Executive summary

Background: 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. 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 aimed to develop suggestions on best practice for the transition from formal home care to institutional long-term nursing care facilities. Methods: The RightTimePlaceCare Consortium consists of a multidisciplinary group of researchers from Estonia, Finland, France, Germany, Spain, Sweden, the Netherlands, and United Kingdom. Work Package (WP) 1 aimed at coordinating and managing the project and WP 6 at dissemination of project results. WP 2 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 intersectorial communication. WP 3 comprised a survey which a) assessed factors influencing institutionalisation of people with dementia and b) investigated their living conditions. The related economic impact was investigated in WP4. WP5 aimed at generating best practice strategies. First, a literature review was conducted and second the Balance of Care approach applied, examining whether people with dementia on the threshold of nursing 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. Results: The descriptive part of WP 2 for instance indicates that nursing staff skills in dementia care are very heterogeneous throughout participating countries. Early diagnosis and application of non-pharmacological interventions could be improved. Palliative care is not widely implemented for people with dementia. The findings of focus group interviews point to a familyoriented approach and individual adaptation of care but also to the need for proactive care planning. Establishing a trustful relationship and having one person or organisation to refer to throughout the trajectory was regarded as a sign of best practice and tailor-made care indicated compliance with the concept of person-centred care. WP 3 revealed that there is no universal indicator predicting admission of people with dementia to a nursing home throughout Europe. Also, considerable variation in quality of life, quality of care and burden for informal carers was found. WP 4 showed that transition into institutional long-term nursing care seems to increase the total costs of dementia care from a societal perspective. There is pronounced variation related to the country and severity of dementia. Variation is also sensitive to alternative methods for the valuation of informal caregiving and nursing home accommodation. WP 5 indicated that the availability of enhanced community services, could allow at least a quarter of people with dementia currently admitted to a residential or nursing home to be more appropriately supported in their own homes. Thus, the pattern of admissions to institutional long-term care facilities did not regularly correspond with recommendations by experts in WP 5 that were retrieved from structured group discussions of typical case vignettes based on WP 3 data. The findings also provide information about the types of people with dementia in each participating country who would be affected by such re-structuring and the related cost-effectiveness. The results suggest that there could be a potential to save significant resources that could be reinvested in the community. Conclusion: The results of RightTimePlaceCare suggest distinct areas of improvement in practice and also open an agenda for further research. The RightTimePlaceCare recommendations will be directed towards a large target group of policy and decision makers.