* 2013 Nov 9. doi:pii: S1525-8610(13)00546-X. 10.1016/j.jamda.2013.09.010. [Epub ahead of print]

Afram B, Stephan A, Verbeek H, Bleijlevens MH, Suhonen R, Sutcliffe C, Raamat K, Cabrera E, Soto ME, Hallberg IR, Meyer G, Hamers JP; RightTimePlaceCare Consortium. Reasons for Institutionalization of People With Dementia: Informal Caregiver Reports From 8 European Countries. *J Am Med Dir Assoc* 2013 Nov 12. doi:pii: S1525-8610(13)00548-3. 10.1016/j.jamda.2013.09.012. [Epub ahead of print]

### **WP2**

Hallberg IR, Leino-Kilpi H, Meyer G, Raamat K, Soto Martin M, Sutcliffe C, Zabalegui A: Dementia care in eight European Countries: Developing a mapping system to explore. *J Nurs Scholarsh* 2013 Sep 11. doi: 10.1111/jnu.12046. [Epub ahead of print]

## ***Family-oriented approach and proactive care planning***

Work Package 2 aimed at exploring the communication between different care providers and the experiences of patients/consumers with dementia and their informal caregivers with intersectorial information delivery throughout the trajectory of care, from diagnosis to end-of-life in the eight countries participating in the study.

The data collection aimed at generating potential-oriented rather than deficit-oriented concepts in an attempt to explore how intersectorial information delivery could be improved.

Focus groups with formal and informal caregivers and persons with dementia were conducted in all countries. Overall, 136 care recipients (group size n=10-27) and 131 care providers (group size n=12 to 26) were interviewed.

The results of the focus groups in the eight participating countries reflected a rather consistent view of communication between the countries as well as between the two types of focus groups, those with professionals versus those with patients, family caregivers or stakeholders.

### **The core findings are:**

- The primary focus of the information, collaboration and communication is on the person with dementia and his or her family/informal caregiver.
- Entering and living through the trajectory of the disease and its consequences following diagnosis was marked by comments particularly on the diagnostic phase and the following phase but not so much on the end-of-life phase of the disease.
- The care process in terms of information, collaboration and interaction was addressed on two levels; from a relational perspective i.e. the emotional quality of the relation between the professionals and the patient and the family caregiver; and from a task perspective i.e. the activities and content of the care process. The services and care offered to the patients and their informal caregivers as well as staff requirements and the skills needed were addressed.
- Information, collaboration and interactions during the care process should center on the patient and the family caregiver. Along the trajectory of the disease communication,

collaboration and interaction with professionals was emphasised and spoken about in terms of establishing a trusting relationship, emphasising the relational aspect of the communication and interaction with professionals.

- Participants wanted to have one person to turn to and tailor-made care that recognises the patient as well as caregivers and informal caregivers as persons.
- Variation in service and care should be offered addressing the personal needs of the patient and the informal caregiver.

Overall, the findings point to a family-oriented approach (Figure 2) and individual adaptation but also to the need for proactive care planning. Establishing a trustful relationship and having one person or organisation to turn to throughout the trajectory was regarded as a sign of best practice and tailor-made care indicated compliance with the concept of person-centered care.

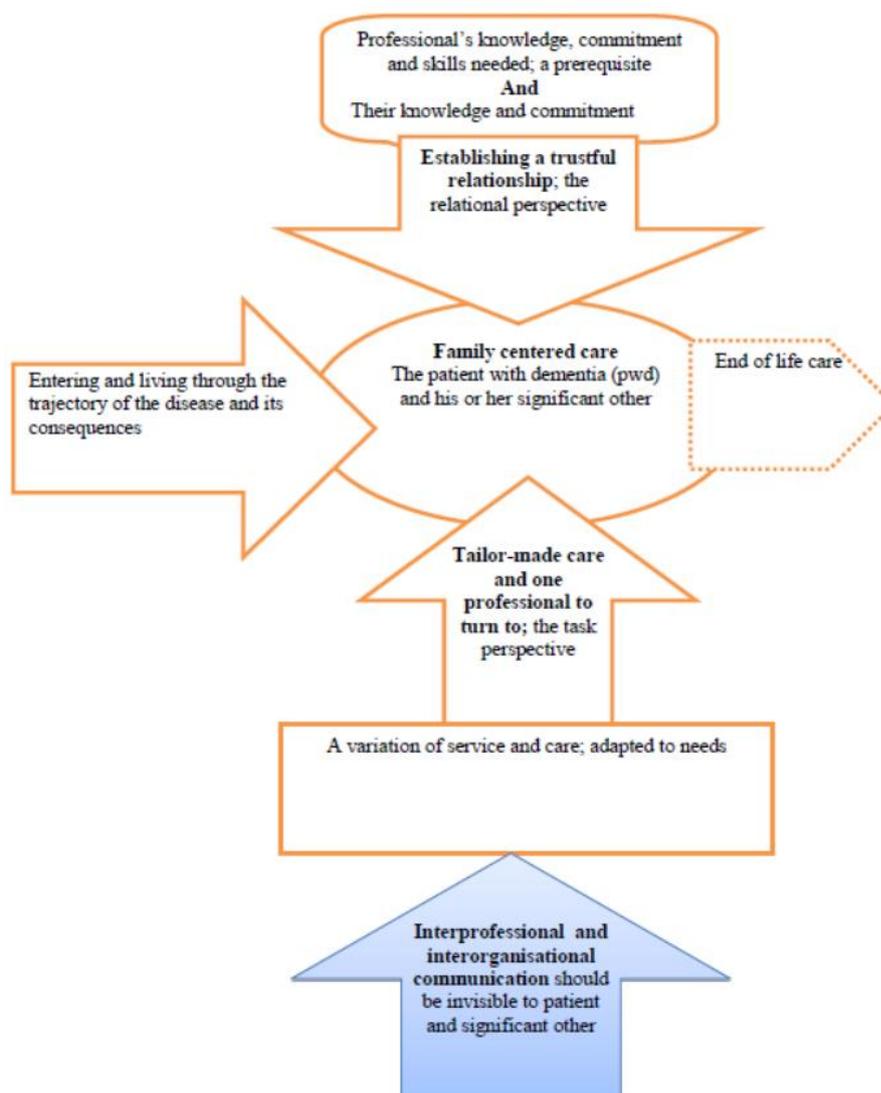


Figure 2: Characteristics of optimal communication, interaction and collaboration.

## ***Pronounced variation between countries in terms of reasons and predictors of institutionalization and quality of care***

In Work Package 3, a survey on long-term formal professional home care and institutional long-term care was conducted aimed at investigating the situation of 2014 people with dementia who were in the on the threshold between between home and institutional long-term care, i.e. in the transitional phase 'from care at home to the nursing home'. The main questions were: why are these people being admitted to a nursing home, what is the quality of life of people with dementia, what is the quality of care provided, and what is the burden for informal carers?

### **Reasons for admission to the nursing home**

The study examined in various ways the reasons why people with dementia are admitted to nursing homes. The study reveals that on a European scale there is no one single reason for admission to a nursing home. There is a lot of variation between countries. For example, the severity of dementia can be an important reason for nursing home admission in one country, whereas in another country that is less important.

There is no universal indicator that predicts whether people with dementia will be admitted to a nursing home in Europe. Considerable variations in the quality of life, quality of care and burden for informal carers are also found.

Despite the lack of an unequivocal predictor for nursing home admission there are still three factors that can be distinguished as the most important, namely: dependency in performing activities of daily living (such as washing and getting dressed), having behavioural problems (such as aggression) and a high care burden for informal carers.

### **Quality of life and quality of care**

Quality of life of people with dementia was rated by people with dementia themselves as well as by caregivers. The measurements reveal that the quality of life is generally assessed as positive. That applies to both people with dementia living at home and those who live in a nursing home. Care providers rank the quality of life of people with dementia in the nursing home as better than of those still living at home. The quality of life of people in the

Netherlands together with those in the United Kingdom, Germany and Sweden was assessed as the best.

The quality of care was assessed by examining the use of physical restraints, weight loss, pain, pressure sores, fall incidents, psychotropic drugs, depressive symptoms, and mortality within three months of moving to a nursing home. The variation in scores for these indicators between the European countries and the different living environments is remarkable; all have stronger and weaker aspects. To illustrate: in Estonia the number of pressure sores in nursing homes is high, whereas in German and Spanish home care many physical restraints are applied.

### **Informal carers**

In most countries, the caregiver burden of informal carers seems to be associated with nursing home admission. Both the objective burden (how many hours of care are provided) as well as the subjective burden (how much burden is experienced by informal carers) reveal that there is once again considerable variation in Europe. The most informal care in the home situation is provided in Estonia and Spain, and the least in the Netherlands. The amount of burden experienced by Dutch informal carers is also the least. Finally, informal carers in nursing homes report less burden than informal carers at home.

### ***Are costs mainly driven by institutional long-term nursing care?***

Work Package 4 was conducted alongside the Work Package 3 survey and aimed at comparing costs for people with dementia receiving professional home care but at risk of being institutionalized with the costs for PwD recently admitted to institutional long-term nursing care in eight European countries. Special emphasis was placed on differences in cost patterns across settings and countries; on the main predictors of costs and on a comprehensive assessment of costs from a societal perspective. Costs of care were assessed with the Resource Utilization in Dementia instrument (RUD). A log link Generalized Linear Model assuming gamma distributed costs was applied to identify the most important cost drivers of dementia care.

**The core findings are:**

On average, costs for institutional long term nursing care amounted to 4491 Euro per month and were 1.8 times higher than professional home care costs (2491 Euro). The relation of costs between settings ranged from 2.4 (SE) to 1.4 (UK). Costs in the institutional setting were dominated by nursing home costs (on average 94 %). In the home care setting informal care giving was the most important cost contributor (on average 52 %). In all countries costs in the home care setting increased sharply with disease severity. The most important predictor was independency in activities of daily living in all countries, except in Spain and France where severity of neuropsychiatric symptoms was the most important cost driver. A standard deviation increase in independency in activities of daily living translated on average into a cost decrease of about 22%.

Transition into institutional long-term nursing care seems to increase the total costs of dementia care from a societal perspective. Figure 3 shows estimates of mean total costs per month for each country and both settings. The estimates took the heterogeneity across countries, settings and disease severity into account.

However, there is a pronounced variation related to the country on its own and the severity of dementia. It is also sensitive to alternative methods for the valuation of informal caregiving and nursing home accommodation.

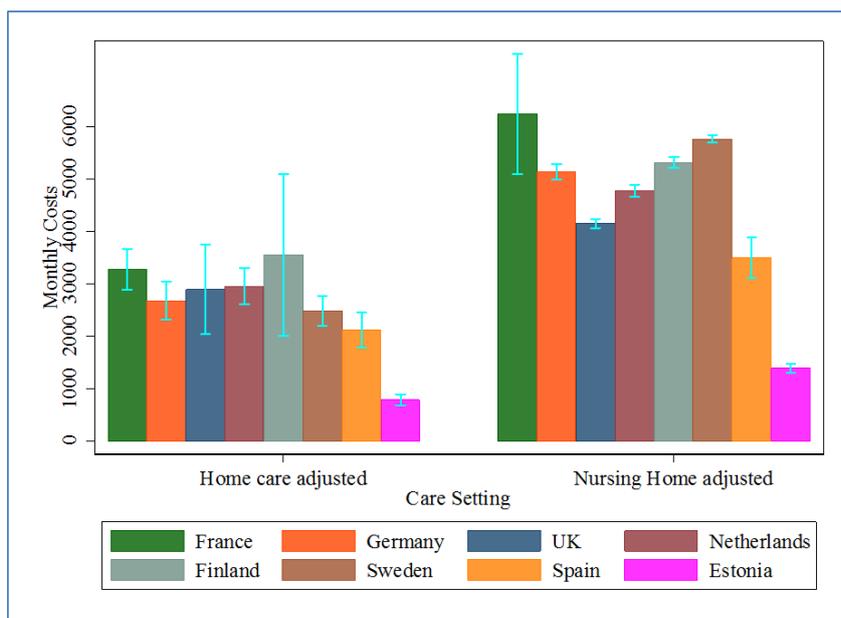


Figure 3: Mean (95 % confidence interval) total costs per month by country and setting (adjusted for differences in disease severity and socio-demographics).

## ***Expert suggest that the balance of care for people with dementia could be improved***

Finally, in Work Package 5 the RightTimePlaceCare project applied the Balance of Care approach, examining whether people with dementia on the threshold of care home entry receive the most appropriate care according to professional judgement, and whether, how and with what consequences the mix of institutional and community services offered by care providers could be improved.

Briefly, data from the Work Package 3 baseline assessment of n=2014 people with dementia and their caregivers were used for classifying people with dementia into case-types according to functional and cognitive status, behavioural symptoms, caregiver burden and living situation. A total of 14 case-types were selected and vignettes were written as if the person was living at home. At least 15 experts who had the expertise to assess care needs for people with dementia (e.g. case managers, district nurses, geriatric team members, general practitioners and specialist physicians) in each country were invited to group discussions. Participants were divided into small multidisciplinary groups and each group worked with randomly pre-selected vignettes. The experts discussed the appropriate care location. Detailed care plans were requested for vignettes where the group's choice was in favour of home care or assisted living.

### **The core findings suggest:**

If enhanced community services were available, at least a quarter of the people with dementia currently admitted to a residential or nursing home, in all but one country, might be more appropriately supported in their own homes. That is to say, the current pattern of admissions to institutional long-term care facilities did not always correspond with experts' recommendations. The findings also provide information about the types of people who would be affected by these shifts in each participating country, and the extent to which such moves would be cost-effective. These suggest there could be the potential to release significant resources (of up to €1,288 million in total) for reinvestment in the community.

### What are the implications?

Whilst the results indicate that governments seeking to make strategic shifts away from institutional care will each face different challenges and opportunities (including the need to reconfigure services in ways that are appropriate for their particular context and culture) they also highlight a number of common components that will need to be in place for such shifts to occur.

### These may be seen to constitute an agenda for action, and include:

- An increase in the provision of those community services necessary to enable vulnerable older people to remain in their own homes, including home and day care (either generic or dementia-specific), the delivery of meals, and transport services
- The use of standardised multidisciplinary assessments when making decisions about people with dementia on the margins of care
- The need to co-ordinate care for people with dementia by, for example, the development of intensive care/ case management arrangements
- The development of staff skills in the management of challenging behavior
- Setting up information networks that can support both front line staff and service planning
- Contemplation of the different services and systems operating in other countries and their relative strengths and weaknesses

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