

Grant proposal ZONMW Dementia-friendly societies, 2nd round

Part 1 Memorabel project

1.1 Titel:

Improving and sustaining positive health of people with dementia and caregivers by creating dementia- friendly societies

1.2 Priority of ZONMW = topic area 4.4; Thema 4: Doelmatige zorg en ondersteuning

Planned start date: 01-07-2017; Planned duration: 48 months

1.3 Summary

People with dementia (PWD) and their carers experience social stigma and often refrain from social participation. Participation in social activities is part of the new concept of positive health, important for healthy aging, promoted by the World Health Organization and dementia research theme (Deltaplan Dementia). Empowering self-management of PWD and carers is partly effective to enhance social participation, yet, significant improvement might be achieved through adapting social and physical environments and creating Dementia Friendly Societies (DFS) meeting needs of PWD and carers. Studies on working mechanisms and effectiveness of dementia friendly initiatives in societies are however scarce.

The aim of the present study is to develop, test and disseminate a framework accompanied with an intervention advice manual to create tailor-made DFS for supporting PWD and carers to participate in social activities and hence enhance related health benefits. Our hypotheses are: 1) the framework with manual is feasible to support local societies to acknowledge the needs and potential of PWD and carers, challenge stigma, create accessible and respectful community activities, businesses, services, practical support, reliable travel options, and easy to navigate environments; 2) the framework with manual is feasible to support local societies to create sustainable DFS with well-connected collaborating agencies, services and social networks to enhance social participation of PWD and carers and to increase related health benefits.

The study design consists of a mixed methods approach, a combination of qualitative and quantitative research based on the realist method (including literature search, ethnographic/participatory research, scrutiny of documents and other contemporaneous materials, semi-structured interviews and focus groups) to develop the framework for DFS. Both qualitative and quantitative methods are required to answer the research questions on the feasibility of the framework for creating sustainable DFS. The

study comprises three work packages (A, B, and C). Work package A and B use the method of realist review and realist syntheses to investigate what the underlying mechanisms, successful and influencing factors (i.e. barriers and facilitators) of DFS and social participation are concerning the academic and grey literature and experiences of PWD, caregivers, (non) health and welfare stakeholders. Work package A (0-8 months) includes literature search. Work package B (6-23 months) includes ethnographic, participatory research of ongoing initiatives in six DFS. Based on synthesis of the gathered data of work package A and B, a CMO (Context, Mechanisms, and Outcomes) framework will be developed. In work package C (24-48 months), the CMO framework for DFS will be tested on its feasibility for implementation in four DFS pilot regions (i.e. Heerlen, Maasgouw, Wijchen and Nijmegen). Feasibility is based on the opinion of participating stakeholders on the criteria by Bowen et al. acceptability, demand, implementation, practicality, possible effectiveness, and adaptation. Most important is whether PWD and carers experience that initiatives following use of the framework are according their needs and have impact on social participation.

Measurements are conducted at the start of the pilot study, after 6 and after 12 months, to evaluate the progress on DFS based on the framework and the outcomes of social participation, health, quality of life of PWD and carers, on the effect of connecting activities, services, agencies and networks and economic outcomes. Based on the feasibility data, the identified facilitators and barriers experienced on the different feasibility topics, an intervention advice manual, including the framework and recommendations for developing sustainable DFS for common practice, will be developed and disseminated through diverse stakeholders and channels. This manual or practical guide, with examples from daily practice, will enable unexperienced communities to develop DFS.

1.3 Projectgroup

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Part 2

2.1 COFINANCE

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Budget proposal (see appendix

2.3 Problem definition

Currently, in the Netherlands, 200.000 PWD (number expected to have doubled in 2050; AN, 2015) and their carers live in the community of whom many face restrictions in social participation. Social participation is part of the new concept of positive health (Huber, 2011) and a dementia research theme (Deltaplan Dementia, 2016; JPND Call 2013; Moniz-Cook, 2011). Participation in social activities is associated with physical and mental health and well-being (Glei, 2005; Minagawa, 2014; Penninx, 1999; Fratiglioni, 2000; Zunzunegui, 2003; Crowe, 2003; Berkman, 1995; 2000; Guse, 1999; Levasseur, 2010; Law, 2002; Kanamori, 2014) and positive social behavior (Piskur, 2014). As social participation is considered an important element of successful and healthy aging, the WHO advocates its improvement among the aging population (Gordon, 2013).

Due to cognitive disabilities and social stigma on dementia, PWD often refrain from social participation. They show (increasingly) impairments in social skills, taking initiative, behavior, and functioning (Bediou, 2009; Wilson, 2007), already at the very early stages of the disease (Henry et al., 2012). PWD encounter difficulties in activities of daily living, social relations with others and community activities and hence become socially isolated (Dubois, 2010; Rocha, 2013; Barberger-Gateau, 2002; Muo, 2005; Sorensen, 2008). Besides stigma, an important explanation for restrictions in social participation is that services do not accommodate to PWDs' impairments and that organizations lack collaboration in meeting needs of PWD. PWD become confused when trying to be active in a non-dementia-friendly society with services that do not accommodate to their abilities, in non-supportive physical environments like supermarkets, banks, sporting facilities, or public transport (Donkers, 2017; outcomes PPI meeting RAC Nijmegen, 2016, ACI, 2016).

Dementia importantly interferes with positive health of PWD *and* their informal caregivers. Being a family caregiver for someone with cognitive problems causes burden and stress, and may also result in social isolation (Samuelsson et al., 2001) underlining the need for carers' support as well (Adelman, 2014). For instance, carers are relieved when those they care for participate in activities outdoors. This gives them the opportunity to participate in activities on their own (Soderhamn, 2013).

Empowering self-management and inclusion of PWD and carers in meaningful activities appeared to be partly effective in enhancing their social participation (Donkers, 2016, Haaften van Dijk, 2016; Cohen-Mansfield, 2015, Pitkala, 2010, Graff, 2006, 2007). Health and welfare interventions, however, are merely offered for a limited time and are not part of the PWDs daily life. Significant improvement might be achieved through adapting social and physical environments to create Dementia Friendly Societies (DFS). As the society is the environment people live their daily life, a focus of the environment on acceptance and inclusion of PWD and their caregivers can enhance social participation significantly.

Several initiatives on DFS have been undertaken in the UK and the Netherlands. Besides, several studies worldwide have attempted to identify relevant factors and to develop models or templates for creating dementia-friendly societies (Handley, 2015; Lin, 2017). In 2016, the Alzheimer's Disease International (ADI) and the European multi-country study both identified key elements and cornerstones in developing DFS, i.e. people (involvement of PWD), communities (social and physical environments), organizations

(DF organizations and access to appropriate health care), and partnerships (support, collective commitment, and collaboration of organizations) (ADI, 2016; Lin 2017). Other studies identified similar, additional, or (slightly) different factors (Waller, 2017). However, studies on working mechanisms and underlying components related to effectiveness of dementia friendly initiatives acknowledging contextual factors are scarce. Therefore, the current proposal is focused on investigating DFS initiatives in different contexts, as well as PWD and carers social needs, and barriers and influencing factors for social participation experienced by all stakeholders (PWD, carers, their social networks, health and welfare professionals, community agencies and services) and how these factors are related to each other. Based on this information, a framework and an intervention advice manual will be created aiming to support societies on how multiple agencies, services and social networks could be best connected to enhance social participation of PWD and carers and related health benefits. In conclusion, our research aim is to develop, test and disseminate a framework with intervention advice manual to creating tailor-made DFS.

2.4 Relevance

1. SUITABILITY TO MEMORABEL

This project aims at the development and sustainable implementation of DFS in the Netherlands and contributes to one of the four strategic priority areas of Health 2020, the WHO policy framework for health and well-being in Europe to create resilient communities and supportive environments (WHO, 2016). This project therefore highly suits the Memorabel priority 4.4.

2. BENEFITS

Societal benefits: In response to a growing ageing population, the preferences of most older adults to live in their own environment, a focus on positive health (Huber, 2014), and the policy of the Dutch government to reduce expensive residential long-term care, local governments focus on facilitating ageing at home and in local communities, by creating DFS (Heward, 2016). The Dutch government emphasizes the development of DFS (Alzheimer Nederland (AN), 2016).

Knowledge benefits: PWD and carers, care professionals, informal and voluntary services, local governments, and non-health stakeholders can benefit from generated knowledge on how to develop and sustain DFS, including community activities, businesses, services, local agencies, practical support, reliable public transport, and easy to navigate environments in- and outside buildings.

Quality of care benefits: By creating DFS, communities can help to foster ageing in place of PWD and help them to maintain their ability to do things that are important to them (WHO, 2016) and their carers and stimulate social participation (Trahan, 2014) and health (Gordon, 2013; Huber, 2011).

Scientific relevance: Although several initiatives exist worldwide, thorough research into the underlying components, mechanisms, and contextual conditions of DFS is still lacking. The project will contribute to scientific knowledge on understanding how to develop and sustain DFS and on new research methodology, 'realist method (review & synthesis)'.

3. IMPLEMENTABILITY

In the project, societies with different levels of experience on dementia-friendliness participate to learn from their expertise (e.g. Amstelveen, Utrechtse Heuvelrug, Oisterwijk, Waalwijk, Roermond). Different settings and contexts are included to increase variability and diversity to ultimately increase its implementability of the framework. Patient and carer organizations, such as AN, Huis voor de Zorg, stichting Zorgbelang Limburg, Mantelzorg platforms, Samendementievriendelijk will be involved in the development, testing and dissemination of the framework nationwide.

PWD and their carers will first benefit from the results of the project in the pilot regions. Afterwards, the results of the study will be applicable for many stakeholders in all regions and societies by means of an expert advice manual to AN, the ZONMW knowledge platform, and the Dutch Association for local governments and other relevant organizations in the networks of project group members. Since all relevant parties are involved throughout the project in our study regions, this ensures a sustainable implementation in these regions, which will be an example for other starting regions in the Netherlands.

4. INPUT EXPERIENCE EXPERTS, ATTENTION TO DIVERSITY

The project has a strong focus on involvement of PWD and carers as experienced experts, informants, and research subjects. Expertise on PPI is covered by Huis voor de Zorg and Zuyd/EIZT (work group 'Client participation', the Radboudumc Alzheimer Center panel of PWD and carers). The project and the research design (i.e. realist review, 2.4: workplan) accounts for broad attention to diversity. In work package A and B, stakeholders from experienced societies with different levels of DFS experience (DFS Hallmark), both cities and villages will be interviewed in these regions (e.g. Amstelveen, Utrechtse Heuvelrug, Oisterwijk, Waalwijk, Roermond) in the Netherlands. Also experiences from stakeholders of Sheffield (experienced DSF in UK) will be included in work package A and B. In work package C, the new to develop DFS societies, which are two cities and two villages (Nijmegen, Heerlen, Wijchen and Maasgouw), with differences in the number and kind of inhabitants, availability of facilities (e.g. social services, public transport), different levels of dementia-friendliness, differences in SES, age, and structure, will participate.

5. DATA COLLECTION & ACCESSIBILITY

Literature review, qualitative data collection and qualitative analysis methods are needed in work package A and B (see workplan 3.4) to gain knowledge about DFS. For testing of the feasibility of the Framework (see workplan), qualitative and quantitative data analysis is needed. Municipality data will be derived from the local governments data bases and be used for the process analysis as well. Public health data will be accessible through the universities, AN and the Dutch Dementia register. Data, we collect in this study, related to 'care' will be available for the 'Nationaal Register Dementie' to contribute to digital accessibility to care.

2.5 Knowledge exchange

This project is of importance for the Netherlands and other countries intending to develop DFS. Our activities concerning knowledge utilization/implementation are:

USER INVOLVEMENT

Relevant stakeholders (i.e. PWD/their representatives and their carers, professionals, inhabitants/enthusiastic volunteers, agencies) will be involved throughout the project. Knowledge exchange with academic partners in the UK (the University of Nottingham and Sheffield University and DFS initiatives Sheffield), people with dementia and carers, people involved in the 'Samendementievriendelijk' initiatives, practitioners, insurance agencies (who already contributed to the development of this proposal) will be continued by incorporating them in the project group or the advisory group (See workplan and appendix 6).

LOCAL DISSEMINATION/IMPLEMENTATION

A communication and dissemination plan will structure how we communicate and interact with stakeholders and how the academic partners and collaborators will be involved (see organogram appendix 6A). Dissemination of results will take place among all participating parties, using their regular channels (e.g. websites, newsletters, information brochures, local meetings with members, working conferences);

- In region Limburg (Heerlen and Maasgouw): in collaboration with Zuyd University of Applied Sciences, Centre of Expertise for Innovations in Care and Technology (EIZT), Maastricht University/CAPHRI School for Public Health and Primary Care, Academic Collaboration Centre Care of Older People (ACC-COP living lab), Alzheimer Stichting Parkstad Limburg, Hulp bij Dementie, the Provinciale Werkplaats Dementie en Ouderenzorg, DementieNet, Huis voor de Zorg, Stichting Zorgbelang Limburg, and with local governments, participating agencies and services.
- In region Nijmegen/Wijchen: in collaboration with Radboudumc, Radboudumc Alzheimer Center, DementieNet, Alzheimer Café's, Alzheimer Netherlands region Nijmegen, Samendementievriendelijk, local governments, participating agencies, and services.
- In region Amsterdam/Amstelveen: in collaboration with Free University Medical Center (VUmc) Amsterdam, Amsterdam Center on Aging VUmc-VU, Alzheimer Association Amsterdam, Network National Working Group Meeting Centers, Alzheimer café's.

Lecturers and researchers from the three educational institutes (Radboudumc, Zuyd University, VUmc Amsterdam) will integrate the results of the study in various curricula (e.g. bachelor, master studies), like inter-professional minors, the bachelor studies of Nursing, Occupational Therapy, Social Studies and Facility Management, and the research Masters Advanced Nursing Practice, Master of Innovation in Complex Care, Care & Technology, Neurorehabilitation, and CARE research school. Radboudumc Nijmegen collaborates with HAN University and Donders Center for Brain, Cognition and Behavior, VUmc will closely collaborate with HvA university and Amsterdam Center on Aging VUmc in Amsterdam, to integrate results in their health and social educations. Students from different studies will be involved in various phases of the project.

NATIONAL AND INTERNATIONAL DISSEMINATION/IMPLEMENTATION

Some of the local dissemination strategies also cover stakeholders on the national level. Additionally, results will be disseminated through AN, Ergotherapie Nederland, Kennisplein ZonMw, and on regional level by Huis voor de Zorg, Stichting Zorgbelang Limburg, Alzheimer café's and Radboud, Maastricht and Amsterdam Alzheimer centers. Other strategies include presentations and scientific meetings (e.g. Innovatiekring dementie) and publications in national journals or platforms/newsletters for people with dementia (Alzheimer Café's, Alzheimer Magazine, informal care journals, civilians (Burgerkracht) and/or (public) health and social care professionals (Nursing TVV, Denkbeeld, Maatschappij en Gezondheid), but also welfare, corporate agencies.

Knowledge exchange internationally will take place with network partners of the University of Nottingham and Sheffield Hallam University, the Interdem group in Europe, and the Community Occupational Therapy in Dementia Network in Europe. Results will also be disseminated at international conferences and symposia (e.g. Alzheimer Europe, and European Occupational Therapy conferences) and articles will be submitted for publication in scientific journals (e.g. 'Dementia').

CONSOLIDATION

All parties involved endorse the relevance of the development and testing of the framework/expert advice manual to improve social inclusion and to achieve related health benefits. The mixed-methods approach of the study is expected to generate extensive data on the complex situation of PWD to develop a solid framework. If feasible, the framework and knowledge will be incorporated in the policies of the participating parties and in educational activities at different levels.

Part 3:

3.1 Doelstelling = Research aim

This project is focused at 'what kind of DFS initiatives work, for whom, in what circumstances, in what respect, to what extent, why and how are these related' (Pawson et al, 2005). The aim is to develop, test and disseminate a framework with intervention manual to create tailor-made DFS for supporting social participation of PWD and carers and hence enhance related health benefits.

The project will test the feasibility of implementing the framework with manual in different DFS settings and contexts, to gain insight in how multiple agencies and social networks could be connected for creating sustainable DFS. In this way, we can recognize achievements, and encourage agencies to take action, or improve services. All agencies may tackle stigma through raising awareness and addressing negative language and actions. Health and welfare agencies may improve access to services and outreach to identify people with dementia in need of support. Third sector and corporate agencies may provide services or activities specifically for PWD, or through reasonable adjustments of existing services. The aim is to get understanding of the sum-total, and relations of relevant components of these efforts included in DFS and how they may be experienced by PWD, carers, health and welfare professionals, and

stakeholders from agencies and public services. In this project PWD and carers will participate as informants, co-creators, co-researchers and study subjects.

RESEARCH QUESTIONS ARE:

- 1a) Which DFS initiatives are/were running in practice?
- 1b) How are/were these initiatives experienced by PWD and carers?
- 2a) What are good initiatives according to PWD, carers, (non)health and welfare stakeholders?
- 2b) What are according to them influencing factors?
- 3) What are components and underlying mechanisms of good working DFS initiatives in stakeholders' opinions?
- 4 a) How does a framework for developing good working DFS, based on these components, factors, and mechanisms, look like?
- 4b) What are possible outcomes?
- 5) What is this framework's feasibility when testing in 4 different societies on a tailor-made way (covering both cities and villages; established and new interventions)?
- 6) What are recommendations for creating future sustainable DFS?
- 7a) How should an intervention advice manual, based on the framework, expert advice, and recommendations of stakeholders, look like?
- 7b) What information is needed for nationwide dissemination of this framework with manual to policymakers?

3.2 Work plan (=60.000 characters total, nu 31.177characters)

1.HYPOTHESES:

Our hypotheses are:

1. The framework with intervention manual for creating tailor-made DFS is feasible to support local societies to acknowledge the needs and potential of PWD and carers, to challenge stigma, to create accessible and respectful community activities, businesses, services, practical support, reliable travel options, and easy to navigate environments, through successfully dealing with the influences of underlying factors and mechanisms for social participation of PWD and carers.

2. The framework with intervention manual for creating tailor-made DFS is feasible to support local societies to create sustainable DFS with well-connected collaborating agencies, services, and social networks to enhance social participation of PWD and carers and related health benefits, through successfully dealing with the influences of underlying factors and mechanisms for social participation of PWD and carers.

2. ADDED VALUE:

This study is dedicated to extensive reflection and thorough realist review of the underlying factors and mechanisms for social participation and social inclusion of PWD and carers. This will result in a feasible framework with an intervention advice manual for supporting societies to tailor-made creating sustainable DFS through successfully dealing with the underlying factors and mechanisms for social participation of PWD and carers. A dissemination plan and network will be available for interested societies to create DFS in the Netherlands and UK. DFS. (For more information about added value also see 'benefits' as described in paragraph 2.4. Relevance).

3. BUDGET:

Both at the Radboudumc, Scientific Institute for Quality of Healthcare and at Zuyd Hogeschool Heerlen a project leader (6 hours/week project management), a halftime researcher, and a secretary (for 2 hours/week) will be employed and is requested for in the budget proposal. Also for some parts of the research the co-researcher and expert of Nottingham University on realist review & synthesis (Neil Chadman) and the dementia friendliness expert and co-researcher of Sheffield University (Claire Craig), will be hired for some hours/week as experts for their supporting research tasks in these specific research parts. Additionally, collaborating and project group advisors are partly paid and partly invest in kind hours for project group and advisory group meetings (50% in kind, or some do 100% in kind, see appendix 1), but their travel costs are fully covered by the project budget. Advisors of the UK (Universities of Nottingham and Sheffield) will participate by skype meetings. Experienced experts (PWD and carers) are also part of the project group, their costs for advice and travel are fully covered. Local community stakeholders of the 4 pilot DFS workgroups (PWD, carers, (non)health, welfare stakeholders, patient organizations, local agencies) will partly be paid for the hours spent in the workgroups and will invest partly in kind (stakeholders DFS 50% paid, 50% in kind) their hours for the work group and preparational activities for the workgroup. Travel costs, rooms hire, and costs for implementation, are covered by the project budget (*see Appendix 1A, extended budget proposal and appendix 1B to 1D for signed declarations of collaboration to the project and in kind investments to be delivered by project group members, collaborating project advisors and local agencies*). Maasgouw, although willing to participate as 4th pilot region, and willing to partly in kind invest their efforts, could not yet sign the collaboration contract in time, but this signed contract will be sent to ZONMw after the deadline for these research proposals.

4. STUDY DESIGN:

We will use a mixed methods design, a combination of qualitative and quantitative research methods. The research proposal is based on qualitative research using the realist method in phase A and B (literature search, ethnographic /participatory research, scrutiny of documents and other contemporaneous materials, semi-structured interviews, focus groups) to develop the framework for DFS. In the feasibility phase C, we will use both qualitative and quantitative methods to answer the overall research questions (RQ) on the feasibility of the framework and develop an intervention advice manual to creating tailored sustainable DFS. Important is whether initiatives following use of the framework and manual are experienced by PWD and carers as according to their needs and enhancing social participation.

Work package A and B will both answer research questions 1a, 1b, 2a, 2b and 3. These are: 1a) Which DFS initiatives are/were running in practice? 1b) How are/were these initiatives experienced by PWD and carers?, 2a) What are good initiatives according to PWD, carers, (non)health, and welfare stakeholders?, 2b) What are according to them influencing factors?, 3) What are components and underlying mechanisms of good working DFS initiatives in stakeholders' opinions?

Work package B will additionally answer research question 4a: How does a framework for developing good working DFS, based on these components, factors, and mechanisms, look like?

Work package C accordingly, will answer research questions 4b, 5, 6, 7a and 7b. These are: 4b) What are 'possible outcomes?', 5) What is this framework's feasibility when testing in 4 different societies on a tailor-made way (covering both cities and villages; established and new interventions)?; 6)What are recommendations for creating future sustainable DFS?, 7a) How should an intervention advice manual, based on the framework, expert advice, and recommendations of stakeholders, look like?, 7b) What information is needed for nationwide dissemination of this framework with intervention manual to policymakers?

REALIST REVIEW

For work package A and B we will use the method of realist review and realist synthesis (Plesk & Greenhalgh, 2001; Marchal, 2013) to investigate what the underlying mechanisms, successful and influencing factors (i.e. barriers and facilitators) of DFS and social participation are concerning the academic and grey literature and experienced by PWD, caregivers, (non) health, and welfare stakeholders. The main question for a realist review is: '*What kind of DFS initiatives work, for whom, in what circumstances, in what respect, to what extent, why and how are these related*' (Pawson et al., 2005). Thus, realist review explores the links between contextual factors and the processes or mechanisms these trigger, to explain why and how different outcomes have been achieved (Pawson et al., 2005). Realist review is often an iterative process where the scope and focus is refined as work proceeds.

Organization of the project

This project has the following organization structure: a project group, an advisory/steering group and 4 work groups for each of the participating DFS initiatives in work package C (see Appendix 6).

- The advisory/steering group consists of experts to ensure that the study protocol is followed and to provide input and advice based on their direct experience on the topic of this study. Members of national and local organizations regarding dementia care (e.g. Alzheimer Nederland, Huis voor de Zorg), local authorities, health insurance company CZ, carer of a PWD and other participants of relevant national health and welfare organizations will participate. The advisory group will meet at least twice a year.
- The project group consists of the members and researchers who actively work on one or more phases of the project. Representatives of the DFS initiatives of work package A, B and C will be represented in the project team: they know the daily practice and deliver important input, experience, and knowledge. The duties of the team members in this study include contributing to and executing the project objectives, providing expertise and documenting the process. The project group will meet (face-to-face) every 3-4 months and on a regularly base they have contact by e-mail.
- In work package C, we work together in work groups on the 4 pilot DFS of Nijmegen, Wijchen, Heerlen and Maasgouw. Knowledge and experiences will be exchanged between the workgroups and the DFS of work package A and B, and to learn from each other.

WORK PACKAGE A (0-8 months)

LITERATURE SEARCH:

Research questions

In this work package A, we will address Research Questions (RQ) 1a, 1b ,2a, 2b, and 3 based on academic/scientific and grey literature (0-4 months; Appendix 5, Activity 1). The research questions are:

RQ 1a) Which DFS initiatives are/were running in practice?

RQ 1b) How are/were these initiatives experienced by PWD and carers?

RQ 2a) What are good initiatives according to PWD, carers, (non-)health and welfare stakeholders?

RQ 2b) What are according to them influencing factors?

RQ 3) What are components and underlying mechanisms of good working DFS initiatives in stakeholders' opinions?

Methods:

To answer these three research questions on social participation and DFS, the researchers will search the academic literature on pubmed, and the (grey) literature in the Netherlands: by the Internet Google search engines for national websites such as www.samendementievriendelijk.nl, information of national stakeholders (Alzheimer Nederland), other relevant organizations and members of the public, also documents and materials from services, programs, and communities. Information on successful initiatives, influencing factors and underlying mechanisms and the experiences of PWD, their carers and

other stakeholders, theories and models on these topics will be extracted from academic and grey literature. Data will be synthesized and described. A draft theory will be developed (4-6 months; Appendix 5, Activity 2), a so-called Context, Mechanisms, and Outcomes (CMO) based on these results on successful initiatives and influencing factors and underlying mechanisms and on theories found in the literature. This theory will be refined after consulting the project and advisory group and discussing about this draft theory. Consequently, a first/concept theory is formulated (6-8 months; Appendix 5, Activity 3).

Tasks, roles, and responsibilities:

Both researchers (of Nijmegen and Zuyd) and the co-researcher and realist expert of Nottingham (Neil Chadman) and dementia friendliness researcher of Sheffield (Claire Craig), with support of master students will together perform the tasks of literature review, participatory observation, and interviews in the experienced DFS regions. Therefore, they divide the regions between them. They both will be supported by students supported by the researchers from Zuyd Hogeschool and from Nijmegen University. The researchers will analyze the data by qualitative content analysis, and subsequently they will synthesize the data and describe the results. They will then develop a draft theory (4-6 months; Appendix 5, Activity 2). This theory will be refined after consulting the project and advisory group and discussion about this draft theory. Consequently, a first/concept theory is formulated by the researchers (6-8 months; Appendix 5, Activity 3).

Deliverables:

- An overview of the scientific and grey literature on social participation, interventions and DFS, success factors, influencing factors and underlining mechanisms;
- A global theory based on the configuration of Context, Mechanisms, and Outcomes (CMO).

WORK PACKAGE B (6-24 months)

ETHNOGRAPHIC/PARTICIPATORY RESEARCH OF INITIATIVES in 5 to 6 DFS:

Research questions and methods:

The main question for this ethnographic part of the realist review is to understand 'what works for whom in what circumstances'. The data collected by this research activities will result in a CMO (Context, Mechanisms, and Outcomes). This Context, Mechanisms and Outcomes and the information on their interactions/mutual relationships is necessary information to build suitable theories (Tilley, 2000). The DFS regions (both cities and their surrounding villages) we will visit and explore to answer the research questions of work package B are: Amstelveen/Amsterdam, Utrechtse Heuvelrug, Oisterwijk, Waalwijk, Roermond. We will make use of ethnographic/participatory research (Lambert et al., 2010), including participatory observations and interviews with all relevant stakeholders in these societies.

In this workpackage we will address RQ 1a, 1b, 2a, 2b, 3, and 4a.

RQ 1a) Which DFS initiatives are/were running in practice?

RQ 1b) How are/were these initiatives experienced by PWD and carers?

RQ 1a and 1b will be explored by participatory observations and interviews. We will perform participatory observations during activities, meetings, using services and local agencies and we will during and after these observations perform interviews with PWD, carers, and (non-) health and welfare stakeholders about their experiences with these and other initiatives (6-18 months, Appendix 5, Activity 4).

RQ 2a) What are good initiatives according to PWD, carers, (non-)health and welfare stakeholders?

RQ 2b) What are according to them influencing factors?

RQ 3) What are components and underlying mechanisms of good working DFS initiatives in stakeholders' opinions?

Research questions 2a, 2b and 3 will also be answered by participatory observations and interviews with these stakeholders. We will interview in each region different stakeholders (3 PWD, 3 carers, 2 health professionals, 2 welfare professionals, 2 stakeholders from business and 2 stakeholders from local agencies) and will make use from information gathered by the observations in their local society by these interviews. Also, interviews will be performed with stakeholders from Sheffield to add experiences from the UK. Their experiences with good DFS initiatives, underlying factors and mechanisms will be explored as well (6-18 months, Appendix 5, Activity 5).

RQ 4a) How does a framework for developing good working DFS, based on these components, factors, and mechanisms, look like?

Tasks and roles:

The researchers from Radboudumc and Zuyd will analyze the data gathered from observations and interviews on the success factors, influencing factors and underlying mechanism observed and mentioned, for the DFS as divided between both universities. Together, together with the co-researcher and realist expert of Nottingham (Neil Chadman) and dementia friendliness researcher of Sheffield (Claire Craig), they will synthesize and describe the data found in this ethnographic research into a concept theory (19-22 months, Appendix 5, Activity 5). Accordingly, these data will be integrated with the data found in work package A. Based on these combined data of the grey literature and realist experience from the interviews and observations in different local societies, the concept theory will be refined and discussed with the project and advisory group. Based on these Context, Mechanisms, and Outcomes (CMO) and their interactions a CMO model will be configured. A CMO model allows a researcher to understand 'what works for whom in what circumstances'. This CMO-configuration model is necessary to build suitable theories (Tilley, 2000). This CMO configuration model will be the framework that will be discussed with the project and advisory group and based on this discussion the CMO framework will be refined again (month 23, Appendix 5, Activity 7).

Deliverables:

- A tested concept theory to improve creating successful and sustainable DFS;
- Insight into the experiences, success factors, influencing factors and underlying mechanisms; of stakeholders in 6 running DFS initiatives;
- A set of relevant outcomes and economic measures for social values;
- A framework for creating successful and sustainable DFS Publication of these results in a professional and/or in scientific papers.

WORK PACKAGE C (24-48 months)

REALISTIC SYNTHESIS AND FEASIBILITY FRAMEWORK

In this work package C, we will address the RQ 4b, 5, 6, 7a and 7b.

Research questions 4b and 5:

4b) What are possible outcomes?

5) What is this frameworks feasibility when testing in 4 different societies in a tailor-made way (covering both cities and villages; established and new interventions)?

Methods research questions 4b and 5:

In work package C, specific outcomes of the DFS will be first prepared by the researchers based on the framework, accordingly be discussed in the project group and the advisory group and finally determined (month 24, Appendix 5, Activity 8). Accordingly, the feasibility of the implementation of the DFS framework will be investigated (proof of concept pilot study). Therefore, the CMO framework for DFS will be tested in 4 starting DFS pilot regions (Heerlen, Maasgouw, Wijchen and Nijmegen) to produce specific data in different contexts (25-34 months, Appendix 5, Activity 9).

Tasks/roles and responsibilities:

The local governments of these pilot regions work together in workgroups with all stakeholders of their region and discuss and plan activities to be created based on the DFS framework. All 4 workgroups of all four pilot regions also collaborate by meeting each other with the project group one in 3 month. The project leader will meet or contact each region workgroup one per month for advice and guidance of the implementation process. The researchers will measure at start, after 6 and 12 month the progress of the pilot implementation in these regions and analyze and describe the data. Also interviews and focus groups with stakeholders in the different regions will be held on the different feasibility topics. See described below.

Methods feasibility study:

Feasibility is based on the opinion of all stakeholders (PWD, carers, their social networks, health and welfare professionals, community agencies and services) on the feasibility topics of Bowen (et al; 2009). These topics are: acceptability, demand, implementation, practicality, possible effectiveness, and adaptation.

We will test the feasibility of implementing the framework with stakeholders (PWD, carers, health, welfare, non-health stakeholders, local agencies, and others, if relevant) experience in these 4 pilot DFS regions (6-18 months, Appendix 5, Activity 10). One of the most important questions is whether developed dementia-friendly initiatives are in line with needs of PWD and their carers.

-Acceptability: refers to suitability of the framework according to service deliverers (health and welfare professionals and stakeholders from business and local agencies and service users (PWD and carers) of the pilot DFS;

-Demand is the extent the framework is likely to be used or what should be adapted;

Interviews will be held with all stakeholders (5 PWD, 5 carers, 2 healthcare, 2 welfare, and 2 non-health stakeholders, 1 local authority stakeholder, and others, if relevant) to get insight in these topics. Based on the outcomes of the interviews on acceptability and demand of this pilot DFS the framework is adapted to enable tailored implementation in this pilot DFS.

-Implementation: addresses the implementation of the activities based on the framework and context and characteristics of this pilot DFS society. A proof of concept pilot study will start by implementing the tailor-made adapted framework in this pilot DFS. We will evaluate if the DFS framework is implemented according to the implementation plan for creating tailor-made DFS adapted for this region, which

adaptations are defined at the start of the pilot study based on the needs assessment in this specific pilot region.

- Practicability refers to the extent the DFS framework is applied as intended in the proof of concept study. A process evaluation will be performed to collect data on the implementation of this framework. Both interviews and a focus group with service deliverers (2 healthcare, 2 welfare, and 2 non-health stakeholders, 1 local authority stakeholder, and others, if relevant). Also interviews and a focus group (5 PWD, 5 carers) with PWD and carers will be held.

-Limited efficacy/potentially effectiveness: addresses the promise the DFS framework shows of possibly being successful. We expect that PWD and carers living in DFS have better (self-reported) positive health after 12-months-follow-up than at start before implementing the framework. We expect the limited efficacy could be found on social participation (e.g. more social participation, more social contacts, more social activities), health and quality of life (e.g. greater happiness, better mood, better quality of life) of PWD and carers, better access to formal and informal care/support and effect of connecting activities, services, agencies and networks and possible economic outcome measures (social value for money). However, we will choose best outcomes for this work package C. These outcomes will be chosen on the data from observations and interviews with stakeholders in work package A and B and C interviews on acceptability and demand of the pilot DFS. In each of the 4 pilot DFS (Heerlen, Maasgouw, Nijmegen, Wijchen) we will evaluate these outcomes at the start of the implementation of the framework in the pilot DFS, after 6 and after 12 months, to evaluate the progress on creating DFS based on the framework. For the evaluation, we will include PWD (n=15), carers, health care (f.e. general practice or physiotherapy practice, or home care organisation), welfare and other non-healthcare stakeholders (f.e. shops, supermarkets, busses, banks) (in total n=5) and local authority (n=1) per DFS pilot region. Per region it will be different who these health, welfare, non-health and local agency people will be. In total, for all 4 pilot DFS we aim to include 60 PWD and 60 carers, 20 health care, welfare, and non-health care stakeholders and 4 local authorities.

The data on these feasibility topics will be analyzed by descriptive statistics, qualitative content analysis (interviews) and by quantitative statistical analyses, and will be described.

Research questions 6 and 7a

RQ 6) What are recommendations for creating future sustainable DFS?

RQ 7a) How should an intervention advice manual, based on the framework, expert advice, and recommendations of stakeholders, look like?

Methods research questions 6 and 7a

- Adaptation finally, the last topic of feasibility, refers to adaptations to be made to the framework based on the results found on the other feasibility topics in the specific context of this pilot DFS and its characteristics (see also 2.4 .4 Diversity). Based on these results of the proof of concept process and limited efficacy study and the results of the other topics of feasibility, adaptations to the DFS framework will be made per pilot DFS. Recommendations, and steps to be followed for creating sustainable DFS will

be defined together with the stakeholders of the 4 pilot DFS, the stakeholders of the DFS societies of work package A and B and these recommendations, steps will be discussed in the project and advisory group (month 41, Appendix 5, Activity 12)

Finally, based on all this information, the intervention advice manual for creating tailor-made DFS, including process steps, practical recommendations, and examples from practice, will be developed (42-44 months, Appendix 5, Activity 13).

Research question 7b

RQ 7b) What information is needed for nationwide dissemination of this framework with manual to policy makers?

Methods research question 7b & tasks/roles and responsibilities:

The intervention advice manual, together with the framework and recommendations for developing sustainable DFS for common practice, will be disseminated through diverse stakeholders and channels (44-48 months, Appendix 5, Activity 14). This manual, with examples from daily practice, enables un-experienced communities to develop as Dementia Friendly Societies (DFS). Financial and time consuming aspects about the creation of a DFS will be part of the guide as well.

The manual with the best practice examples, will encourage communities to develop initiatives that are well suited to their local context and available resources. Feasibility of using the guide in this manner will be tested by implementing the framework manual and using realist review to explore stakeholders' experiences and perspectives (PWD, carers, health, welfare, and non-health stakeholders) in the 4 DFS: Nijmegen, Wychen, Maasgouw, and Heerlen. The intervention manual guide will be disseminated via the website of national organizations (See 2.5. Knowledge transfer).

Deliverables:

- A pilot tested framework in 4 new to develop DFS with measurements at start, 6 and 12 months of follow-up
- Insight into the feasibility of the framework
- A definitive framework and intervention advice manual, including recommendations for future sustainable DFS
- A locally, nationally, and internationally disseminated framework and manual
- Publication of these results in professionals and/or scientific papers
- Presentations of the results at national and international scientific meetings, conferences, and symposia.

5. DATA COLLECTION & ANALYSIS (months 37-40; Appendix 5, Activity 11) & ESTIMATED TIME FRAME

Qualitative data will be gathered from participatory research, observations, interviews, and focus groups with all stakeholders (local government, health/social care, wider public services etc.) to address RQ 1-5. After obtaining oral informed consent, all qualitative data will be recorded and transcribed verbatim. These transcripts will be thematically analyzed through content analysis (Hsieh & Shannon, 2005). To

ensure reliability, two researchers independently will code the focus groups and interviews (a random sample of 10% of the focus groups and the interviews?). Analysis will be performed using a qualitative data-analysis program Atlas.ti. The results will be used for designing and adapting the framework and manual for DFS. The analyses of the qualitative data will be interpretive, which explores the Context-Mechanism-Outcome relationships using the guiding question “*what works, for whom, under what circumstances?*” What are barriers to successful initiatives, influencing factors, underlying mechanisms, and outcomes?

Quantitative data on characteristics of participants (PWD and carers) will be analyzed with descriptive statistics. Quantitative data on possible effects as part of the feasibility of the framework on relevant outcomes (see work package C, if relevant based on the outcomes of workpackage A and B, we will use one or more outcomes from TOPICS-MDS) will be collected and analyzed with descriptive, qualitative, and quantitative analyses for the 4 regions separately and together. The data extracted for the feasibility for testing the possible effectiveness of the DFS framework in the DFS regions will be analyzed with descriptive statistics, and quantitative analyses, using SPSS.

ESTIMATED TIME FRAME

A detailed overview of the project planning is presented in the Gantt table and the accompanying table with description of the main activities in more detail in Appendix 5. Work package A has a total duration of 8 months. Three main activities are performed in this work package: 1) literature search of academic/scientific and grey literature (0-6 months), 2) development of a configuration of Context, Mechanisms, and Outcomes (CMO) and building a first draft of a theory (4-6 months), 3) Refinement of the global theory (6-8 months).

Work package B will start after 6 months and end after 24 months (total duration of 18 months). This work package includes four main activities: 4) testing the global theory in 6 running DFS initiatives (6-18 months); 5) exploration of experience with networks, relationships within the society, quality of life, health outcomes and economic measures for social values with all stakeholders (6-18 months); 6) analyses and description of success factors, influencing factors and underlying mechanisms (19-22 months); 7) refinement of the global theory of work package A into a specific theory based (month 23).

Work package C has a total duration of two years (24-48 months) and includes 7 main activities: 8) identification of outcome measures (month 24); 9) Pilot study among 4 new to develop DFSs (25-34 months); 10) evaluation of the feasibility topics on implementation of the framework (34-36 months); 11) analysis of the qualitative and quantitative data (37-40 months); 12) refinement of the framework of DFS (month 41); 13) recommendations for creating future DFS and writing the intervention advice manual (42-44 months); 14) dissemination of the manual and framework (44-48 months).

(see appendix 5 for the table of the time-frame)

6.REPORTING & DISSEMINATION: -

Study findings will be reported and disseminated via ZONMW kennisplatform, Radboudumc Alzheimercentrum (RAC), AN (www.dementie.nl), DementieNet, SamenDementievriendelijk, Huis voor

de Zorg, other relevant websites and organisations, conferences, articles in scientific, professional & public journals, social media. (see further under the paragraph knowledge exchange 2.5, where the reporting and dissemination is extensively described)

7. QUALITY & EXPERTISE OF THE RESEARCH TEAM:

Our multidisciplinary research team is complementary and represents high quality expertise, not only in qualitative and quantitative observational, realist method, intervention, and implementation research - with a focus on quality of care, care-needs of PWD and carers -, but also in clinical experience in dementia community care. The consortium consists of five research and educational centres collaborating as project commission members and/or advisors (Radboudumc Maud Graff, Marjolein van der Marck, prof. Myrra Vernooij-Dassen, implementation fellow Marieke Zeegers, coordinator/researcher Jose Peeters), Zuyd University for Applied Sciences (Dr. and lector Ramon Daniels, Dr. and lector Erik v. Rossum), Maastricht University, Academische Werkplaats Ouderenzorg (Dr. R. Daniels, Dr. E. v. Rossum, Dr. M. Veenstra), and collaborating VUmc (Rosemarie Droës), Nottingham University, which covers a lot of knowledge about the method of realist review, public health research and research on occupational therapy and other rehabilitation and psychosocial interventions in dementia and cognitive problems (associate professor Kate Radford, Dr. Neil Chadman, prof. Justine Schneider, Dr. Veronica Wardt and prof. Pip Logan,, visiting associate professor Maud Graff and fellowship dr. Marjolein vd Marck), Sheffield University (dr. Claire Craig) advisor UK dementia-friendliness, and private parties as general practitioner (dr. Marieke Perry), professional welfare organisation (SWON), dementia network (DementieNet, dr. Marjolein van der Marck & Minke Nieuwboer), AN (Claudia Lemmens, , region coordinator; Marjolein van der Marck was Board Member); Radboud Alzheimer Center (Maud Graff, Board member), regional patient and caregiver organisations (Huis voor de Zorg, Dr. M. Veenstra), Samendementievriendelijk (Saskia De Jong); Mezzo (Pieter de Boer, caregiver, representative PWD), and Frans Lemmers (workgroep Dementievriendelijk Roermond, caregiver, representatives PWD), CZ health insurance partner drs. Willeke Vos (projectleader dementia), representatives of 4 local agencies of Heerlen, Wijchen, Maasgouw and Nijmegen. Many parties collaborated successfully in previous projects.

3.3 Expertise (7500 characters)

MAUD GRAFF (MG), PhD is health scientist and occupational therapist and works as associate professor at the Radboudumc, Scientific Institute for Quality of Healthcare, Department of Rehabilitation, and Radboud Alzheimer Center (board member). She received an honorary chair at the University of Nottingham and 7 scientific awards for her research projects on the development, evaluation and implementation of occupational therapy and other psychosocial interventions for older people with dementia, and carers. Her research focuses on the dignity, self-reliance and participation in meaningful activities and quality of life of older people with dementia and carers, and quality of care from client, professional and organizational perspective.

RAMON DANIELS (RM), PhD, occupational therapist, and MSc in occupational therapy, works as senior researcher and project leader on studies to identify frail elderly and interventions directed on the prevention of disabilities in activities, with special focus on inter-professional collaboration, person-centered care and self-management. He also is project leader of studies for optimizing, clarification and problem-solving of questions on WMO topics, and he is appointed as associated professor (“lector”) in the domain of Assistive Technology in Care, with focus on ageing and sustainable communities and housing.

MARIEKE PERRY (MP), PhD, general practitioner, and senior researcher at the depts. of Geriatric Medicine and of Primary and Community Care. Her thesis on a dementia training programme for primary care was awarded twice. Current dementia research projects are DementiaNet (implementation of integrated primary dementia care) and Decidem (advance care planning with dementia patients in primary care). She contributed to several Dutch Dementia Guidelines, and she writes columns for the Dutch Alzheimer Association about her experiences with dementia care in daily practice.

MARJOLEIN VAN DER MARCK (MvdM), (PhD), projectleader and post-doc/senior researcher at the dept of Geriatric Medicine. Her expertise lies within complex, multispecialty care and related evaluations on (cost)effectiveness within clinical settings with teamcare and tailored approaches as core themes. She is project leader of the DementiaNet project, on network-based primary care; PI for GOUDMantel project (on peer support of former informal caregiver to support informal caregivers in dementia) and a project on crisis reduction in dementia care. MvdM has a knowledge exchange fellowship together with dr Neil Chadborn (Nottingham) on community support for people living with dementia.

MARJA VEENSTRA (MV), PhD is working as an advisor at ‘Huis voor de Zorg’, an independent organisation dedicated to the interests of all (potential) health care recipients in the province of Limburg, the Netherlands. Their main target is to promote the involvement of patients/carers and the public in all aspects of healthcare. She is specialised in issues around the theme of family care, informal care and in promoting patient’s perspective and patient involvement in for example research.

She is also working at Maastricht University who is lead partner of euPrevent project ‘senior-friendly community with an accent on Mental health’. She is coordinator in this project of 30 participating communities from Meuse Rhine Eurregion.

FRANS LEMMERS (FL) is since 2012 carer of his wife who has Fronto Temporale Dementia. She went first 2, than 3 and 4 days a week to daycare for young-onset dementia. Her severe behavioral problems and decline of language and communication skills are the characteristic features of her dementia. She recently reached the age of 66 years. In September she was admitted to the Zorggroep-Venlo, since October in Van Gogh in Venray and since March in Landrijt/Eindhoven. Her dementia is progressive, which is different from Alzheimer and is not so common. For me as a carer it means that I have a lot of difficult discussions with healthcare professionals, family and friends, because they do not understand her dementia. She is so difficult compared to what they know from other people with dementia. On request of the local government of Roermond and SWalmen I held three introductory talks/interviews (table meetings) with 50-80 carers. Besides, I am member of the work group public health education in the project Dementia Friendly Roermond.

KATE RADFORD (KR), PhD. Since qualifying as an OT in 1990, Dr. Kate Radford has worked clinically and academically in neurological rehabilitation. Her expertise is in developing and evaluating complex interventions using mixed methods research. Research includes studies to develop and validate cognitive tests to predict 'fitness-to-drive' in brain injury and dementia, trials of complex interventions with embedded economic analysis and mixed methods process evaluations adopting Implementation frameworks and systems and realist methodologies.

CLAUDIA LEMMENS (CL), is coordinator regional activities of the Dutch Alzheimer Association (AN) for the regions Nijmegen and Limburg. Her expertise is on representing PWD and to develop initiatives (Wereld Alzheimer Dag, support and implementation of Alzheimer Café's, project 'dementievrienden') to support PWD together with many relevant stakeholders, such as local authorities, municipalities, health care organizations, informal carers, volunteers, etcetera. All these activities contribute to the development of DFS in the Netherlands.

(The expertise of the collaborating partners of the advisory group is added in appendix 6C).

3.4 Publications

Some relevant publications of the project group members are presented below

(Maud Graff)

Graff MJL, Vernooij-Dassen MJFJ, Thijssen M, Olde Rikkert, MGM, Hoefnagels WHL, Dekker J. Community occupational therapy for dementia patients and their primary caregivers: a randomized controlled trial. *BMJ* 2006; 333:1196; doi:10.1136/BMJ 39001. 688843.BE

Graff MJL, Adang EMM, Vernooij-Dassen MJM, Dekker J, Jönsson L, Thijssen M, Hoefnagels WHL, Olde Rikkert MGM. Community occupational therapy for older patients with dementia and their caregivers: a cost-effectiveness study *BMJ* 2008; 336:134-138; doi:10.1136/BMJ.39408.481898.BE

Graff M. Ergotherapie bij ouderen met dementie aan huis: landelijke implementatie van effectieve en kosteneffectieve EDOMAH- interventie. *Denkbeeld*, April 2012

Graff MJL. Hoofdstuk 11. Hulp bij het omgaan met de eigen beperkingen, pagina 185-201. In: Droes, Scheltens & Schols. Meer kwaliteit van leven. Basisboek Integratieve, persoonsgerichte dementiezorg, 2015. ISBN: 978-94-91969-05-8

Donkers HW, Veen DJ van der, Vernooij-Dassen MJ, Nijhuis-van der Sanden MWG, Graff MJL. Social participation of people with cognitive problems and their caregivers: a feasibility evaluation of the multidisciplinary Social Fitness Programme. *Int J Ger Psych* 2017, pg 1-14.

Döpp CM, Graff MJ, Olde Rikkert MG, Nijhuis-van der Sanden MW, Vernooij-Dassen MJ. Determinants for the effectiveness of implementing an occupational therapy intervention in routine dementia care. *Implementation Science*, 2013, Nov 7;8(1):131.

Leven van 't N, Graff MJL, Marleen Kaijen, Bert J.M. de Swart, Marcel G.M. Olde Rikkert and Myrra J.M. Vernooij-Dassen. Barriers to and facilitators for the use of an evidence-based occupational therapy guideline for older people with dementia and their carers. *Int J Geriatr Psychiatr*, 2012 Jul;27(7):742-8. doi:10.1002/gps.2782. Epub 2011 Sep 27.

Kerkhof Y. Bergsma A., Graff MJL, Droës R. Better self-management and more meaningful activities thanks to tablets? Design of a tailor-made program for the use of apps for tablets for people with dementia and carers. *Int Psychogeriatr*, 2017.

(Ramon Daniels)

Van Dongen JJJ, van Bokhoven MA, Daniëls R, Emonts WWWG, van der Weijden T, Beurskens A. Developing interprofessional care plans in chronic care; a scoping review. *BMC Fam Pract* 2016;17(1):137.

Lenzen SA, van Dongen JJJ, Daniëls R, van Bokhoven MA, van der Weijden T, Beurskens A. What does it take to set goals for self-management in primary care? a qualitative study. *Fam pract*. 2016 July: 1-6.

Van Soest K, Daniëls R. Lenzen. S. Stimuleren van zelfmanagement; hoe beslis je samen over doelen en acties? *Tijdschr Maatsch&Gezondh*, 2015; 15 (3): 18-20.

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Part 4

4.1 Additional information (I will fill in), (CMO, no. Is observational study, also pilots uncontrolled, no RCT)

4.2 Earlier sent in as proposal to ZONMW? No

4.3 Appendixes (see appendix 1 to 6, per appendix one pdf)