



Access to Timely Formal Care (Actifcare) Newsletter

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Issue 1

Website: www.actifcare.eu

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Editorial

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Most dementia strategies are aimed at promoting an early diagnosis of dementia as it opens the way to timely future care and treatment, and can help people take control of their lives and plan ahead. However, from previous research (including our own) people with moderate to severe dementia and their carers do often not receive services of the type, quality and timing that they need. There is a paradox in that people in early and middle stages of dementia often reject formal support, but this is regretted in later stages.



Actifcare (Access to Timely Formal Care) is an exciting new European dementia research project, performed by a team of excellent researchers from eight EU countries (the Netherlands, Germany, United Kingdom, Sweden, Norway, Ireland, Portugal and Italy). The study was part of the large Joint Program on Neurodegeneration, initiated by president Sarkozy from France who called upon more collaboration across Europe.

The ultimate goal of this ambitious study is to optimize the care for Europeans with dementia in the middle phase by identifying best practices and finding the best fit between needs and appropriate access and use of care services. We aim to better understand the reasons for this miss-match between the need for, access to and use of formal care services. The objectives are threefold: first, motives are explored why people with dementia and their carers use, or do not use formal care services. Second, current health care services in the European countries are described aimed at finding innovations to improve health care. And

last, but certainly not less important, the costs and consequences will be evaluated of existing pathway through formal care for people with dementia. A mix of methods will be used to obtain these objectives (literature review, focus groups, expert consultation and a longitudinal cohort study).

Since the kick-off in January 2013, several research meetings were organized to discuss the progression of the study. In all countries, focus groups with people with dementia, carers and health care professionals have now been performed, compared, and analyzed. We have been able to include the target number of participants, and we are now performing our last follow-up assessments. The majority of the people are interviewed at home. Participants are very positive and indicate it is "great to have someone visit you who listens to your experiences" and that "it is nice to contribute to such an important topic".

We hope to inform you about the first results of this cohort study in our next newsletter.

Meanwhile, I wish you all the best for a happy and healthy 2016.

Professor Frans Verhey

We welcome feedback on this newsletter and questions about the Actifcare project. If you would like to contact us, please email the editor:

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Or use the 'Contact Us' page of the Actifcare website



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Barriers and facilitators to formal care access – a focus group study with healthcare professionals, people with dementia and informal carers in 8 countries (WP2)

In this study, 55 focus groups were held with 261 healthcare professionals, informal carers and people with dementia (between 09/2014 and 04/2015). The participants (see Table 1) were invited to discuss their experiences with access to and use of formal dementia care. A qualitative content analysis was then conducted, focusing on barriers and facilitators to care. The findings of all the participating countries were summarised and an excerpt is presented here.

Table 1. Participant characteristics

	Informal Carers	People with Dementia	Healthcare Professionals
Groups, n	21	14	20
Participants, n	96	51	114
Women, n (%)	77 (80)	28 (55)	97 (86)
Mean age in years (range)	63 (37-91)	76 (54-96)	45 (23-62)

What emerged was a complex interplay of factors that seem to influence access to and the of formal dementia care, with the situation and characteristics of people with dementia and their carers playing a decisive role. People with dementia and their carers may have certain attitudes towards formal care and towards dementia that form inner barriers to seeking professional support. Accordingly, healthcare professionals describe people with dementia and their carers as being reserved with regard to professional support, often seeking help too late or waiting until a crisis occurs. The stigma connected with dementia is still described as an important obstacle. Moreover, caregiving may have a certain meaning for informal carers, e.g. fulfilling a promise or giving something in return to the person with dementia. They may feel obliged to provide care and accepting professional support may be regarded as a personal failure. Moreover, formal care may not merely be a relief but also may have negative implications for the family, such as losing control over the caregiving situation or accepting strangers invading their privacy, and thus may cause ambiguous feelings. This is all the more serious when professional support itself is perceived as stigmatising.

“That stigma behind ... social services ... with certain generations when they hear social services, people think they're going to be put in a home.” (Healthcare professional/United Kingdom)

As a consequence of the disease, people with dementia may not have full insight into their needs and may thus reject support. Some people in an early stage of the disease who participated in the focus groups were quite aware that this moment may come and that they will then rely on others for fulfilling their needs and avoiding dangerous situations. From the perspectives of people with dementia, formal care was predominantly perceived as a threat to their independence, and thus they sought to avoid it for as long as possible. Being independent and being involved in decision-making emerged as a fundamental wish of people with dementia that was often contradictory to their perceptions of or experiences with professional support.

“They think of us as worse than children (...) but it's a mistake because we always carried on by ourselves until now and we're doing it even now.” (Person with dementia/Italy)

The characteristics of healthcare professionals, such as their social competencies, attitudes and knowledge, are also important aspects, serving as either barriers to or facilitators of care. Having a key contact person, who is constantly approachable for people with dementia and their families and who establishes a bond of trust, was considered a key facilitator to access, but this is apparently lacking in most countries. Such a key contact person would also enhance continuity in care and reduce system-related barriers such as complex legal regulations and disjointed long-term care systems.

“There has to be one person who knows everything in order for a decision relating to a person to be made in the best interests of that person with their wishes and their needs and their wants and likes and stuff, but there's not. People take responsibility for their part of it.” (Healthcare professional/Ireland)

“As a result of the fact perhaps that I don't know at all how things function in the healthcare system, maybe I don't have the same demands.” (Informal carer/Sweden)

These findings provide other Work Packages with information about the ActifCare project and also give important insight into the range of aspects influencing the uptake of services by people with dementia and their families across eight European countries.

Anja Bieber, Gabriele Meyer, Astrid Stephan

The Actifcare Cohort Study (WP3)

An important part of Actifcare is the cohort study, in which people with dementia and their caregivers will be followed for one year. These people with dementia do not yet use formal care (such as personal home care) at baseline, but are expected to start using formal care within the next year. This allows us to closely monitor the process of finding (non)-timely access to care. Approximately fifty dyads have been included in each country: in this way we can compare the needs, quality of life and service use of people in Europe. This will increase our understanding of why people with dementia and their caregivers use, or fail to use formal care services across Europe, and how the use of formal care is experienced.

Country	Participating Dyads
UK	76
Norway	60
Portugal	66
Italy	53
Germany	51
The Netherlands	51
Sweden	50
Ireland	43

Costs and Consequences (WP4)

As part of Work Package 4, we want to understand the costs and consequences of formal care services use by people with met and unmet needs across the eight countries in our study. We also want to determine the major drivers of these costs and of people's quality of life, and the relationship these drivers have with formal care services.

We have developed a health economics analysis plan to guide this work and we have begun to identify unit price costs for the provision of healthcare in each country. This work will continue in 2016.

Once the results of the cohort study are available (from WP3 in 2016), we will also validate the use of two new measurement instruments for the assessment of quality of life in relation to the timing of formal care: (1) the ICECAP-O and (2) the CarerQoL.

Results from this Work Package will be presented in later editions of this newsletter.

Identifying Best Practice (WP5)

A protocol for a review on the existing literature on interventions aiming at increasing access and utilization of formal care for people with dementia, has been prepared. We planned to do a systematic review, but after a pilot search, we decided that a scoping review would be more appropriate. The literature search will be conducted in December 2015.

In order to collect corresponding information from national sources (including legal document and grey literature) a template has been circulated to each national group. They will deliver the results of the national searches by mid December.

We will present preliminary results at the next meeting in the Actifcare research group in Oslo in February.

The review will be the first step in the work with the best practice recommendations, which in addition will be based on results of WPs 2, 3 and 4 and a Delphi-process. The Delphi-process, an iterative approach to achieving consensus, will be conducted in 2016.

Recent Actifcare Presentations and Publications

A range of conference presentations and posters describing the Actifcare project and our results to date are available on our website on the **Publications—Actifcare Publications** page. Highlights from the last year include presentations at the:

- International Association of Gerontology and Geriatrics European Congress in Dublin in April 2015
- Alzheimer Association International Conference 2015, in Washington DC in July 2015
- 25th Alzheimer Europe Conference in Ljubljana in September 2015
- International Psychogeriatric Association (IPA) International Meeting in Berlin in October 2015

National language presentations are also available from the Portuguese and Norwegian teams.

Actifcare in the News

Plenary meeting—September 2015



At our last meeting, the WP2 team presented initial results from the cross

country analysis of the focus groups described on page 2. The WP3 team presented an overview of the baseline recruitment for the 1-year cohort study (more on this in the next issue). WP4 and WP5 gave updates of their current progress and we will also be hearing more from them in future issues.

National language interviews about the Actifcare project are available on the **News** page of our website. Visit this page to hear interviews with:



Prof Frans Verhey
Maastricht University

Prof Gabriele Meyer
Martin-Luther University
Halle-Wittenberg



And to view a variety
Of newspaper articles that have been
printed over the last year.

Also visit the news section of our website to listen to Dr. Kate Irving dispel the four myths of Dementia in her compelling TED X talk in Dublin City University

<http://actifcare.eu/wp-content/uploads/2015/08/watch.html>



Forthcoming Events

- The next Actifcare Plenary Meeting will be in Oslo on the 4th and 5th of February 2015.
- We would also like to draw your attention to the upcoming Nursing Congress 2016 in Rotterdam (<http://rotterdam2016.eu>). Dementia is one of the main topics of the conference and it will be an excellent platform for networking and exchange.
- Abstract calls are currently open for the World Gerontology Conference (Nice, 2016) and for the AAIC Conference in Toronto in July 2016.

In the Next Issue (April/May 2016)

- An update from WP3 on the progress of the 1-year cohort study.
- Commentary from WP5 regarding the guidelines currently available for formal home-based and community-based care across our eight partner countries.
- An update from the February 2016 plenary meeting.
- Other news items from around the project.

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- Ireland, Health Research Board (HRB)
- Italy, Italian Ministry of Health
- Netherlands, The Netherlands Organisation for Health Research and Development (ZonMW)
- Norway, The Research Council of Norway
- Portugal, Fundacao para a Ciencia e a Tecnologia (FCT)
- Sweden, Swedish Research Council (SRC)
- United Kingdom, Economic and Social Research Council (ESRC)

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