Welcome to the second newsletter of our European dementia research project Actifcare (ACcess to TImely Formal Care), of which the ultimate goal is to optimize the care for Europeans with moderate dementia by identifying best practices and finding the best fit between needs and appropriate access and use of formal care services.

Excellent results were achieved in the past year due to the hard work of all Actifcare team members and pleasant collaboration within the consortium. All baseline measurements of the cohort study (WP3) were finished in February this year. A total of 453 people with dementia and their informal caregivers were visited at their homes. Meanwhile the follow-up measurements (i.e. six and 12 months) are ongoing. There are only a few study drop-outs so far and the researchers were welcomed back when visiting the participants again. The plan is that all measurements will be finished in July of this year. A MACRO data management system has been developed for the study and it was frequently updated based on researchers’ experiences. During the fifth research meeting in Oslo in February 2016 some baseline demographic data and some clinical data were presented and discussed. So far we have a very good database with very few missing data due to the great dedication of all members of the consortium! Currently, WP1 and WP3 are developing a detailed analyses-plan for the analyses of the cohort study. You can read more about this study on page 2 of this newsletter.

Besides the cohort study, a lot of work was performed in the other work-packages as well. Regarding WP2, two deliverables have already been completed (see newsletter 1 for more information) and thorough cross-country reports have been written. The analyses of the expert interviews with decision-makers are still on going. WP4 finished the analyses plan and is working on the validation of the new quality of life instruments. WP5 is currently analysing and synthesizing the literature scoping review. A summary of this review is presented on page 3 of this newsletter. WP6 has worked hard on the dissemination of the project, by hosting and maintaining a website and social media presence, issuing press releases, disseminating project presentations and publications, and by developing and issuing the Actifcare Newsletters. In each partner country, one person is responsible for all of our social media dissemination.

We will keep up the hard work! More results of the Actifcare study will be presented to you in our next autumn newsletter. Meanwhile, I wish you all a sunny spring and summer season!

Professor Frans Verhey
The cohort study, in which people with dementia and their caregivers are visited three times during one year, is an important part of Actifcare. The group of people that we follow were not using formal care at baseline, but were expected to start using formal care within the next year. This study allows us to closely monitor the process of finding (non-)timely access to care. Within Actifcare, formal care includes home nursing care, day care service, community or long-term medical care, nursing and social care structures. It excludes domestic home help, housekeepers, volunteers, support groups, transport services and meal programs.

Table 1. Participant inclusion rates in partner countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>Participants at baseline</th>
<th>Loss to date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Netherlands</td>
<td>51</td>
<td>4</td>
</tr>
<tr>
<td>Germany</td>
<td>54</td>
<td>3</td>
</tr>
<tr>
<td>UK</td>
<td>76</td>
<td>2</td>
</tr>
<tr>
<td>Ireland</td>
<td>43</td>
<td>1</td>
</tr>
<tr>
<td>Sweden</td>
<td>50</td>
<td>2</td>
</tr>
<tr>
<td>Norway</td>
<td>60</td>
<td>4</td>
</tr>
<tr>
<td>Italy</td>
<td>53</td>
<td>5</td>
</tr>
<tr>
<td>Portugal</td>
<td>66</td>
<td>4</td>
</tr>
</tbody>
</table>

We have included 453 dyads across the eight countries. All baseline data have been entered into a database and here we present the preliminary demographic information. We have included 207 male and 246 female people with dementia (54% is female). The mean age in our group is 78 years old, with the youngest person being only 47 years old, and the oldest person 98 years old. The mean years of education is 10 years.

We included people with different types of dementia. The majority (48%) have Alzheimer’s Disease (AD), 12% have Vascular Dementia (VD), and a minority have other forms of dementia (e.g. mixed AD/VD, Lewy Body Dementia, or unknown); 69% of the people with dementia are married, while 24% are widowed. There is a small group (19%) who live alone.

We administer a short test with everyone in our sample to get an estimate of overall cognitive function. This test looks at memory, orientation in time and place, attention, calculation, language and ability to follow simple commands. The mean score in this group is 19 out of 30.

In the group of informal carers, we found a variety of relationships with the person with dementia. The majority (60%) are a spouse of the person with dementia. A smaller group of 30% are children. Other relations are partner (4%), son- or daughter in law (1.6%), sibling (1.1%), friend (0.4%) or neighbor (0.4%). The mean age of the carers is 66 years old (SD=14 years), with the youngest carer being 25 years old, and the oldest 92; 66% of the carers are female.

The majority of people have been visited at home. The 6-month and 12-month visits are currently taking place. There are only a few people who have dropped out due to various reasons, such as illness, death, or overburdening of the carer of the person with dementia, but the majority of dyads are still participating.

Along the way you really get to know each of the participants, as they share personal information and views with you. This makes the visits very pleasant for the researchers and participants alike. In the next edition we can tell you more about our findings at baseline!
The Actifcare Scoping Review (WP5):
Title: Interventions, policies and recommendations to improve timely access to and utilization of community care services for home dwelling persons with dementia and their informal caregivers.

The work with the WP5 scoping review is progressing. The purpose of this type of review is to present an overview of the research field. It can also be used to identify gaps in the evidence base and draw conclusions from existing literature regarding the overall state of research activity.

The main difference between a systematic literature review and a scoping review is that a scoping review does not include a synthesis of evidence, nor does it assess the quality of the evidence, which is the purpose of a critical systematic literature review or a meta-analysis. A scoping review will have a broader “scope” and less restrictive inclusion criteria and includes studies with different designs and methods as well as grey literature. For the purpose of the Actifcare project a scoping review is considered a useful approach to mapping and collating existing literature in a summary format that can be useful for policy makers.

The search for literature in international databases has been conducted, as well as the searches to collect corresponding information from national sources of the Actifcare countries. To be included, studies must evaluate an intervention to enhance access, and the outcome must be access to, or use of, formal community care services defined as home nursing care, day care services, in-home long-term medical nursing, and social care structures. We are interested in which methods and outcomes are used to evaluate the interventions, as well as their results.

We also search for national and international grey literature, including existing policies and recommendations for guiding the improvement of timely access, and will look at the type of evidence these are based on.

After duplicates were removed, approximately 3000 studies were retrieved from the search in international journal databases. Papers that concerned medication or nursing home populations were excluded based on screening of titles. The majority of the papers that were excluded based on screening of abstract or full text did not have access to community services as outcome.

Experts in the area are contacted and asked if they have knowledge of papers that fulfill the inclusion criteria but have been omitted in our search. The work with the scoping review is planned to be finalized in 2016.

Scientific Modelling for Alzheimer’s and Related Dementias (SMARD)

The SMARD platform has been created by researchers within the Actifcare project to provide open source health technology assessment (HTA) material with a focus on decision analytic modelling.

The decision model simulates diagnostic procedures and disease progression in Alzheimer’s disease, and it is based on the published work of international researchers in the area. Decision models in are continuously improving and many aspects regarding methodology remain to be learned. Sharing this knowledge is of major importance.

We see databases like ADNI travel all over the world providing a major boost to scientific knowledge. In our opinion the logical next step is to share (pieces of) decision analytic modelling code to be discussed and improved by the community.

Recent Actifcare Presentations and Publications

Conference presentations and posters describing the Actifcare project and our results to date are available on our website on the Publications—Actifcare Publications page. Recent highlights include:

- Care Alliance Research Conference in Dublin in November 2015
Actifcare in the News

Plenary meeting—Oslo, February 2016

At our last meeting, the WP3 and WP4 teams presented initial findings from the baseline data of the cohort study. The analysis plan was discussed and this will be a key topic for our next meeting. WP5 presented some preliminary results from the scoping review and the Norwegian team spoke of their experiences with the qualitative interviews at the final data collection point. WP6 outlined current dissemination progress and brainstormed some ideas for the final project meeting.

A Norwegian web-site for children and teenagers who have a mother or a father with dementia was launched in December 2015. This site has tailored information about dementia and advice to children and teenagers, written in an easily understandable language, and there are links to people and organizations that can help. The site is run by Ageing and health in cooperation with the national Alzheimer’s organization (NGO) with funding from the Norwegian Directorate of Health. The short film has just won a prize, “Gullblyanten” (the golden pencil) for its good communication. The film is in Norwegian (English audio due shortly).

web-site: http://hvemsermeg.no/
(hvem=who, ser=sees, meg=me)
The mascot of the site is the owl Huske (=Remember)

Forthcoming Events

- The next Actifcare Plenary Meeting will be in Lisbon on the 21st and 22nd of October 2016.
- 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. Two Actifcare papers will also be presented.
- Abstract calls are currently open for the Alzheimer Europe Conference in Copenhagen in October 2016.

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- Germany, Bundesministerium für Bildung und Forschung (BMBF)
- 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, Fundação para a Ciência e a Tecnologia (FCT)
- Sweden, Swedish Research Council (SRC)
- United Kingdom, Economic and Social Research Council (ESRC)

In the Next Issue (Autumn 2016)

- An update from WP3 on the progress of the 1-year cohort study and the conclusion of data collection in each country.
- Commentary from WP3/WP4 regarding the analysis plans for the data from the cohort study and initial results from baseline data.
- Plans for the October 2016 plenary meeting.
- Other news items from around the project.

Actifcare Partners