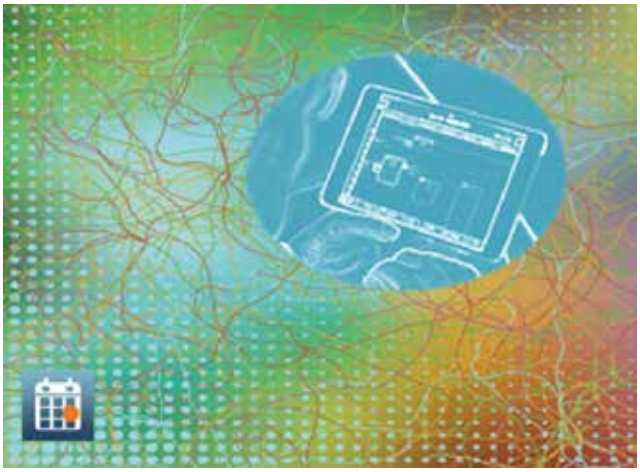
UNIVERSITY OF COPENHAGEN
FACULTY OF HEALTH AND MEDICAL SCIENCES

# Assistive technology to support self-management of people with dementia

## The ReACT project



PhD thesis
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GLOBAL EXCELLENCE IN HEALTH

REGION H Rigshospitalet

This thesis was submitted to the Graduate School of Health and Medical Sciences, University of Copenhagen, 7 June 2019

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*The ReACT project*

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# Preface and acknowledgements

This PhD thesis presents results from the ReACT study and was conducted at Danish Dementia Research Centre, Department of Neurology, Rigshospitalet from May 2015 to May 2019.

My engagement in research is deeply inspired by the many people with dementia and caregivers I have met during my work as neuropsychologist. You have opened your hearts and minds to me, shared the experience of living with dementia, and you have truly convinced me of the importance of finding suitable and efficient solutions to support you in coping with dementia in everyday life. This has inspired me to take the step from clinical practise into research and nourished my ambition of contributing with new knowledge and methods that are of true value to you.

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Above all, I would like to thank my principal supervisor Gunhild Waldemar for the immense support and inspiration you have given me, and the great confidence you have shown me in the process of navigating this research project. Thank you for making this project and my PhD study possible.
My co-supervisor professor Bob Woods has also played an essential role in inspiring and guiding this research project and my PhD study.
I am deeply honoured and grateful that you have both been involved in my PhD study. The expertise and excellence you both have from long careers in dementia research has been essential to this research project, and a source of great inspiration for me.

During the research project, people with dementia, family caregivers and professionals have been involved in all phases. From the initial exploration of the possible benefits and challenges of assistive technology for people with dementia, over the iterative design and testing of the ReACT app, and they are still essential partners in our exploration of long-term use of assistive technology. I am very grateful for your cooperation and engagement.

Thank you to the dementia meeting centre in Odense, Kallerupvej, and the adult education centre in Ålborg, where focus group interviews were conducted as part of study 2. A special

thanks to the staff at Herlev Hospital, Roskilde University Hospital and Rigshospitalet, where the group-based intervention in study 3 was conducted. I am also very grateful to all the staff from memory clinics at Aalborg University Hospital, Aarhus University Hospital, Herlev Hospital, Odense University Hospital, Rigshospitalet, Roskilde University Hospital, Slagelse Hospital, Svendborg Hospital and Vordingborg Hospital, where participants for study 4 were recruited.

I also greatly appreciate the cooperation with BridgeIT Aps during in the development of the ReACT app as part of a public-private innovation partnership.

A special and very warm thanks must go to all my colleagues at Danish Dementia Research Centre and Copenhagen Memory Clinic. It would not have been possible to accomplish what we have in this research project without your support and engagement. Especially Mette Tandrup Hansen, who played an essential role in the design of the ReACT app. She and Marie Ejlersen have also been essential to the dissemination of the app. I am also grateful to Kathrine Ruth, who worked as my research assistant during parts of the research project.

I would like to thank the Alzheimer Research Foundation for financial support of the final parts of the ReACT research project, which enabled further studies and open access to the ReACT app. Also, a warm thanks to the Danish Alzheimer Association for your interest and support throughout this project.

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My greatest gratitude goes to my husband and children for their patience and support during this journey. Jes, Sune and Silje you are my firm base and the essence of life. I love you.

Laila Øksnebjerg
Copenhagen, June 2019

# Abstract

Assistive technology is promoted as having potential to reinforce and relieve care and support for people with dementia. One perspective is that assistive technology can be designed to support self-management and capacity to cope independently when living with dementia. There is, however, generally little evidence for the applicability, usability and effectiveness of assistive technology in dementia care and support, and there is a great need for research within this field to provide evidence-based solutions and methods to promote implementation.

This PhD thesis presents results from the ReACT study conducted at Danish Dementia Research Centre. The study involved several complex interacting components and was designed according to the principles of the Medical Research Council's framework for development and evaluation of complex interventions. The results are presented in four papers included in this thesis.

The overall aim of the study was to investigate how assistive technology can be designed and implemented to support self-management of people with dementia.

First, to meet the objective of gaining an overview of the present state within this field, a literature review was conducted in study 1. In addition, people with dementia, caregivers and professionals were interviewed in study 2 to investigate their perspectives, request and needs in relation to assistive technology. The results of these studies underlined the benefits of user-involvement to promote design, functionalities and implementation methods that match the capacity and preferences of people with dementia. The studies also revealed the need for methods to promote implementation and adoption of assistive technology. The review showed that research is highly heterogeneous in addressing user-involvement and implementation. Methods for user-involvement and implementation were neither clearly defined nor addressed as gold standard in research. These results were used to guide the design, test and delivery of an assistive technology solution in the succeeding studies.

The second objective was to design and test assistive technology to support self-management of people with early stage dementia. This was done through an iterative user-involving design process in study 2. The result was the ReACT app, a holistic and adaptable app solution. Functionalities directly reflected needs and requests from potential end-users in relation to self-management. Support of various aspects of memory and structure were essential features in the app. Agile user-tests of the app was conducted as part of the two implementation studies, study 3 and 4. Results of these studies confirmed the overall the feasibility and usability of the ReACT app for participants who adopted the app.

Study 3 and 4 were also designed to address the third objective of investigating methods to promote implementation and adoption of assistive technology among people with dementia. Study 3 involved a programme merging group-based self-management and individual rehabilitation approaches, and study 4 involved a self-applied method, where implementation and adoption were supported by paper-manuals and online and telephone support. Caregivers could be involved in adoption and daily use of the app in both studies. Results of these studies indicated that both methods were applicable and could support implementation and adoption of assistive technology, and since the methods were quite distinct, they could comply with varied individual needs among people with dementia. Results from study 4 also underlined the importance of timely introduction of assistive technology for people with dementia. In addition, results also indicated that caregiver involvement could have a significant impact on successful adoption of technology among people with dementia.

Finally, study 3 and 4 also addressed the fourth objective of exploring outcome measures that could capture the possible benefits and challenges of using assistive technology to support self-management among people with dementia. In both studies a mixed methods design was applied to explore outcome measures, and both qualitative and quantitative outcome measures were applied, including log data. The results of the studies demonstrated that a mixed-methods design, including log data, could provide rich and detailed dataset to assess applicability, usability and factors influencing adoption of assistive technology among people with dementia.

In conclusion, the studies included in this thesis demonstrated that user-involvement is feasible when designing assistive technology for people with dementia and can generate a solution that is applicable and useful for target users. The combination of assistive technology and psychosocial interventions addressed in these studies underlined the benefits of applying methods to promote implementation and adoption. Delivering assistive technology should not be addressed as an isolated process of providing technology-based solutions, but as an integrated part of psychosocial interventions offered to a person with dementia.

Further research should be conducted to elaborate and refine the perspectives raised in these studies, including large-scale studies to assess effectiveness of the assistive technology and implementation methods.

# Resumé (Danish summary)

Det fremhæves ofte, at velfærdsteknologi har potentiale til at styrke og understøtte pleje og støtte til mennesker med demens. Én vision er, at velfærdsteknologi kan designes til at fremme mestring og selvstændigt funktionsniveau. Der er dog generelt mangel på evidens for anvendelighed, brugbarhed og effektivitet af velfærdsteknologi til mennesker med demens, og der er et stort behov for forskning indenfor dette område, som kan sikre evidensbaseret velfærdsteknologi og metoder, som fremmer implementering af teknologien.

Denne PhD afhandling præsenterer resultater fra ReACT forskningsprojektet, som er gennemført ved Nationalt Videnscenter for Demens. Projektet indebar flere komplekse komponenter, og det var designet med udgangspunkt i principperne fra Medical Research Council for udvikling og evaluering af komplekse interventioner. Resultaterne præsenteres i fire artikler, som er inkluderet i denne afhandling.

Det overordnede formål med forskningsprojektet var at undersøge, hvordan velfærdsteknologi kan designes og implementeres, således at det støtter mestring hos mennesker med demens.

For at skabe et overblik over dette felt, blev der foretaget en litteraturgennemgang i studie 1. I studie 2 blev der desuden gennemført interviews med mennesker med demens, pårørende og fagpersoner, for at undersøge deres perspektiver, ønsker og behov i relation til velværdsteknologi. Resultaterne af disse studier understregede fordelene ved bruger-involvering, for at sikre, at design, funktionalitet og implementering matcher kapacitet og præferencer hos mennesker med demens. Studierne viste også, at der er behov for metoder til at understøtte at teknologien implementeres og anvendes af mennesker med demens. Resultaterne af litteraturgennemgangen viste, at metoder vedrørende brugerinvolvering og implementering ikke var klart definerede og heller ikke var standard i forskningen. Disse indledende resultater dannede grundlag for design, test og implementering af en velfærdsteknologisk løsning i de efterfølgende studier.

Det efterfølgende mål var at designe og teste velfærdsteknologi, som kunne støtte mestring hos mennesker med demens. Dette skete via en iterative bruger-involverende designproces i studie 2. Resultatet af processen var ReACT appen, en holistisk app, der kan tilpasses individuelle ønsker og behov. Funktionerne i appen afspejlede direkte behov og ønsker hos potentielle brugere. Støtte af forskellige aspekter ved hukommelse samt struktur var centrale funktioner i appen. Agile brugertests blev gennemført som en del af implementeringsstudierne i studie 3 og 4, og resultaterne af disse studier bekræftede, at appen generelt var brugbar og nyttig for de deltagere, der blev brugere af teknologien.

Studie 3 og 4 var også designet til at adressere det tredje mål for forskningsprojektet: at undersøge metoder til implementering og brug af velfærdsteknologi blandt mennesker med demens. Studie 3 omfattede et interventionsprogram, hvor metoder fra gruppe-baserede støtte af mestring blev kombineret med metoder fra individuelle kognitiv rehabilitering. Studie 4 omfattede metoder til selvstændig implementering af velfærdsteknologi. Her blev implementering og brug af appen støttet af manualer, samt online og telefon support. Pårørende kunne være involveret i implementering og daglig brug af appen i begge studier. Resultaterne viste, at begge implementeringsmetoder var anvendelige og kunne støtte implementering og brug af appen. I og med metoderne var relativt forskellige, kunne de imødekomme forskellige individuelle behov hos mennesker med demens. Resultater af studie 4 understregede ydermere betydning af rettidig introduktion af velfærdsteknologi til mennesker med demens. Resultaterne viste også, at pårørendes involvering i brug af velfærdsteknologi kunne have signifikant indflydelse på hvorvidt mennesker med demens blev brugere af teknologien.

Studie 3 og 4 adresserede også det fjerde mål for forskningsprojektet: at udforske effektmål, som kan opfange mulige fordele og udfordringer ved at bruge velfærdsteknologi til at støtte mestring hos mennesker med demens. I begge studier blev der anvendt et mixed-methods design, med både kvalitative og kvantitative effektmål, herunder log data. Resultaterne viste, at et sådan mixed-methods design kan give et rigt og detaljeret datasæt, som kan belyse anvendelighed og nytte af teknologi, samt belyse faktorer, som har indflydelse på om mennesker med demens bliver brugere af velfærdsteknologi.

På baggrund af disse studer kan det konkluderes, at bruger-involvering er gennemførlig i processen med at designe velfærdsteknologi til mennesker med demens, og at bruger-involvering fører til, at der skabes løsninger, som er brugbare og nyttige for målgruppen. Kombinationen af velfærdsteknologi og psykosociale metoder, som blev adresseret i disse studier, understregede fordelene ved at anvende metoder, som kan fremme implementering og brug af teknologien. Velfærdsteknologi bør ikke ses som en isoleret proces, der blot handler om at tilbyde teknologiske løsninger, men som en integreret del af psykosociale tilbud til et menneske med demens.

Yderligere forskning bør gennemføres, for at arbejde videre med og forbedre de perspektiver, der er rejst i disse studier. Herunder større studier, som er designet til at undersøge effekter og effektivitet af velfærdsteknologi og implementeringsmetoder.

# List of papers

*Paper I:*

**Laila Øksnebjerg**, Janet Janbek, Bob Woods and Gunhild Waldemar: Assistive technology designed to support self-management of people with dementia: User-involvement, dissemination and adoption. A scoping review. Submitted and in review.

*Paper II:*

**Laila Øksnebjerg**, Bob Woods and Gunhild Waldemar: Designing the ReACT app to support self-management of people with dementia: An iterative user-involving process. Accepted: Gerontology.

*Paper III:*

**Laila Øksnebjerg**, Bob Woods, Christina Rytter Vilsen, Kathrine Ruth, Moa Gustafsson, Signe Pertou Ringkøbing and Gunhild Waldemar: Self-management and cognitive rehabilitation in early stage dementia – merging methods to promote coping and adoption of assistive technology. A pilot study. Accepted: Aging and Mental Health.

*Paper IV:*

**Laila Øksnebjerg**, Bob Woods, Kathrine Ruth, Annette Lauridsen, Susanne Kristiansen, Helle Dalsgaard Holst and Gunhild Waldemar: A tablet app supporting self-management of people with dementia: Analysis of adoption and use patterns. Submitted and in review.

# Abbreviations

| | |
|---|---|
| ACE | Addenbrooke's Cognitive Examination |
| AD | Alzheimer's disease |
| AT | Assistive technology |
| B-ADL | Bayer Activities of Daily Living Scale |
| BGSI | Bangor Goal Setting Interview |
| CeHRes | Centre for eHealth Research and Disease Management |
| DLB | Lewy Body dementia |
| FTD | Frontotemporal dementia |
| GREAT | Global Research, Innovation and Education on Assistive Technology |
| ICECAP-O | Investigating Choice Experiments CAPability measure - for Older people |
| ICT | Information and Communication Technology |
| MMSE | Mini-Mental State Examination |
| MRC | Medical Research Council |
| NICE | National Institute for Health and care excellence |
| RCT | Randomised Controlled Trial |
| ReACT | Rehabilitation in Alzheimer's disease using cognitive supportive technology |
| RBANS | Repeatable Battery for the Assessment of Neuropsychological Status |
| SDMT | Symbol Digit Modalities Test |
| USEdem | Usefulness, Satisfaction with and Ease of use questionnaire - dementia |
| VaD | Vascular dementia |
| WHO | World Health Organisation |

# 1. Introduction

Dementia is a major public health and socioeconomic challenge. On a global scale, more than 46 million people live with dementia,[1] and in Denmark the number is estimated to be 89.000.[2] Despite optimism that reduction of risk factors and promotion of preventive interventions can reduce incidence of dementia[3,4] the total number of people living with dementia is expected to increase dramatically in the next decades, due to increasing age of the general population.[1] Consequently, dementia has become a major focus in politics and society in general. The G8 countries have committed to a global action on dementia[5] and the World Health Organization (WHO) has announced dementia as a public health priority.[6] At a national level, dementia has also been put on the political and societal agenda in Denmark, led by the National Action Plan on Dementia 2025[7] and fortified by many nationwide and local initiatives from NGOs and other stakeholders.

Pharmaceutical treatment is a major focus of research, but currently available pharmacological treatments are symptomatic. Regrettably, major breakthroughs are still awaited within this field of research,[3,8] and it has high priority to find efficient treatment and hopefully to cure dementia diseases in the future. Dementia research has also expanded. In recent decades, a more holistic approach to dementia has emerged and generated a still increasing emphasis on psychosocial and care interventions as essential for the health and well-being of people dementia.[3,8] It is now widely acknowledged that good dementia support and care spans pharmaceutical, non-pharmaceutical and psychosocial interventions,[9,10] including interventions to support family caregivers, who's health is often at risk because of the strain of being a primary caregiver to a person with dementia.[3]

There is concern, however, of the large amount of resources needed to comply with support and care needs of the growing number of people living with dementia, and there is a great request for efficient and flexible solutions to meet these challenges.[11] The huge advances in digitalisation and the widespread use of information and communication technology (ICT) across generations is often put forward as key solutions to these challenges,[3,6,11] almost leaving the impression that it can be a panacea to most of the challenges within the field of dementia.[12] Based on these perspectives, there is a rapid growth in technology promoted as applicable in dementia support and care,[13,14] most often discussed as assistive technology (AT). One promising perspective is that AT may enable people with dementia to cope with and compensate for cognitive symptoms and thereby support their self-management and ability to remain independent for as long as possible.[15,16]

Despite the potential benefits of AT in dementia support and care, a range of impediments remain and need to be addressed. Development, design and dissemination of AT within this field is often based on a pragmatic and solution focused approach and is not evidence-based. Furthermore, though AT is often delivered by the public sector, innovation is in most cases often driven by a commercial perspective, where AT is expected to optimize or reduce the use of resources in dementia care and support.[14,17] There is a general lack of high-quality research to provide evidence for the usability and effectiveness of AT solutions[13,15,18,19] and there is also need for research to explore how deployment, adoption and sustainability of these solutions can be promoted.[15,19] User-centred design is essential to provide AT that match the needs, preferences and capacity of people with dementia, and should be addressed in research, to promote such user-centred design methodology. These perspectives will be addressed in this thesis.

# 2. Theoretical and methodological background

Development and implementation of AT for people with dementia, and assessment of possible effects of such interventions, is influenced by multiple theoretical and methodological perspectives, which are essential to consider and incorporate when conducting research within this field.

This chapter outlines the terminology, theories and methods that together constitute the background of this thesis and form the basis of later discussions. First, topics related to AT are addressed, including terminology, definition and classification of AT, and models and frameworks for AT development and implementation. Secondly, approaches and models to understand dementia and the situation of living with dementia will be introduced, both from an etiological perspective and from a holistic perspective. Building on this, psychosocial interventions to promote coping and self-management of people with dementia are introduced. Finally, the wide-ranging field of outcome measures is introduced. Both outcome measures applied in research involving technology and outcome measures in psychosocial dementia research are discussed.

## 2.1 Definition and classification of assistive technology

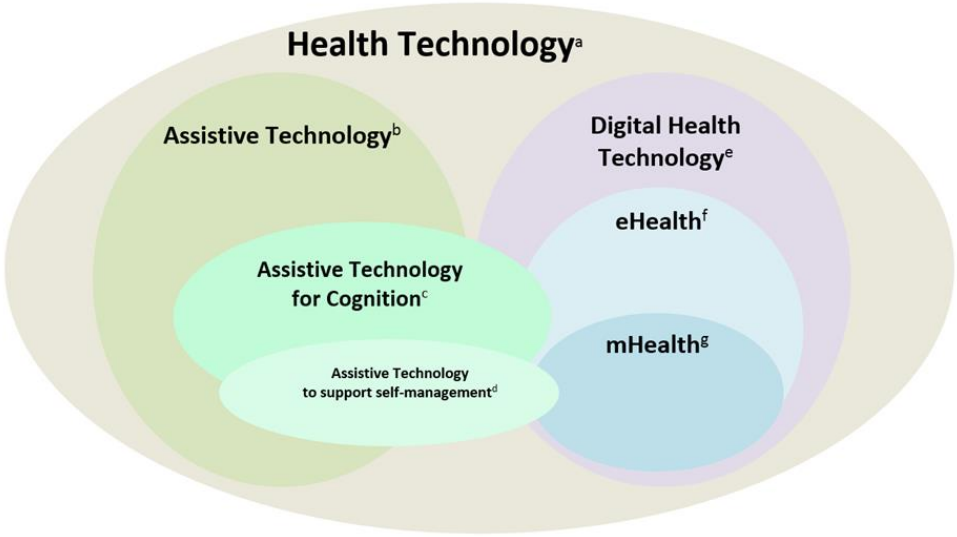
The terminology used to describe and classify AT within the field of dementia is rather varied. A range of terms are often used interchangeably both to describe technology from a broader perspective and specific areas of application. A discussion of terminology can be futile, and though not always well defined or explained in daily praxis or literature, preference for a specific terminology can be based on tradition, practical aspects and theoretical considerations. However, from a research perspective a more well-defined and clear terminology and classification provides an essential point of reference.

### 2.1.1 Assistive technology and related terminology

The terms used most widely to describe technology applied within the field of dementia are summarised in Figure 1, together with terms from overlapping classifications of technology and the terminology used in this thesis. As illustrated in Figure 1, Health Technology can be used as a generic term to describe this field of technology application,[20] but the term not only covers technology, it covers a large variety of solutions and systems applied to solve health problems and improve quality of life.[21] The term Assistive Technology (AT) can be defined as "Any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities."[22] From this

perspective it is an umbrella term, covering a range of solutions from basic low-tech aids or devices, for instance physical aids or non-electronic devices to support memory or communication (e.g. a whiteboard calendar system) to advanced special-purpose hardware or software.[22]

In dementia literature the term AT is widely used to describe various kinds of technology.[15,19,23] More specific terms are also used in literature to conceptualise specific areas of application of AT for people with dementia, e.g. Assistive Technology for Cognition, to describe technologies applied to support compensation for cognitive deficits.[24] However, some authors also use the very broad term "technology" to comprise all these varied technology solutions.[17]




[a]Health technology: "The application of organized knowledge and skills in the form of devices, medicines, vaccines, procedures and systems developed to solve a health problem and improve quality of lives"[21]

[b]Assistive technology: "Any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities"[22]

[c]Assistive technology for Cognition: "Any technology which compensates for cognitive deficit during task performance"[24]

[d]Assistive technology to support self-management (definition used in this thesis): AT designed to support a person with dementia in managing and adapting to the changes caused by living with dementia (according to the definition of self-management for people with dementia by Quinn et al.[25]).

[e]Digital Health Technology: "…apps, programmes and software used in the health and care system"[26]

[f]eHealth: "…the use of information and communication technologies (ICT) for health"[27]

[g]mHealth: "The delivery of healthcare services via mobile communication devices"[28]

Figure 1. Terminology and classification of technology

In this thesis the term AT is used as a generic term to discuss electronically powered AT, non-electronic low-tech solutions are not addressed. In addition, the term self-management will be used when defining the subtype of AT addressed in this research project. The

theoretical background for self-management is discussed below. The term AT to support self-management was considered well suited because it emphasises a more comprehensive approach, where AT is not purely seen as a solution to support specific cognition functions. Instead it is viewed from a more holistic perspective, as a tool to support a person with dementia's capacity to manage and adapt to the changes caused by living with dementia.

Parallel to AT is the field of Digital Health Technology, a generic term for technologies applied in health and care system.[26] Here the term eHealth is used more narrowly to define health technologies applied via the internet.[27] In some instances, the even more specific term mHealth is used to describe health technologies applied on mobile devices.[28] In some cases, specific technology solutions can be encompassed by several of these definitions, e.g. if an app is designed to support memory (AT solution) and at the same time provides advice on health management and/or implies monitoring of health-related measures (mHealth).

### 2.1.2 Assistive technology in dementia support and care

In dementia literature AT has been subdivided and categorised based on various criteria. In their position paper Meiland et al.[15] defined AT for people with dementia according to the global needs of the main user and presented three categories: 1: AT to support people with dementia manage everyday life. 2: AT to support engagement in meaningful and pleasurable activities. 3: AT to support professionals and systems within dementia health and social care. Gibson et al.[14] defined three categories with similar characteristics, they however subdivided AT as used "by", "with" or "on" people with dementia. Others have categorised AT according to the specific features and areas of application, e.g. safety or communication[29] and AT has also been categorised according to specific cognitive or functional domains.[16,24,30] In this thesis, categorisation of AT is mainly inspired by the approach presented by Meiland et al.[15] and the focus is on AT designed to support people with dementia manage everyday life.

## 2.2 Models and frameworks for technology development and implementation

Alongside the fast-emerging innovation and provision of AT, eHealth and mHealth solutions there is an increasing focus on how technology can be developed, designed, disseminated and implemented in end-user's everyday life. This has led to formulation of various iterative models and frameworks for technology development and implementation, which aim to incorporate the many complex factors influencing this process.

Based on an exhaustive review of multidisciplinary frameworks addressing development and implementation of eHealth technologies, van Gemert-Pijnen et al.[31] suggested the CeHRes

(Centre for eHealth Research and Disease Management) Roadmap as a holistic framework for the uptake and impact of eHealth technologies. This framework involves 6 principles, including participatory development, continuous development cycles, intertwining development and implementation, interaction with health care organisation, persuasive design techniques and methods to assess the impact of eHealth.

In an AT perspective, similar themes and principles have emerged. WHO proposed five areas (5P) of focus to improve access to AT. These included: a user-centred approach (People), policies promoting access to AT (Policy), guidance to enhance production, procurement and service provision (Products), guidance on innovative models of service provision, including integration of AT into health systems (Provision), and AT training package addressing professionals support of the provision of AT (Personnel).[20,32] WHO has also addressed the special ethical considerations that needs to be addressed when developing and implementing AT for people with dementia, including how human rights can both be violated and promoted by AT, e.g. by violating privacy or by promoting access to society.[23]

No comprehensive frameworks have been proposed specifically addressing AT for people with dementia, However, the principles and areas of focus promoted by these frameworks are generally consistent with results from recent reviews and position papers addressing AT for people with dementia. These underline e.g. the importance of user-involvement in design and test of AT, the need for effective and suitable methods for implementation, the request for high quality research on usability and effectiveness of AT, and importance of ethical considerations in both development and implementation of AT.[12,15,18,19,29,33-35] This consistency in major themes and areas of focus underlines that such evidence-based frameworks can be of great value to both research, health and social care systems, and industry when developing and implementing AT for people with dementia.

## 2.3 Background and approaches to understand “living with dementia”

### 2.3.1 MCI and dementia diseases

Dementia is linked to a large number of underlying brain disorders, and it is beyond the scope of this thesis to provide a detailed presentation of all diseases that can cause dementia, including details on pathology and disease progression. However, Mild Cognitive Impairment is shortly introduced, and the four most common dementia diseases, Alzheimer’s disease, vascular dementia, Lewy Body dementia and frontotemporal dementia are briefly presented with emphasis on cognitive symptoms in early stage of the diseases, since this is the main focus of the studies included in this thesis.

Mild Cognitive Impairment (MCI) is characterised by subjective and objective cognitive symptoms. The condition covers a spectrum of symptoms, reflecting neuropathological heterogeneity. Reduced memory is often a prominent symptom, but various cognitive domains can be affected, e.g. language or visuospatial functions.[36] It is estimated that a person living with MCI has a 6 -10 percent risk per year of progressing and being diagnosed with a dementia disease,[37] but symptoms do not always progress. It has been estimated that over a period of 10 years more than 50 percent who fulfils criteria for MCI do not progress to full criteria for a dementia disease.[37] However, people living with MCI do have marked cognitive symptoms and can benefit from interventions to prevent symptom progression[3] and interventions to support cognitive functions and everyday functional ability.[38]

Alzheimer's disease (AD) is the most common cause of dementia. It is estimated to account for more than 50-70 percent of all dementia cases.[39,40] The pathology causing AD develops over many years, and at the stage where a person is diagnosed with early stage AD the most prominent symptom is often severe memory problems, especially learning and recalling new episodic memories is affected, but other aspects of memory, e.g. prospective memory and semantic memory will also be reduced.[41] Other cognitive domains such as language, visuospatial functions, executive functions is also to some degree affected.[40,41] The main target group when designing the ReACT app, as described later in paper II (Appendix B) was people with early stage AD with such a predominant amnesic profile. More rarely, early AD is marked by other cognitive symptoms than amnesia, e.g. in cases where visuoperceptual and visuospatial deficits are predominant, cases of primary progressive aphasia, where AD can be the underlying etiology, and a behavioural variant AD[41]. These cases are rare but none the less important to diagnose and address when tailoring interventions to people with dementia. As the disease progresses, cognitive symptoms will severely affect the person's ability to manage independently and eventually result in the need for full time support and care. Neuropsychiatric symptoms such as depression, apathy and agitation are more common at later stages of the disease, but can also be predominant at early stage AD, e.g. depression.[42]

Vascular dementia (VaD) is estimated to be the second most common cause of dementia.[39] VaD is not a neurodegenerative dementia disease, the term covers a heterogeneous group of conditions where vascular neuropathology causes dementia symptoms.[43] The cognitive symptoms of VaD are quite heterogeneous, reflecting variation in underlying vascular pathology, but reduction of processing speed and attention and executive dysfunction are often predominant, reflecting subcortical vascular lesions.[43] Memory is also often affected, but this is often secondary to reduced attention and executive functions, affecting e.g. ability to retrieve stored memory.[44]

Lewy Body dementia (DLB) is the second most common neurodegenerative dementia. Prevalence is much debated, but by some estimated to account for around 7 percent of all dementia cases.[45] DLB is characterised by both cognitive and motor symptoms, with either simultaneous onset or within one-year onset of motor symptoms.[45] Symptoms and pathology is overlapping with both Alzheimer's disease and Parkinsons disease.[45] Cognitive symptoms are characterised by reduction of attention, visuospatial functions, executive functions and memory. People with DLB often have better delayed recognition memory compared with people with AD with a predominant amnestic profile, indicating that memory problems in DLB can be due to impaired retrieval.[45] Characteristic symptoms are also visual hallucinations and fluctuation in cognitive impairment.[45]

Frontotemporal dementia (FTD) accounts for approximately 3 percent of all dementia cases, but has a higher prevalence among people young onset dementia, where it is estimated to account for around 10 percent of all cases.[46] FTD is classified as three clinical variants. The most common type of FTD is the behavioural-variant, which is characterised by progressive behavioural and executive deficits. The other two variants are progressive non-fluent aphasia, which is characterised by progressive deficits in speech, grammar and word output, and semantic-variant FTD, characterised by progressive disorder of semantic knowledge.[47] Not all cases can however be clearly defined in one of these variants, and as the disease progresses, symptoms often occur across these three disease variants. In some cases, FTD progress as motor neuron disease or atypical parkinsonian disorder.[48]

Reduced awareness of symptoms (anosognosia) is a well-known neurological symptom[49] and it is a predominant neuropsychiatric symptom across dementia diseases, associated with disease etiology and stage.[50] It is often a predominant symptom in moderate and severe stage of dementia diseases, but it can also be a marked symptom in the early stage of all dementia diseases, and is a core symptom in FTD behavioural variant.[48] Reduced awareness can of course greatly influence which interventions are suitable for a person with dementia and how the person can engage in interventions, and it must therefore be considered when support and care is planned and delivered to meet the individual needs, preferences and capacity of a person with dementia.

### 2.3.2 A holistic perspective on living with dementia

From a diagnostic and pharmaceutical perspective, biological and disease specific factors, as presented above, are essential to provide the correct and most efficient treatment for people with dementia. Moreover, extensive knowledge of disease specific factors is a basic precondition when designing and implementing various all kinds of interventions for people with

dementia, to tailor interventions according to specific preconditions and needs. This also applies when designing and implementing AT. To provide suitable and effective AT solutions to people with dementia it is essential to consider the capacity of potential end-users, including typical profiles of cognitive symptoms, and to integrate this in understanding their needs and preferences.

However, to fully encompass the factors influencing a person living with dementia, it is essential to move beyond a purely biological understanding of dementia and to consider the complex interactions between biological, psychological and social factors that influence a person with dementia. During the last decades there has been a shift in paradigm in dementia care and support. Focus has moved away from mainly addressing decline and deficits and into a more holistic approach, where focus is on how positive aspects can be promoted to enhance the individual's well-being and health, and capacity to live well with dementia.

In 2010 Spector and Orrell[51] proposed a model that encompass the complex interactions between biological and psychosocial factors that influence a person with dementia. The model is based on previous models for person-centred care, as presented by Kitwood[52] and further elaborated by Brooker[53]. Spector and Orrell's model provided a detailed bio-psychosocial model to demonstrate the complex interaction between fixed and tractable biological and psychosocial factors, including how biological and psychosocial interventions can influence the functional ability of a person with dementia.

In recent years, the concept of social health has been introduced as a theoretical framework for the paradigm shift towards a dynamic view on the balance between limitations and capacity, including the possibilities to compensate for deficits.[54] This theory is in line with the concept of personhood in a social context as introduced by introduced by Kitwood and integrated in the models mentioned above. The concept of social health originates from the more dynamic definition of health as the ability to physically, mentally and socially adapt and self-manage despite living with a chronic condition, as proposed by Huber et al.[55] In the context of dementia, Dröes et al.[56] has operationalised Huber et al.s three domains of social health as 1: "the ability of a person living with dementia to function in society according to his or her competencies and talents (p. 6), 2: "the ability of the person with dementia to preserve autonomy and to solve problems in daily life, as well as to adapt to and cope with the practical and emotional consequences" (p. 8), and 3: "the act of being occupied or involved in meaningful activities and social interactions" (p. 9).

These theoretical frameworks originate from different theoretical traditions, but they both represent a holistic approach to understand the complex interacting factors that influence living

with dementia, and how interventions and activities can influence such factors and promote well-being and capacity of a person with dementia.

## 2.4 Psychosocial interventions to promote coping and self-management

It is widely acknowledged that timely psychosocial interventions that match individualised needs, preferences and capacity can reduce dementia symptoms and promote living well with dementia.[9,10,57] People living with a dementia disease at an early stage often put forward a wish to build capacity and live as independently as possible.[58,59] Accordingly, interventions offered to people at this stage are often designed to promote adaption and coping with the psychological, social, and functional consequences of living with dementia. This perspective is in line with the shift i paradigm, including the bio-psychosocial model and the understanding of social health in relation to dementia, as discussed above, and they constitute favourable frameworks for the design and implementation of interventions to promote coping and self-management of people with dementia.

It is not within the scope of this thesis to give an exhaustive overview of psychosocial interventions for people with dementia, only the methods that are included in this research project will be addressed here: cognitive rehabilitation and self-management.

### 2.4.1 Cognitive rehabilitation

In general terms, rehabilitation can be defined as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”.[60] In recent years there has been an increasing focus on how a rehabilitation approach and related concepts of reablement, restorative care and tertiary prevention can be operationalised and implemented for people with dementia.[61,62] Various methods within the field of psychosocial interventions for people with dementia contain elements that place them in rehabilitation perspective, e.g. programmes of community based occupational therapy[63] and self-management interventions as discussed below.

One specific rehabilitation method that has been adapted to people with early stage dementia is cognitive rehabilitation, which has its origin in the field of acquired brain injury.[64] The rationale behind cognitive rehabilitation for people with dementia is that not all cognitive functions are equally severely affected at the early stage of a dementia disease, and this method emphasis how more well-preserved abilities and capacities of the individual can support and compensate for the impaired functions. For example, people who have the most common

variant of Alzheimer's disease, with severe memory problems, will have severe impairments in learning and recalling new information, where as other cognitive domains, e.g. language, visuospatial and executive functions, are often less affected at this early stage of the disease. Another resource often addressed in cognitive rehabilitation is that in most dementia diseases procedural learning is often relatively spared until later stages.[65,66] By providing appropriate support through cognitive rehabilitation the person with dementia can train and implement new strategies and tools to maintain or improve everyday functioning and independence.[67] Accordingly, cognitive rehabilitation can be defined as "a person-centred, goal-oriented, problem-solving therapy aimed at managing or reducing functional disability, mitigating excess disability, and maximising engagement and social participation" (Clare et al.[67] p. 710).

### 2.4.2 Self-management programmes

For decades the self-management approach has been applied as a model of care in various chronic conditions, including psychiatric and neurological diseases.[68,69] It has been defined as the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition" (Barlow et al.[68] p. 178). Self-management groups have become a cornerstone of self-management programmes. They typically include elements of psycho-education and peer-support, aiming to modify both clinical outcomes, quality of life and the use of health and social services among people with chronic conditions.[68,69]

In the context of dementia, self-management programmes have been discussed and introduced as an applicable method to support people with dementia in developing skills to manage and adapt to the life-changes cause by living with dementia.[69,70] However, self-management programmes are apparently not widely applied to people with dementia and a limited number of studies have been conducted.[70] This is probably due to a various reasons. Specific disease related factors, including reduced symptom awareness, as discussed above, is probably one reason for the limited deployment of this kind of intervention.[69,70] Though the shift in paradigm has been in progress for years, the focus on cognitive decline and neuropsychiatric symptoms is still prevalent, both among many professionals and in society in general. There is still a need to promote an individualised perspective on living with dementia and underline that progression of diseases and symptoms varies, including reduced awareness.[69] There is still stigmatising and exclusion of people with dementia. In many cases people with dementia are not even informed about their diagnosis and treatment.[71] Of course, self-management interventions for people with dementia must be tailored to take into account

preconditions caused by dementia symptoms and address the special needs of people with dementia.[70,72]

Self-management groups for people with dementia are often based on elements from psychoeducation, problem solving and coping skills training[70,72] and are tailored to address a combination of cognitive, psychological and social functioning. When conducted in a group setting, participants also benefit from sharing, socialising and learning from people in a similar situation. Such benefits from peer interaction and support are requested by people with dementia as essential elements of psychosocial interventions.[73,74] Based on these perspectives, self-management programmes are in line with the perspective of social health to support the person with dementia to adapt and cope with the various impacts of living with dementia.

## 2.5 Assessment of interventions for people with dementia

The assessment of AT and related eHealth solutions has two equally important and often interwoven objectives. One is to assess the quality of the AT, whether it has the qualities in design, functionality and implementation that was intended and whether it is accessible, applicable and feasible for the users. The other is to assess the effect of the technology, whether the essential aim(s) of applying the technology were fulfilled, also sometimes referred to as clinical outcomes.

However, when assessing the effects of AT for people with dementia both these parallel objectives are complicated by several factors that need to be considered in the design of studies and planning of outcome measures. First, AT is subject to the general preconditions of technology development, where a high speed in product innovation and the changeable nature of existing technology, by way of updates and adaptions, set the scene and are basic preconditions in the life-circle of AT.[17,20] Secondly, when AT is applied within the field of dementia further preconditions complicate assessment of quality and effect, e.g. the need for tailormade AT to match individual needs, preferences and capacity.[17,20] Furthermore, this field of research is also influenced by the precondition that outcome measures must be suitable for the person with dementia addressed, matching and not underestimating their capacity to engage in assessing the outcome of an intervention. Just as important, the outcome measures should mirror the essence of an intervention as experienced by the participants.[74]

As specified below, one of the objectives of this thesis was to explore relevant outcome measures to investigate the use of AT to support self-management among people with dementia. A mixed methods design was applied, integrating methods and outcome measures

from the field of AT/eHealth research and psychosocial interventions research. The goal was to identify methods of assessment that are applicable for this group of end-users and can provide evidence for both the quality and effect of the AT solution and methods of implementation.

### 2.5.1 Assessment of assistive technology and eHealth technology

Mechanisms related to uptake, use and sustainability are often addressed when assessing the quality and effect of AT or eHealth solutions, and these mechanisms are often conceptualised as acceptance, adoption and adherence.[75,76] Acceptance relates to the decision of a potential user on if, how and when they would use a technology and it is of course a precondition for adoption and adherence. Adoption relates to the decision of the user to start using a new technology, and adherence relates to whether the technology is continually used as it is intended to obtain the intended goal or benefit.[76] Both acceptance, adoption and adherence depend on multiple complex individual and contextual factors, as discussed later in this thesis.

The multiple complex factors influencing technology acceptance has been described in various theoretical models. e.g. by Venkatesh et al.,[77] who suggested a unified theory of acceptance and use of technology, based on analysis if 8 previous models. Such complex factors can be difficult to capture in structured outcome measures but can be explored in e.g. interviews with users.[78]

Usability of technology has great influence on both adoption and adherence, and usability is often assessed by questionnaires.[78,79] However, usability can also be addressed in the professional's formal evaluation of AT use, e.g. as part of a rehabilitation programme, where cognitive tests and tools to assessment functional ability are applied.[80,81] A few research teams have also proposed complex models aiming to predict adoption of AT among people with dementia based on analysis of individual and contextual factors.[82,83]

Since the use of AT and eHealth often takes place in the private domain of users it is not straight forward to conduct an objective assessment of the mechanisms in acceptance, adoption and adherence. As discussed previously, various types of AT are often defined according to areas of application or functional domains, reflecting that a solution has been designed to meet one or more specific goals, e.g. supporting a person to remember medication or navigate. However, despite being designed for a specific goal and specific ways of use there is no guarantee that the technology is applied and used accordingly, or if and how the use of technology caused the changes that was registered in an intervention. This has been referred to as the "black box" phenomenon in eHealth literature.[84] However, by a combination of appropriate outcome measures this black box can be illuminated.

Analysing detailed records of user's real-time actions when using technology, referred to as log data analyses,[84] can provide essential objective data to document usage and use-patterns. This method of course has limitations, for instance log data does not provide information on factors influencing certain use-patterns, but in combination with other outcome measures it can provide a rich mixed methods dataset. For instance, in combination with quantitative data, describing user-characteristics, clinical outcome measures, assessing the goal of the intervention, and qualitative data, addressing acceptance, adoption and adherence. In the context of AT for people with dementia, the use of log data analysis as an outcome measure also has the great advantage that it is easy to collect without any effort from the user.

### 2.5.2 Outcome measures in psychosocial intervention research

In psychosocial intervention research outcome measures are of course applied to mirror the theoretical background and nature of the specific psychosocial interventions. Accordingly, outcome measures included in studies target various domains such as cognition, emotional aspects, quality of life, well-being, activities of daily living etc. Since psychosocial interventions often consist of complex interventions, as introduced later in this thesis, they can potentially address multiple domains or sub-domains and consequently a mixed design methodology is often applied,[85] including both quantitative and qualitative outcome measures.

The shift i paradigm towards a holistic view and positive constructs of living with dementia, as previously discussed, has large influence on the current movement towards new outcome measures in psychosocial interventions research, which are designed to capture constructs related to e.g. well-being, resilience, self-efficacy and capacity.[74,86] This development of new outcome measures is also highly influence by the paradigm of positive psychology.[87]

The selection of outcome measures for the studies included in this thesis was of course based on complex nature of the intervention, drawing on outcome measures and assessment tools from both the field of AT/eHealth interventions and psychosocial intervention research.

# 3. Objectives and hypotheses

The overall aim of this thesis was to investigate how assistive technology can be designed and implemented to support self-management of people with dementia.
The study was guided by four objectives as outlined below and illustrated in Figure 2.

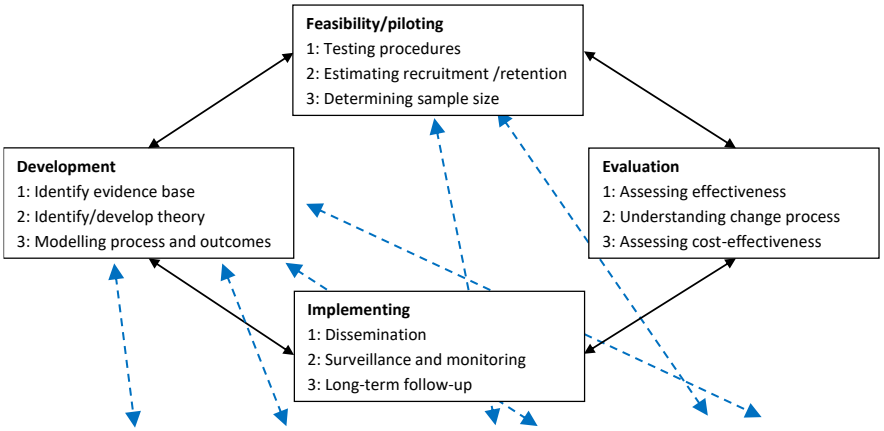
1. Provide an overview of the present state of AT designed to support self-management of people with dementia.
   It was hypothesised that such an overview could provide important information to guide the design and delivery of an AT solution in the succeeding sub-studies of this research project.
   This objective was addressed in study 1 and 2.

2. Design and test of specific AT, the ReACT app, that could support self-management of people with early stage dementia. This also provided an AT solution that could be used to address the remaining study objectives.
   It was hypothesised that by conducting an extensive iterative user-involving design process and test phase of the app it would be possible to design an applicable and useful AT solution that could meet the needs of end-users in relation to self-management.
   This objective was mainly addressed in study 2. User-tests of the app was also addressed in study 3 and 4.

3. Develop and assess methods to promote implementation and adoption of AT among people with dementia.
   It was hypothesised that interventions tailormade for implementation of AT among people with dementia could promote adoption of AT.
   This objective was addressed in study 3 and 4.

4. Explore outcome measures that could capture the possible benefits and challenges of using AT to support self-management of people with dementia.
   It was hypothesised that a mixed methods design, applying both qualitative and quantitative methods, including log data analysis, could contribute with nuanced and relevant data.
   This objective was addressed in study 3 and 4.

**MRC framework for developing and evaluating complex interventions**[89]




| | **Objective 1**<br>Present state of AT for self-management | **Objective 2**<br>Design and test of the ReACT app | **Objective 3**<br>Develop/assess implementation methods | **Objective 4**<br>Explore out-come measures |
|---|---|---|---|---|
| **Study 1**<br>Scoping review (paper I)<br>  | X<br>Research aim 1 | X<br>Research aim 2 | X<br>Research aim 3 | X<br>Addressed in discussions |
| **Study 2**<br>Iterative design process (paper II)<br>  | X<br>Explored in 3 steps:<br>1: Pilot-study<br>2: Focus groups<br>2: Benchmark | X<br>The overall aim of the study | | |
| **Study 3**<br>Self-management and cognitive rehabilitation programme (paper III)<br>  | | X<br>User-tests were an additional aim of the study | X<br>Main aim of the study | X<br>Additional aim of the study |
| **Study 4**<br>Self-applied implementation (paper IV)<br>  | | X<br>User-tests were an additional aim of the study | X<br>Main aim of the study | X<br>Additional aim of the study |

Figure 2. Overview of the sub-studies in the research project according to research objectives - and structured according to the MRC framework for development and evaluation of complex interventions.

# 4. Methods

The ReACT study included several interacting components and was therefore designed according to the principles of the Medical Research Council (MRC) framework for development and evaluation of complex interventions.[88,89] This framework outlines the iterative process of developing interventions, conducting feasibility/pilot studies, evaluation and implementation. Figure 2 illustrates how the series of sub-studies, addressing the four research objectives, were designed to address these iterative processes summarised in the MRC framework.

Our study design also took into account the paradigm shift in relation to the MRC framework suggested by Vernooij-Dassen & Moniz-Cook.[90] They advocated that to avoid implementation errors in psychosocial intervention it is essential to a conduct highly controlled exploratory trials in an ideal setting as part of the evaluation process. The pilot studies described in paper III and IV were designed and conducted according to these recommendations. We aimed for ideal settings in relation to participants, practitioners and places of conducting the studies to be able to evaluate feasibility and applicability of the interventions under conditions where treatment fidelity was as high as possible.

## 4.1 Participants

Participants were recruited consecutively as the sub-studies were conducted. Specific locations and methods for inclusion, periods of inclusion, as well as inclusion and exclusion criteria are outlined in paper II, III and IV, where the sub-studies involving people with dementia and caregivers are described. In both this thesis and in the papers the term participant refer to the person with dementia, who were the primary participant throughout this research project, and the term caregiver refers to the family caregivers or other relatives who participated in studies as adjacent co-participants. One exception is the focus group interviews and the design process described in step 2 and 4 in paper II, where both family caregivers and professional caregivers were involved and are referred to by these two separate terms.

## 4.2 Outcome measures

According to the mixed methods design of this research project, various outcome measures were applied in the sub-studies. The outcome measures are listed in this section and the rationale behind applying specific outcome measures, specific details on the application and summarising/scoring of the outcome measures, are referred in paper II, III and IV respectively.

### *Demographic and background information*

Demographic and background information were collected for both participants and caregivers in the studies described in paper II, III and IV. Background information was also collected for professional caregivers who participated in the study described in paper II.

### *Interviews and surveys*

Qualitative data from focus-group interviews were collected in the sub-study referred in paper II, data from individual interviews was collected in the sub-studies referred in paper II and III, and free-text comments from surveys were collected in the sub-study referred in paper IV. These data were collected by either audio recordings or note-taking as specified in the papers.

### *Questionnaires*

The following two questionnaires were applied in the group-based intervention described in paper III. Activities of daily living was assessed with the Bayer Activities of Daily Living Scale (B-ADL)[91] and ICEpop CAPability (ICECAP-O)[92] was applied to assess capability-related well-being. Both these scales were translated into Danish to be used in this PhD study. Translations was done according to standard procedures for scale translation and back-translation and with permission from authors. These Danish versions of the scales are included in Appendix E. In addition, the EQ-5D-5L[93] was applied in this study to assess Health-related quality of life.

To evaluate the usability and applicability of the ReACT app in the sub-studies described in paper III and IV a modified version of the Usefulness, Satisfaction with and Ease of use (USE) Questionnaire[79] was produced for this PhD study, it was named the USEdem questionnaire. Permission to translate and modify the USE Questionnaire was obtained from the author. The USEdem questionnaire is also included in Appendix E.

### *Goal attainment evaluation*

Goal attainment was the primary outcome measures applied in the group-based intervention described in paper III, and also as part of this PhD study the Bangor Goal Setting Interview (BGSI)[94] was translated to Danish. Authors gave permission for translation and standard procedures for scale translation and back-translation were applied. This Danish version of the BGSI is likewise included in Appendix E.

***Cognitive tests***

The Mini-Mental State Examination (MMSE)[95] was used among base-line information in the sub-studies described in paper III and IV. It was also included as outcome measure in the study described in paper III. In this study the following cognitive tests were also applied: Addenbrooke's Cognitive Examination (ACE)[96], list learning and visual memory tests from the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)[97]. Symbol Digit Modalities Test (SDMT)[98], Trail making A and B tests[99], verbal fluency (number of animals and words beginning with S for 1 min)[100] and non-verbal fluency measured with the Five Point test.[101]

***Log data***

The use of the ReACT app was monitored through log data from participants and caregivers in the sub-studies described in paper III and IV. These data both provided information on action types and timestamps for these actions.

## 4.3 Data analysis

According to the mixed methodology various methods of data analysis were applied. Qualitative data from interviews and surveys were processed and analysed according to the principles of the Constant Comparison Analysis.[102] Quantitative data, including baseline characteristics, data obtained from questionnaires, goal attainment evaluation, cognitive tests and log data, were analysed using IBM SPSS Statistics v.22. Specific statistical procedures applied in sub-studies are summarised in paper III and IV.

## 4.4 Ethics approval, consent to participate and data management procedures

The protocol for the ReACT study was sent to the regional scientific ethical committees of The Capital Region of Denmark (protocol number H-15005558) for evaluation. Here it was decided the study did not need approval, since it was not considered to be within the framework of biomedical research.

Participants and co-participating caregivers in the sub-studies received oral and written information about the study objectives and methods, and they all gave written informed consent.

Procedures for data protection and management were approved and monitored according to procedures from the regional data protection agency.

# 5. Results and discussion

The following sections (5.1 through 5.4) contain a summary of results and discussions as presented in the four papers (Appendices A-D). The sections are organised according to the objectives of the study, as presented earlier in section 3 and illustrated in Figure 2. Additional results that were not included in the papers are also presented and discussed. Finally, section 5.5 includes an overall discussion of results, and limitations are discussed in section 5.6.

## 5.1 Assistive technology designed to support self-management of people with dementia – state of the art *(results presented in paper I and II)*

This initial part of the research project was conducted to gain an overview of present state and current challenges in AT designed to support self-management of people with dementia. The aim was to obtain information and inspiration to guide the design of our AT solution, the ReACT app, and to guide the design of methods to promote implementation and adoption of this app. To address this aim, a review of existing research literature was conducted, as presented in paper I. Literature review was of course an underlying and ongoing process when planning and conduction the research project, and the scoping review presented in paper I was a result of a final systematic scoping review. Moreover, potential end-users were interviewed, and existing AT solutions were benchmarked, as presented in step 1-3 in paper II. Major themes emerging from these results are summarised and discussed here.

### 5.1.1. Results

The interviews with people with dementia and caregivers, summarised in paper II, underlined the importance of designing and implementing AT solutions that meet the special request and needs of people with dementia. Participants in both our initial pilot study in step 1 and focus groups interviews in step 2 requested that AT could support them in managing everyday life as independently as possible and could supported them in gaining access to society in general. To meet these needs, user-friendly, individualised and adaptable features were requested in the design of AT. It was also underlined that AT solutions should be fully reliable and efficient when used in daily life. The results of these interviews also demonstrated the special needs of people with dementia for easily accessible education and support to adopt and continue using AT. They emphasised both the benefit of support from professionals and from family caregivers. Family caregivers also requested support and advice on how they could assist and support the person with dementia in using AT.

The scoping review, summarised in paper I, identified 8 studies where AT had been designed to be used by people with dementia for self-management,[103-107] including three studies where complementary data from design and test of AT was presented in two separate papers.[108-113] They were in general small-scale studies addressing the design and test of AT prototypes. The studies presented quite distinct AT solutions, ranging from extensive multi-device holistic solutions[109-112] or holistic app solutions[104,107] to AT containing one main feature[103,108,113] or designed to support one specific functional domain.[105,106] People with dementia and/or other stakeholders were involved in the design and test of AT in 6 of the studies.[103,106-113] The involvement however varied widely, ranging from non-specified consultations with other stakeholders, and no involvement of people with dementia,[107] to extensive user-involvement throughout iterative design and test phases.[106,110,112] Five of the studies reported methods used to support people with dementia in adopting technology,[104,105,109,111,113] but only during the prototype test phase. Methods varied from extensive individual education and support[104] to shorter individual training sessions.[105,109,111,113] One study also provided a user manual and help-desk/telephone support[111] and in another study audio-based guidance was included as part of the AT solution.[107] One study only addressed caregivers with instructions and support.[103]

As summarised in step 3 of paper II, a product benchmarking process was conducted to gain an overview of AT solutions to support self-management that were accessible on market for people with dementia in Denmark. This review of existing AT identified three solutions promoted as applicable for people with dementia and within the scope of self-management. They were all holistic software/app solutions with multiple features to support various functions in everyday life. The solutions identified were not exclusively promoted as applicable for people with dementia. They were also described as suitable for a heterogeneous spectrum of people with cognitive symptoms due other conditions. No information was accessible to specify if and how the solutions were designed, tested or validated in relation to people with dementia or any other group of potential end-users.

### 5.1.2. Discussion

As introduced earlier there is great optimism regarding the potential of AT for people with dementia, and the results summarised above underline that AT solutions are requested by people with dementia and caregivers. Results from the interviews demonstrated that, as potential end-users, they contribute with essential perspectives on AT design, functionalities and implementation to match their capacity, needs and preferences when living with dementia. This supports the perspective that user-involvement should be golden standard in AT design, test

and implementation. However, as the results of our review indicated, user-involvement is not self-evident in AT design and test. The methods applied, and the extent of user-involvement varied greatly. This is in line with results from other reviews[12,15] addressing AT for people with dementia but not focussing specifically on self-management. These reviews also discussed the general lack of user-involvement. The benchmarking process in our study also indicated that user-involvement was not standard in the on-market solutions.

The need for applicable and effective methods to support adoption, adherence and everyday use of AT was also underlined by the results of the interviews. However, results from our review indicated that this is not addressed as a specific research objective. Adoption was generally addressed in the studies, but methods varied greatly and only targeted the prototype testing process. Feasibility and applicability of these adoption methods was generally not reflected upon. This limited focus in research on how to support implementation and adoption of AT by people with dementia has also been discussed elsewhere.[17,114,115]

Overall, the results from our studies indicate that this field of research has been characterised by a narrow focus on the design-process and could benefit from a holistic approach to the dynamic interrelationship between technology, user and context. This is in line with WHO's five areas of focus to improve access to AT[20,32] and in accordance with principles of the CeHRes framework[31] as discussed earlier (section 2.2), which can be introduced as an agile framework to guide an iterative process of developing, implementing and evaluating AT for people with dementia.[116]

As demonstrated by our review, there appears to be limited research activity addressing AT used by people with dementia for self-management, the studies vary greatly in quality and were not designed or powered to assess effectiveness. This lack of research literature could reflect a publication bias where studies that did not result in successful AT design are disregarded, but it is also likely to mirror that AT solutions promoted as applicable for self-management of people with dementia are generally not based on research. This perspective was supported by the results of the benchmarking process where the few solutions identified were apparently not designed or tested based on a research process. This does raise the question of whether research is needed to design AT, and how it can contribute to promote applicable and effective AT solutions for people with dementia. However, this general lack of evidence for AT solutions form a contrast to the general demand for evidence to promote effective treatments and interventions.[3,117] Insufficient evidence is not unique for AT designed for people with dementia. The low level or lack of evidence for eHealth and AT solutions is much debated in digital health technology[118] and also in relation to AT in general.[20] The lack of sound research restrains a balanced view on benefits and limitations of AT for people with

dementia and we do not have access to objective information on applicability and effectiveness of AT solutions, including cost-effectiveness. Consequently, from a societal perspective, we lack evidence-based knowledge to guide investments and promotion of effective solutions. From an individual perspective people with dementia and their caregivers cannot select AT based on independent and evidence-based information.

Overall, these perspectives point to the need for research to provide applicable and effective AT solutions for people with dementia and this research should be based on sound methodology regarding user-involvement to ensure that it genuinely meets the needs and requests of end-users. Moreover, all aspects that are essential to deliver effective and sustainable AT needs to be addressed in research, including methods to promote implementation and adoption.

## 5.2 The iterative user-involving process of designing and testing the ReACT app *(results presented in paper II, III and IV)*

The second objective of this study was to produce specific AT software, the ReACT app, that could be an applicable and efficient solution to support self-management of people with dementia. The app was designed through a process of extensive user-involvement, as described in paper II. Designing specific AT also enabled a controlled intervention (the app) that could be used to investigating the two succeeding objectives: exploring methods of implementation and adoption of AT and exploring outcome measures to capture the essence of using AT to support self-management among people with dementia.

### 5.2.1 Results

The process of designing the ReACT app is summarised in the four steps in paper II and illustrated in Figure 3. The target users that were involved in this process were people with early stage Alzheimer's disease. Other essential stakeholders were also involved, including family caregivers, who could also be regarded as co-users, and dementia professionals. The scope, functionalities and design of the app was gradually narrowed down and specified during the iterative process of exploring their requests and needs in relation to AT design and use, as illustrated in Figure 3.

The process of designing the ReACT was conducted as a public-private innovation partnership to strengthen cooperation between experts of app development and dementia experts. This partnership facilitated the user-involving design process and the partnership was also highly beneficial to obtain the goals of designing AT that is easy to access for end-users and can be applied as an on-market solution.

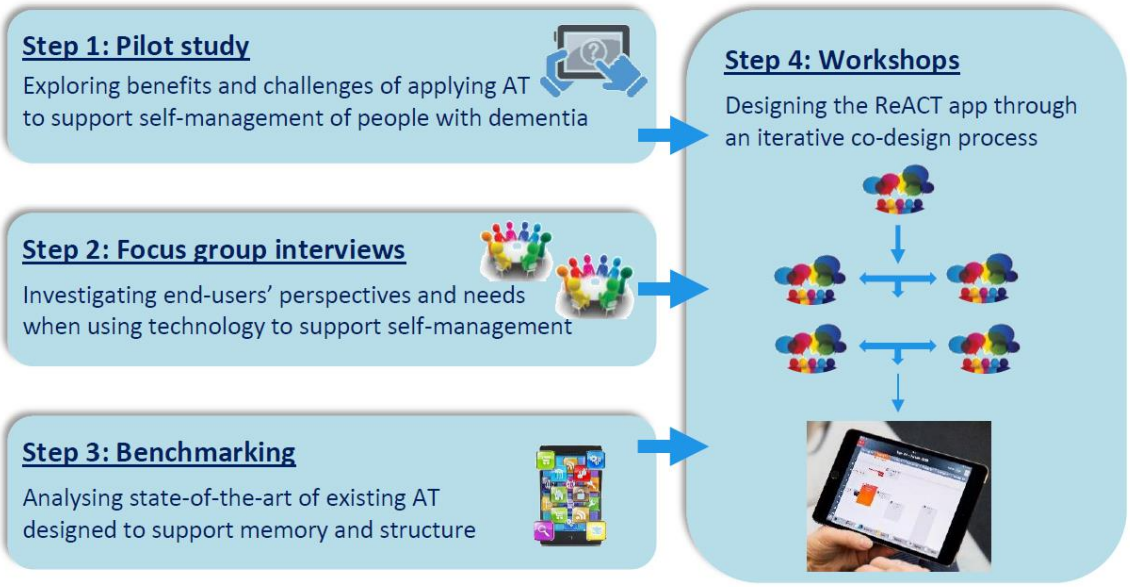
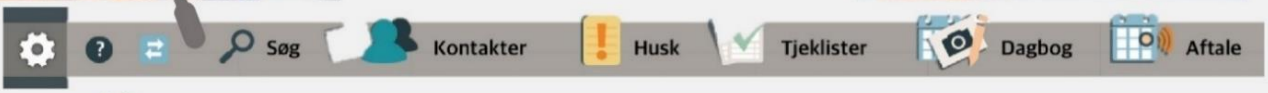



Figure 3. The iterative user-involving design process.

As summarised in Figure 4, the functionalities and design of the app directly reflects the requests and needs of the users in relation to self-management put forward in this iterative design process.

The intervention studies, study 3 and 4, were conducted to explore methods to promote implementation and adoption of AT among people with dementia, as discussed later, but the studies also served as an iterative test process. First the app was tested in a smaller homogeneous group of people with early stage AD (study 3) and secondly in a larger mixed group of people with dementia (study 4).

**Caregiver support:** Caregivers can view, add and edit information via parallel access to the user's app account.




## FEATURES OF THE ReACT APP

### CALENDAR

**Orientation to time:** Current time is indicated by a pulsating "now". User can go back to current time by pushing "show now".

**Three adaptable reminders:** Time to get ready, time to leave for an appointment, time when the appointment starts.

**Access to contact details including navigation:** Contact details can be added from contact, including a link to maps to support navigation.

### DIARY

**Supporting retrograde memory of activities:** Photos, text and contact details can be added.

### CHECKLISTS

**Personalised checklists to support memory of routine or new tasks:** Photos and a 'tick off list' can be created.

**Check-lists can be added to appointments** in the calendar and can be set to pop up with the first reminder.

### MEMOS

**Memo list to support anterograde memory for to-do's.**

**Retrograde memory is also supported:** When pushing "done" the memo goes into the calendar to visualise a completed memo.

### CONTACTS

**Easy access to contacts details:** Contact persons can be added with all relevant details, including photos to support memory.

**Overview of activities with a contact person:** All activities with a person can be viewed on a timeline.

**Reminders of birthdays and other special days:** These special days are automatically added and marked in the calendar for contact persons, including a photo of the person.

### SEARCH

**Allows the user to search keywords** used in appointments, diary notes and contacts.

### SYNCHRONISE

**Allows the user to synchronise app content with the web server.**

Useful when more users (person with dementia and caregivers) edits content in the same user-account.

### HELP

**Gives direct access to website** with app information, tutorials and hotline support.

### SETTINGS

**Tailoring the app:** Various functionalities of the app can be tailored. In settings the preferred default settings can be selected individually to fit the user, e.g. calendar view (8 hour or week), time intervals for reminders and which functions in the app should be used and hence visible on the menu-bar.

**Simplifying the app:** All functions on the menu-bar can be deselected. Then the user can just view the information in the app and leave editing to caregivers.

Figure 4. Functionalities of the ReACT app

Specific feedback on app design and functionalities were obtained from these studies and they led to small adaptions of specific functionalities of the app. For instance, functionalities were added to prepare the app for self-applied implementation in study 4: the “help-button” (giving access to online support) and the “synchronise-button” (to ensure that the content of the user-account was synchronised to the web-server, which is essential when a caregiver supports the use of the app). These features are also illustrated in Figure 4. Feedback from participants and caregiver also led to a version of the app that could be used on mobile phones, but this was not part of the studies included in this thesis.

Analysis of log data from study 3 and 4 provided detailed data that could be used in the process evaluation of the app (according to the MRC framework). Log data showed that all functionalities in the app were used, but the adaptive features were rarely used. This indicated that such features should be reconsidered in future studies by adoption of the app and/or by promoting these features more strongly when implementing the app.

Overall the study 3 and 4 confirmed applicability and usability of the app, including reliability of the app in a real-world setting.

### 5.2.2 Discussion

The iterative user-involving design methods, as summarised in paper II, are generally in line with the evidence-based and widely applied methods in eHealth design[119] and software development in general,[120] including participatory informant design methods[121] and persona-based design methods[122] that were applied in our design process. The user-involving methods applied in this study were of course adapted to fit the special needs of people with dementia, e.g. by supporting memory and communication during the user-involving activities to promote their full participation and influence. This is in line with general recommendations on user-involvement in dementia research.[123] The results of our study demonstrate that user-involvement is fully feasible and very beneficial when designing AT for people with dementia.

The overall design of this research project, including iterative user-involving design and test phases, the involvement of other stakeholders, including industry, the design and test of methods for implementation and adoption and the wider perspectives on accessibility, is in line with the principles of the CeHRes holistic framework for uptake and impact of eHealth technologies[31] and with the areas of focus to improve access to AT proposed by WHO,[20] as discussed previously in section 2.2 and 5.1.2. This underlines that well-established

frameworks for development and implementation of eHealth and AT are applicable in the field of designing AT for people with dementia.

## 5.3 Methods to promote implementation and adoption of assistive technology among people with dementia *(results presented in paper III and IV)*

The third objective of the research project was to develop and assess methods to promote implementation and adoption of AT among people with dementia. The interviews with people with dementia summarised in paper II clearly indicated that education and support on the use of AT is requested by both people with dementia and caregivers, and results from the review presented in paper I showed a lack of evidence-based methods to promote dissemination and adoption of AT for people with dementia.

Two different methods to promote implementation and adoption of AT among people with dementia were design and assessed. Study 3 investigated a programme merging self-management and rehabilitation approaches, and it was explored if adoption of AT adoption could be promoted through this intervention programme. People with early stage Alzheimer's disease were included in this study (N=19). Study 4 involved a self-applied method of implementation and adoption and was disseminated to a mixed population of people with dementia (N=112).

### 5.3.1 Results

All participants in study 3 accepted being introduced to the ReACT app as part of the self-management rehabilitation programme and 42 percent of the participants adopted the app and continued using it after the programme of 90 days. The self-applied method in study 4 resulted in 16 percent of all participants adopting the app. When only including results from participants who activated the app 28 percent of participants became adoptors.

When analysing differences in baseline characteristics of adopters versus non-adopters none of studies showed significant differences in demographics, baseline cognitive screening or diagnosis. Between group differences in the two studies are summarised in Table 1. Except in study 4, involving self-applied methods of implementation, where there was a significant difference between adoptors and non-adoptors in time since diagnosis (U=595 P=0.046, r=.19, Mdn = 4 and 8 months respectively).

| **Study 3: Self-management rehabilitation programme**[a] | | | |
|---|---|---|---|
| **Characteristics** | **Adoptors**[b] (N = 8) | **Non-adoptors**[b] (N = 11) | **P** |
| **Age** (years) mean (SD, range) | 63.3 (9.3, 52-74) | 70.6 (6.4, 58-79) | .07 |
| **Sex** (women) n (%) | 7 (88) | 8 (73) | .60 |
| **Years of education** mean (SD, range) | 14.5 (3.0, 8-17) | 14.2 (2.0, 11-17) | .52 |
| **Time since diagnosis** (months) (SD, range) | 6.1 (3.9, 2-12) | 5.0 (2.9, 1-10) | .53 |
| **MMSE**[e] mean (SD, range) | 27.1 (2.0, 25-30) | 26 (2.0, 23-29) | .26 |
| **Study 4: Self-applied implementation** | | | |
| **Characteristics** | **Adoptors**[b] (N=18) | **Non-adoptors**[b] (N=94) | **P** |
| **Age** (years) mean (SD, range) | 69 (10, 52-82) | 68 (8.6, 39-86) | .86 |
| **Gender** (women) n (%) | 9 (50) | 40 (43) | .51 |
| **Education level**[b] n (%) | 1: 3 (17)<br>2: 3 (17)<br>3: 2 (11)<br>4: 8 (44)<br>5: 2 (11) | 1: 13 (14)<br>2: 20 (21)<br>3: 23 (25)<br>4: 21 (22)<br>5: 17 (18) | .36 |
| **Diagnosis**[d] n (%) | AD: 12 (67)<br>VaD: 0<br>DLB: 1(6)<br>FTD: 0<br>MCI: 2 (11)<br>Other: 2 (11)<br>Unresolved: 1 (6) | AD: 53 (56)<br>VaD: 2 (2)<br>DLB: 0<br>FTD: 3 (3)<br>MCI: 7 (8)<br>Other: 25 (26)<br>Unresolved: 4 (4) | .29 |
| **Months since diagnosis** mean (SD, range) | 6 (7, 0-25) | 16 (14, 0-73) | .046 |
| **MMSE** score[ef] mean (SD, range) | 25 (5, 11-30) | 25 (4, 11-30) | .69 |

[a]All participants in this study were diagnosed with early stage Alzheimer's disease.

[b]Adoptors/Non-adoptors: Adoption was defined use of the app for ≥ 90 days.

[c]Education level: 1: Primary school/≤10 years, 2: Vocational education/11-12 years, 3: Short higher education/13-14 years, 4: Bachelor's degree/15-16 yeas, 5: Master's degree or more/≥17 years.

[d]Diagnosis: AD: Alzheimer's disease, VaD: Vascular dementia, DLB: dementia with Lewy bodies, FTD: Frontotemporal dementia, MCI: Mild Cognitive Impairment, Other: e.g. Stroke, Huntington's Disease and unspecified dementia diagnosis. Unresolved: Participants who were not diagnosed at the time of inclusion.

[e]MMSE: higher scores indicate higher attainment.

[f]The scores on MMSE are the most recent score documented in the participants' medical record. Data on months between latest MMSE score and study inclusion showed MMSE were on average conducted 9 months prior to inclusion (SD=10, range 0-47), and 79 % of the MMSEs were conducted less than 12 months prior to inclusion.

Table 1: Differences in baseline characteristics for adoptors and non-adoptors in the two studies.

In study 4 there was a significant association between caregiver involvement (caregivers having activated the app) and participants becoming adoptors of the app (p=.02; FET). An

exploratory logistic regression analysis was conducted to assess the impact of baseline characteristics and caregiver's app activities on participant's adoption status. This analysis showed that if caregivers had activated the app the participant was 5 times more likely to become an adoptor (OR 5.1; 95% CI 1.29-19.99; P=.02).

Figure 5 shows the number of actions in the app for participants who became adoptors in both implementation studies. This comparison of data is not included in the papers. The results show that participants in the self-management program (study 3) had significantly more actions in the app during the intervention period of 90 days compared with adoptors who used self-applied implementation methods (study 4) in a similar period of 90 days (U = 5.0, p = .000, r = .73, Mdn = 1470 and 123).

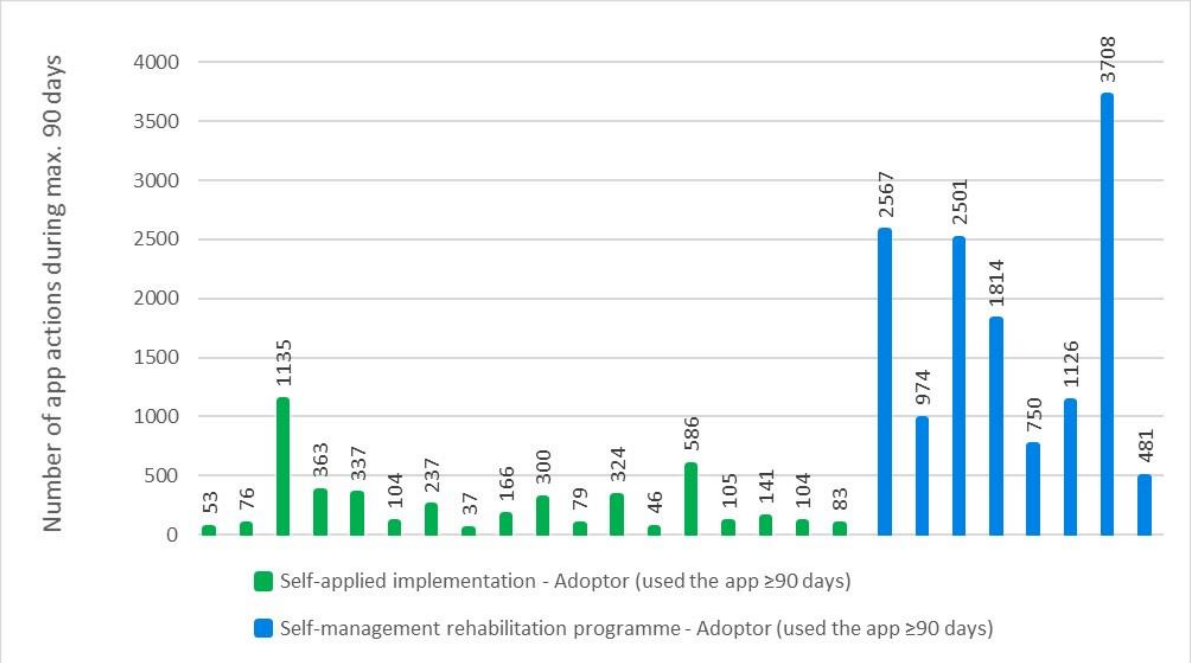



Figure 5. Number of actions in the app during an implementation period of 90 days.

### 5.3.2 Discussion

The results indicated that both methods were feasible and applicable for people with early stage dementia and both methods could promote implementation and adoption of AT. It is difficult however to estimate whether implementation and adoption rates are successful within this field of research. No comparable studies have been conducted in dementia research and there is a general lack of research into adoption- and adherence rates of AT and e-health solutions. It is of course difficult to compare various AT and eHealth interventions, since they are designed for various purposes and target various sub-groups, and perhaps also vary in quality, but a quite large attrition rate is a well-known phenomenon.[124] Some

studies have addressed these questions of “success rate”. In a non-clinical population using e-health apps 45.7 percent of the users stopped using the app(s) they had downloaded,[125] and a mobile app targeting people with post-traumatic stress disorder was abandoned by 52.1 percent of the users within one week after download.[126] This lack of comparable data underlines the need for more studies reporting adoption and adherence rates of AT and e-health in order to compare technology solutions and implementation methods and to evaluate whether an intervention is successful.

When comparing results from the two intervention methods, the self-management rehabilitation programme in study 3 seemed more successful in promoting the use of the app. As summarised above, the percentage of participants who became adopters of the app during this intervention was higher, and the participants in this intervention study used the app significantly more than the participants in the self-applied intervention study, as illustrated in Figure 5. Perhaps the method applied in this intervention, addressing both individual goals and more general self-management approaches, was a more profound and thorough method of implementation. Our results are in line with other studies documenting the impact of guidance on Internet-based mental health interventions.[127] The interventions are of course not directly comparable. The extend and intensity of the methods are by nature quite different, and some of the actions registered for the participants in study 3 of course reflects activities during the programme or actions directly influenced by the intervention programme, but this cannot alone explain the highly significant difference in number of times the app was used by participants in the two groups. The difference could reflect that participants in study 3 were favoured by selection bias. They were included based on criteria that reflected the original target-users of the app, as defined in the design process. However, this underlines the benefit of applying AT which is specifically tailormade for subgroups of people with dementia, to meet their specific requests and needs.

The significant impact of caregiver involvement in the self-applied implementation study indicated that support from caregivers can also significantly influence adoption. This is in line with the results from the interviews with people with dementia and caregivers in paper 2 where education and support from caregivers were emphasised as essential for adoption and adherence to technology. These results indicate that both AT and implementation methods should be designed to promote feasible and acceptable caregiver support.

Overall, the results confirmed that both methods seemed to have potential to promote implementation of AT among people with dementia. Both methods were design according to well-known psychosocial intervention methods and approaches for people with dementia, and the results of our research underline the clear benefits of combining user-centred design of AT

and psychosocial interventions methods. Since the implementation methods are quite distinct, they can comply with varied individual needs among people with dementia. The self-administered implementation method in study 4 can give access to education and support among users who, for various reasons, do not wish or cannot participate in an extensive group-based programme. Also, from a socio-economic point of view such self-administered implementation could be more cost-efficient.

The studies did not reveal any demographic or other baseline factors that could predict the adoption of the app in the studies. A possible explanation for this could be the that the studies were not powered to reveal such predictive factors. Others have explored possible models to predict AT adoption among people with dementia,[82,128] but not with very convincing results. In our studies there was generally a quite large spread in demographic and other baseline factors among adoptors, indicating that AT of this kind can be applicable for a varied group of people with dementia and that adoption might be influenced by a complex interaction between personal and contextual factors. Consequently, characteristics like age, education and well-established use of touch-screen devices should not define and restrict whether AT is introduced to people with dementia. One exception was however time from diagnosis in the self-applied implementation study (study 4), indicating that timely introduction of this kind of AT has influence on adoption. This was supported by qualitative data from the survey applied in this study, where participants and caregivers could comment on reasons for not using the app. Comments indicated that the app was in some cases introduced too early and in other cases introduced too late to be useful and applicable. This also underlines the benefits of applying AT that is tailormade for subgroups of people with dementia and it raises the question of sustainability of AT for people living with a progressive disease. These perspectives have to be addressed in future studies.

## 5.4 Exploring outcome measures when applying assistive technology to support self-management of people with dementia *(results presented in paper III and IV)*

The fourth and final objective of this study was to explore outcome measures that could capture the possible benefits and challenges of using AT to support self-management among people with dementia. The literature review, presented in paper I, showed great variation in outcome measures applied when assessing AT used by people with dementia. The main emphasis was on qualitative methods, including interviews and questionnaires developed for the specific study. Our review clearly indicated that this field of research can benefit from

applying standardised outcome measures to increase reliability and facilitate comparison of studies and research results.

In the implementation studies, study 3 and 4, mixed method designs were applied, combining qualitative and quantitative methods, including log data analysis. The outcome measures were applied to assess the feasibility and applicability of both the ReACT app and the implementation methods. The focus here is on the outcome measures that were introduced as new in a Danish dementia research context.

### 5.4.1 Results

As mentioned in section 4.2, three scales were translated to be used in study 3: Bangor Goal Setting Interview (BGSI),[94] ICEpop CAPability measure for Older people (ICECAP-O)[92] and The Bayer Activities of Daily Living Scale (B-ADL).[91] The details of these outcome measures are outlined and in paper III and the scales are included in Appendix E. These specific outcome measures were applied to target outcomes that are not well covered by outcome measures currently available in Danish, and to explore the applicability of these outcome in an intervention study combining self-management and rehabilitation approaches for people with early stage dementia.

The BGSI can be applied both to identify and to assess individual goals during the intervention, including changes in goal attainment over time,[94] and it has been validated among people with dementia.[67,129] The scope of this assessment tool is in line with the focus on building capacity, support identity and living well with dementia in psychosocial interventions research, as discussed previously in section 2.6.2. The scale was in general successfully applied in our study and it was sensitive to detect change in participant's achievement of goals during the intervention, as summarised in paper III. The process of identifying and assessing goals was however not straight forward for all participants, three participants could only identify one goal, eight participants had two and eight had three goals respectively.

The ICECAP-O[92] target quality of life in relation to the 5 domains: love and friendship, thinking about the future, doing things that make you feel valued, enjoyment and pleasure, and independence. The scope of this scale is also in line with the need for new outcome measures to capture capacity and living well with dementia. The psychometric properties of the ICECAP-O are well established[130] and it has been applied and validated among people with dementia,[131,132] including a study addressing group-based self-management interventions for people with early stage dementia.[70] In our study the scale was generally well

accepted by participants and the items included in the scale appears to be in line with general focus of the intervention to promote self-management.

The B-ADL[91] was introduced as a measure of ADL, targeting people with early stage dementia who have a milder degree of cognitive impairment. The scale addresses functional domains that generally requires a high level of ability, e.g. observing important dates or events and concentrating on reading. It was designed as a by-proxy scale to be completed by a family caregiver and it has been validated to be used in assessment of people with mild to moderate dementia.[133,134] In our study the scale was in general accepted and completed by caregivers, however qualitative observations indicated that the 25 items and the 10-point Likert scale was consider too overwhelming for some.

The USEdem questionnaire was applied in both study 3 and 4. The aim was to introduce a questionnaire that could assess usability of AT for people with dementia and could potentially be applied across studies, both to assess usability of specific AT solutions and allow comparison of results across studies. The USEdem questionnaire is a modified version of the USE Questionnaire assessing usefulness, satisfaction with, and ease of use of technology.[79] The USE Questionnaire has been applied in other studies addressing AT in the field of dementia, but it has only been applied for professional caregivers evaluating an AT solution for people with dementia[109] and to evaluate an eHealth solution addressing caregivers.[135] In the USEdem format the scale was reduced from 30 to 12 items. Item selection and reduction was done based on a pragmatic analytic approach and phrasing of the items was adapted to make items less complex and hence generally applicable for people with dementia.

In addition to these qualitative measures, detailed log data was collected in both study 3 and 4 to register the everyday use of the personal user-account in the app, both among people with dementia and among caregivers, who could access the user-account through a parallel login, as illustrated in Figure 4. The action in the app that was registered in these logs with time stamps included: activating the app, activities related to appointments, diary notes, memos, check lists and search feature, and the use of adaptive features.

### 5.4.2 Discussion

The BGSI has a rather narrow scope as an outcome measure addressing individual goals in intervention studies based on a rehabilitation approach, but within such a scope it seems to have potential as a tool to define and assess individual goals of a person with early stage dementia. Our study also indicated that it is applicable in studies addressing adoption of AT as an individual goal.

The ICECAP-O scale generally appeared applicable as a measure addressing quality of life from a capacity perspective. Further studies are needed to assess the validity of the scale in a Danish context with people with dementia.

The B-ADL was found to address items that are relevant when assessing people with early stage dementia, however qualitative observations indicated that the format of the scale was not found user-friendly by some caregivers and this indicated that the applicability of this scale should be reconsidered before applying it in further studies.

The adaption of the USE questionnaire to the USEdem questionnaire was done from a pragmatic and explorative approach. The USEdem scale seemed generally feasible for people with dementia in our studies, and it seemed to have face validity, since participants' ratings of the ReACT app on this scale was related to whether they adapted the app. The scale should be addressed in a proper validation study to confirm its applicability and to assess psychometric properties.

Collection and analysis of log data was introduced in the two studies to explore how this kind of outcome measure can be used when assessing AT and AT implementation methods applied to people with dementia. This approach to data collection is not widely used in studies within this field of research, as summarised in our review in paper 1. The collection of log data provided detailed data on specific use of the app among participants and caregivers and results showed that such a detailed data log, in combination with other quantitative and qualitative outcome measures, can provide a detailed picture of user-patterns and factors influencing adoption. Hence, this combination of outcome measures provided a view into the "black box" of AT as pictured by Sieverink et al.[84] and discussed in section 2.5.1. Log data also provided objective data essential in user-tests, as part of the process evaluation in the overall study design.

Such a mixed methods approach can provide rich and detailed data that are essential to improve design of AT and methods to promote implementation of AT for people with dementia.

## 5.5 Overall discussion and implications

The results of study 2, 3 and 4 generally supported the feasibility of user-involvement when designing AT for people with dementia and the clear benefits of combining user-centred AT solutions with psychosocial interventions to promote adoption of AT.

Further research is needed to provide evidence for the effectiveness of the AT solution and methods developed in these studies. This research should also address health economic aspects, which is a key issue in research addressing effectiveness of AT. The studies included in this thesis were not designed or powered to address such issues. Further studies should also address how AT and AT implementation methods can be integrated in existing health and social care systems, as emphasised in models and frameworks for technology development and implementation.[31,32]

An obvious next step in a complex intervention study design, according to the MRC framework, would be to plan a randomised controlled trial (RCT), which can be designed and powered to address such issues of effectiveness, including cost-effectiveness, and wider perspectives on implementation. However, an RCT design must be carefully considered and take into account the special conditions that characterise research in AT design and AT implementation. First of all, RCTs within this field are complicated by the rapid evolution of technology, perhaps making an AT solution obsolete by the time the results of the RCT are available.[15,84] As discussed earlier, this field of research is also characterised by attrition as a natural part of technology implementation.[124] Furthermore, the benefits from tailoring AT to individual needs and preferences makes control of interventions and outcomes difficult, and the "black box" phenomenon (as discussed in section 2.5.1*)* reduces the possibility to assess which different components has contributed to key outcomes.[84] These obstacles also influence the possibility of exploring economic aspects of AT.[17] Hence, further studied must to be carefully designed to meet these special preconditions.

Further research is also needed to investigate long term adherences to AT among people with dementia. Analysis of longitudinal log data, as applied in the studies included in this thesis, could provide data that are essential in such longitudinal studies. An additional perspective is to explore if longitudinal log data can be used as an eHealth solution to monitor disease progression, e.g. by monitoring change in use patterns over time.[136]

A further perspective is that the field of AT could benefit from common standards for designing and implementing AT solutions and related e-health technologies, perhaps inspired by evidence standards for digital health technologies as proposed by National Institute for Health and care excellence (NICE).[137] Such common standards could promote collaboration

between research, industry, and public and private organisations on designing and providing effective evidence-based AT solutions. It would also give people with dementia access to evidence-based useful and effective AT solutions.

Common guidelines are also needed to address other essential issues, e.g. data protection and ethical concerns, which also need special consideration in research and everyday use of AT among people with dementia.

## 5.6 Limitations

The overall study design and the methods applied in specific studies this thesis had several limitations that should be acknowledged and addressed in future studies. General limitations across studies were related to participants, data analysis, outcome measures and technology related issues.

The recruitment of participants in study 2, 3 and 4 generally implied risk of bias. The participants recruited in step 1, 2 and 4 of study 2 were recruited through convenience sampling and this involved a risk of neglecting people with early stage dementia who were not engaged in regular activities for people with dementia or were not in close contact with a memory clinic. In study 3 and 4 participants were also recruited from memory clinics, which also excludes participants who was not involved with such a setting. In addition, there was a risk that inclusion in these studies could have been biased by the influence from staff. The design of inclusion procedures implied a risk that staff mainly promoted the studies to people whom they believed could benefit from participation. In addition, participants recruited in the self-management intervention study (study 3) was skewed, a disproportionate part were woman and they were quite well-educated. This skewed and perhaps biased recruitment of participants across studies might influence generalisability of the results of the studies.

There were also limitations in relation to data analysis in study 2, 3 and 4. The analysis of qualitative data from interviews (study 2 and 3) and survey text (study 4) was only analysed by one researcher. Also, in study 3 neither baseline or post-intervention assessment was conducted by independent raters. These limitations in data collection and analysis cause a risk of bias and should be addressed in future studies.

In relation to outcome measures there were also several limitations. The three outcome measures translated to be used in the study 3 (BGSI, ICECAP-O and B-ADL) were applied even thought they had not been properly validated to be used in a Danish study. Also, the USEdem questionnaire was adapted and translated without conducting a strict scale development and validation procedure. Also, in study 4 a more extensive battery of baseline

measures and a pre-post outcome measure design could improve data collection and could further illuminate whether baseline characteristics can predict AT adoption and adherence. These limitations should also be addressed in further studies.

In addition, the fact that the ReACT app could only be used on one series of tablets (iPads) was also a limitation in study 4, involving self-applied implementation where participants had to use their own devices. This excluded potential participants who had access to other kinds of tablets. Due to practical and financial reasons one specific series of tablets had to be selected throughout these studies. Selection was based on various factors, e.g. that the iPad was the most common tablet used in Denmark. In future studies the use of the app across various types of devices can promote a more varied and extensive recruitment of participants and widen the extent to which results can be generalised.

# 6. Conclusions and perspectives

The work presented in this thesis was inspired by the perspective that AT has great potential to benefit people with dementia in the everyday life by supporting and promoting capacity, self-management and independence. However, AT solutions for people with dementia is marked by a general lack of evidence for the suitability, applicability and effectiveness. Furthermore, dissemination and implementation methods to promote acceptance, adoption and adherence to AT are rarely considered and addressed, neither in praxis or in research.

This thesis was guided by the overall aim of investigating how AT can be designed and implemented to support self-management of people with dementia. The studies were designed to explore methods of user-involving design of AT and methods for dissemination and implementation of AT, to promote adoption among end-users. It was also explored how outcomes of such interventions can be assessed.

The main findings and perspectives were:

- There is a general request for AT tailormade to meet the special needs of people with dementia. To ensure that these needs are met it is essential to involve people with dementia and their supporters in both design and test of AT. Our studies showed that such user-involvement is feasible throughout an extensive iterative process of designing, testing and implementing AT for people with dementia.

- User-involvement was very beneficial and essential to the positive outcomes of our study. A holistic AT solution, the ReACT app, was designed to match the needs and preferences of end-users. Implementation studies indicated that it was applicable and useful in everyday life of those who adopted the app.

- Evidence-based methods to promote dissemination and adoption of AT among people with dementia are also highly requested. Two different methods of implementation were designed and assessed in this research project, an extensive programme combining group-based self-management and individual rehabilitation approaches, and a self-applied method of implementation. Results from pilot studies indicated that both methods were feasible and applicable for the end-users, and they could both support adoption of AT. The two distinct methods had potential to comply with different needs for AT education and support among people with dementia.

- Results from the study involving self-applied implementation showed that timely introduction of AT and caregiver support can have significant influence on adoption of AT among people with dementia.

- The implementation studies did not lead to identification of background factors that could predict adoption of AT and this could be due to lack of power in the studies. However, participants who adopted the app were generally quite heterogeneous regarding demographic, disease related and technology related factors. This underlines the complexity of individual and contextual factors that potentially influence adoption of AT, factors that are further complicated by the progressive nature of dementia diseases. Such complex and changeable factors must be considered when designing and implementing AT for people with dementia.

- The studies clearly demonstrated the benefits of applying a mixed methodology approach to assess outcomes within this field of research. The combination of qualitative and quantitative outcome measures, including extensive log data, provided a rich data set that could contribute with a nuanced picture of AT use among people with dementia.

Overall the results of these studies show the benefits of not addressing AT for people with dementia as an isolated process of providing a technology-based tool. Instead design and implementation of AT should be addresses from a user-centred perspective and in combination with established psychosocial methods to promote acceptance, adoption and adherence to AT. Through this perspective, AT can be viewed as an integrated part of an individualised intervention for a person with dementia, where multiple personal and contextual factors should be considered and incorporated.

The studies included in this thesis were designed to address development phases and feasibility studies of a complex intervention. Further studies are needed to comply with the design and methodological limitations of these studies. Future steps could be large-scale studies that are designed and powered to evaluate effectiveness, including cost-effectiveness, and can promote comprehensive implementation of the intervention.

# References


1. Alzheimer's Disease International. World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends. 2015. https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf
2. Jørgensen K, Waldemar G. Prævalens af demens i Danmark. Ugesskrift for Læger. 2015;177(11):1041-1044.
3. Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. The Lancet. 2017;390(10113):2673-2734.
4. World Health Organisation. Risk reduction of cognitive decline and dementia. WHO Guidelines. 2019. https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1
5. G8 dementia summit agreements. 2013. https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-declaration
6. World Health Organisation (WHO). Global action plan on the public health response to dementia 2017–2025. 2017. ttp://apps.who.int/iris/bitstream/handle/10665/259615/?sequence=1
7. Sundheds- og Ældreministeriet. Et trygt og værdigt liv med demens. Den nationale demenshandlingsplan 2025. 2016. https://www.sum.dk/Aktuelt/Nyheder/Aeldre/2016/December/~/media/Filer%20-%20Publikationer_i_pdf/2016/Demenshandlingsplan-2025-PUB-sept-2016/Den-nationale-demenshandlingsplan-2025.ashx
8. Patterson C. World Alzheimer Report 2018—The state of the art of dementia research: New frontiers. Alzheimer's Disease International (ADI): London, UK. 2018.
9. McDermott O, Charlesworth G, Hogervorst E, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. Aging & Mental Health. 2018:1-11.
10. Olazarán J, Reisberg B, Clare L, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. Dementia and Geriatric Cognitive Disorders. 2010;30(2):161-178.
11. World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future. 2016. https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf
12. Bächle M, Daurer S, Judt A, Mettler T. Assistive technology for independent living with dementia: Stylized facts and research gaps. Health policy and technology. 2018;7(1):98-111.
13. Asghar I, Cang S, Yu H. Assistive technology for people with dementia: an overview and bibliometric study. Health Information & Libraries Journal. 2017;34(1):5-19.
14. Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia. 2016;15(4):681-701.
15. Meiland F, Innes A, Mountain G, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR rehabilitation and assistive technologies. 2017;4(1).

16. van der Roest HG, Wenborn J, Pastink C, Droes RM, Orrell M. Assistive technology for memory support in dementia. Cochrane Database of Systematic Reviews. 2017;6:Cd009627.

17. The case for investment in technology to manage the global costs of dementia. 2015. http://eprints.lse.ac.uk/66482/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_LSEE_The%20case%20for%20investment%20in%20technology.pdf

18. Ienca M, Fabrice J, Elger B, et al. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. Journal of Alzheimer's Disease. 2017;56(4):1301-1340.

19. Kenigsberg P-A, Aquino J-P, Bérard A, et al. Assistive technologies to address capabilities of people with dementia: from research to practice. Dementia. 2017:1471301217714093.

20. Smith RO, Scherer M, Cooper R, et al. Assistive technology products: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. Disability and Rehabilitation: Assistive Technology. 2018:1-13.

21. What is a health technology? 2007. https://www.who.int/health-technology-assessment/about/healthtechnology/en/

22. Assistive Technology Industry Association. What is AT? Assistive Technology Industry Association. 2019. http://www.atia.org/at-resources/what-is-at/

23. Bennett B, McDonald F, Beattie E, et al. Assistive technologies for people with dementia: ethical considerations. Bulletin of the World Health Organization. 2017;95(11):749.

24. Gillespie A, Best C, O'Neill B. Cognitive function and assistive technology for cognition: A systematic review. Journal of the International Neuropsychological Society. 2012;18(1):1-19.

25. Quinn C, Toms G, Anderson D, Clare L. A review of self-management interventions for people with dementia and mild cognitive impairment. Journal of Applied Gerontology. 2016;35(11):1154-1188.

26. The National Institute for Health and Care Excellence (NICE). Evidence Standards Framework for Digital Health Technologies. 2018. https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/evidence-standards-framework/digital-evidence-standards-framework.pdf

27. World Health Organisation. What is eHealth. 2005. https://www.who.int/goe/en/

28. World Health Organisation - mHealth Summit. Definition of mHealth. 2009. https://caroltorgan.com/mhealth-summit/

29. Robillard JM, Cleland I, Hoey J, Nugent C. Ethical adoption: A new imperative in the development of technology for dementia. Alzheimer's & Dementia. 2018.

30. Fabricatore C, Radovic D, Lopez X, Grasso-Cladera A, Salas CE. When technology cares for people with dementia: A critical review using neuropsychological rehabilitation as a conceptual framework. Neuropsychological Rehabilitation. 2019:1-40.

31. van Gemert-Pijnen JE, Nijland N, van Limburg M, et al. A holistic framework to improve the uptake and impact of eHealth technologies. Journal of Medical Internet Research. 2011;13(4).

32. World Health Organization. Great Summit Report. 2017. https://apps.who.int/iris/bitstream/handle/10665/259746/WHO-EMP-IAU-2017.16-eng.pdf;jsessionid=5322C26787CCB57CC2F20A1679571A57?sequence=1

33. Holthe T, Halvorsrud L, Karterud D, Hoel K-A, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. Clinical Interventions in Aging. 2018;13:863.

34. King AC, Dwan C. Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. Dementia. 2017:1471301217735180.

35. Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. Ethical design of intelligent assistive technologies for dementia: a descriptive review. Science and engineering ethics. 2017:1-21.

36. Petersen RC, Roberts RO, Knopman DS, et al. Mild cognitive impairment: ten years later. Archives of Neurology. 2009;66(12):1447-1455.

37. Mitchell AJ, Shiri-Feshki M. Rate of progression of mild cognitive impairment to dementia–meta-analysis of 41 robust inception cohort studies. Acta Psychiatrica Scandinavica. 2009;119(4):252-265.

38. Dean K, Wilcock G. Living with mild cognitive impairment: the patient's and carer's experience. International Psychogeriatrics. 2012;24(6):871-881.

39. Lobo A, Launer L, Fratiglioni L, et al. Prevalence of dementia and major subtypes in Europe: a collaborative study of population-based cohorts. Neurology. 2000;54(5):S4.

40. McKhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimer's & dementia. 2011;7(3):263-269.

41. Lam B, Masellis M, Freedman M, Stuss DT, Black SE. Clinical, imaging, and pathological heterogeneity of the Alzheimer's disease syndrome. Alzheimer's Research & Therapy. 2013;5(1):1.

42. Lyketsos CG, Carrillo MC, Ryan JM, et al. Neuropsychiatric symptoms in Alzheimer's disease. In: Elsevier; 2011.

43. O'Brien J, Thomas A. Vascular dementia. The Lancet. 2015;386(10004):1698-1706.

44. Looi JC, Sachdev PS. Differentiation of vascular dementia from AD on neuropsychological tests. Neurology. 1999;53(4):670-670.

45. Walker Z, Possin KL, Boeve BF, Aarsland D. Lewy body dementias. The Lancet. 2015;386(10004):1683-1697.

46. Hogan DB, Jetté N, Fiest KM, et al. The prevalence and incidence of frontotemporal dementia: a systematic review. Canadian Journal of Neurological Sciences. 2016;43(S1):S96-S109.

47. Bang J, Spina S, Miller BL. Frontotemporal dementia. The Lancet. 2015;386(10004):1672-1682.

48. Woollacott IO, Rohrer JD. The clinical spectrum of sporadic and familial forms of frontotemporal dementia. Journal of Neurochemistry. 2016;138:6-31.

49. Vuilleumier P. Anosognosia: the neurology of beliefs and uncertainties. Cortex. 2004;40(1):9-17.

50. Wilson RS, Sytsma J, Barnes LL, Boyle PA. Anosognosia in dementia. Current Neurology and Neuroscience Reports. 2016;16(9):77.

51. Spector A, Orrell M. Using a biopsychosocial model of dementia as a tool to guide clinical practice. International Psychogeriatrics. 2010;22(6):957-965.

52. Kitwood T. Towards a theory of dementia care: the interpersonal process. Ageing & Society. 1993;13(1):51-67.

53. Brooker D. What is person-centred care in dementia? Reviews in Clinical Gerontology. 2003;13(3):215-222.

54. Vernooij-Dassen M, Jeon Y-H. Social health and dementia: the power of human capabilities. International Psychogeriatrics. 2016;28(5):701-703.

55. Huber M, Knottnerus JA, Green L, et al. How should we define health? BMJ. 2011;343:d4163.

56. Dröes R, Chattat R, Diaz A, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. Aging & Mental Health. 2017;21(1):4-17.

57. Moniz-Cook E, Vernooij-Dassen M, Woods B, Orrell M, Interdem. Psychosocial interventions in dementia care research: The INTERDEM manifesto. Aging & Mental Health. 2011;15(3):283-290.

58. Dröes R-M, Van Der Roest HG, Van Mierlo L, et al. Memory problems in dementia: adaptation and coping strategies and psychosocial treatments. Expert Review of Neurotherapeutics. 2011;11(12):1769-1782.

59. Low L-F, Swaffer K, McGrath M, Brodaty H. Do people with early stage dementia experience Prescribed Disengagement®? A systematic review of qualitative studies. International Psychogeriatrics. 2018;30(6):807-831.

60. World Health Organisation. World Report on Disability. 2011. https://www.who.int/disabilities/world_report/2011/report.pdf

61. Clare L. Rehabilitation for people living with dementia: A practical framework of positive support. PLoS Medicine. 2017;14(3):e1002245.

62. Poulos CJ, Bayer A, Beaupre L, et al. A comprehensive approach to reablement in dementia. Alzheimer's & Dementia: Translational Research & Clinical Interventions. 2017;3(3):450-458.

63. Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Rikkert MGO. Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. BMJ. 2006;333(7580):1196.

64. Clare L. Introducing neuropsychological rehabilitation and people with dementia. In: *Neuropsychological Rehabilitation and People with Dementia.* New York: Psychology Press; 2008:1-4.

65. Kawai H, Kawamura M, Mochizuki S, et al. Longitudinal study of procedural memory in patients with Alzheimer-type dementia. Brain and nerve. 2002;54(4):307-311.

66. Kuzis G, Sabe L, Tiberti C, Merello M, Leiguarda R, Starkstein SE. Explicit and implicit learning in patients with Alzheimer disease and Parkinson disease with dementia. Neuropsychiatry, Neuropsychology, and Behavioral Neurology. 1999;12(4):265-269.

67. Clare L, Kudlicka A, Oyebode JR, et al. Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial). International Journal of Geriatric Psychiatry. 2019.

68. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Education and Counseling. 2002;48(2):177-187.

69. Mountain GA. Self-management for people with early dementia: an exploration of concepts and supporting evidence. Dementia. 2006;5(3):429-446.

70. Quinn C, Toms G, Jones C, et al. A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). International Psychogeriatrics. 2016;28(5):787.

71. Woods B, Arosio F, Diaz A, et al. Timely diagnosis of dementia? Family carers' experiences in 5 European countries. International Journal of Geriatric Psychiatry. 2019;34(1):114-121.

72. Mountain GA, Craig CL. What should be in a self-management programme for people with early dementia? Aging & Mental Health. 2012;16(5):576-583.

73. Toms G, Clare L, Nixon J, Quinn C. A systematic narrative review of support groups for people with dementia. International Psychogeriatrics. 2015;27(9):1439-1465.

74. Øksnebjerg L, Diaz-Ponce A, Gove D, et al. Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. Health Expectations. 2018;21(6):1056-1065.

75. Scherer MJ. Technology adoption, acceptance, satisfaction and benefit: integrating various assistive technology outcomes. In: Taylor & Francis; 2017.

76. Triberti S, Kelders SM, Gaggioli A. User engagement. In: *eHealth Research, Theory and Development.* Routledge; 2018:271-289.

77. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: Toward a unified view. MIS quarterly. 2003:425-478.

78. Kernebeck S, Holle D, Pogscheba P, et al. A Tablet App–and Sensor-Based Assistive Technology Intervention for Informal Caregivers to Manage the Challenging Behavior of People With Dementia (the insideDEM Study): Protocol for a Feasibility Study. JMIR research protocols. 2019;8(2):e11630.

79. Lund AM. Measuring usability with the use questionnaire. Usability interface. 2001;8(2):3-6.

80. Imbeault H, Gagnon L, Pigot H, et al. Impact of AP@ LZ in the daily life of three persons with Alzheimer's disease: long-term use and further exploration of its effectiveness. Neuropsychological Rehabilitation. 2018;28(5):755-778.

81. Kysor S, Martinez AP, Maier S, et al. Assessment of Assistive Technology for Individuals with Cognitive Impairments. In: *Assistive Technology Assessment Handbook, Second Edition.* CRC Press; 2017:137-156.

82. Chaurasia P, McClean SI, Nugent CD, et al. Modelling assistive technology adoption for people with dementia. Journal of Biomedical Informatics. 2016;63:235-248.

83. Patterson T, McClean S, Langdon PM, Zhang S, Nugent C, Cleland I. A knowledge-driven approach to predicting technology adoption among persons with dementia. Paper presented at: Engineering in Medicine and Biology Society (EMBC), 2014 36th Annual International Conference of the IEEE2014.

84. Sieverink F, Kelders S, Poel M, van Gemert-Pijnen L. Opening the black box of electronic health: collecting, analyzing, and interpreting log data. JMIR research protocols. 2017;6(8).

85. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. Journal of mixed methods research. 2007;1(2):112-133.

86. Mountain, G. 2016. https://www.neurodegenerationresearch.eu/wp-content/uploads/2015/10/JPND-Report-Fountain.pdf

87. Stoner CR, Orrell M, Spector A. Review of Positive Psychology Outcome Measures for Chronic Illness, Traumatic Brain Injury and Older Adults: Adaptability in Dementia? Dementia and Geriatric Cognitive Disorders. 2015;40(5-6):340-357.

88. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008;337:a1655.

89. Craig P, Dieppe P, MacIntyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: The new Medical Research Council guidance. International Journal of Nursing Studies. 2013;50(5):587-592.

90. Vernooij-Dassen M, Moniz-Cook E. Raising the standard of applied dementia care research: addressing the implementation error. In: Taylor & Francis; 2014.

91. Hindmarch I, Lehfeld H, de Jongh P, Erzigkeit H. The Bayer activities of daily living scale (B-ADL). Dementia and Geriatric Cognitive Disorders. 1998;9(Suppl. 2):20-26.

92. Coast J, Flynn TN, Natarajan L, et al. Valuing the ICECAP capability index for older people. Social Science and Medicine. 2008;67(5):874-882.

93. Group E. EuroQol -a new facility for the measurement of health-related quality of life. Health policy (Amsterdam, Netherlands). 1990;16(3):199.

94. Clare L, Hindle JV, Jones IR, et al. The AgeWell study of behavior change to promote health and wellbeing in later life: study protocol for a randomized controlled trial. Trials. 2012;13(1):115.

95. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975;12(3):189-198.

96. Mathuranath P, Nestor P, Berrios G, Rakowicz W, Hodges J. A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. Neurology. 2000;55(11):1613-1620.

97. Randolph C, Tierney MC, Mohr E, Chase TN. The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): preliminary clinical validity. Journal of Clinical and Experimental Neuropsychology. 1998;20(3):310-319.

98. Smith A. Symbol digit modalities test. Western Psychological Services Los Angeles, Los Angeles, US; 1982.

99. Reitan RM. Trail Making Test: Manual for administration and scoring. Reitan Neuropsychology Laboratory; 1992.

100. Strauss E, Sherman EM, Spreen O. A compendium of neuropsychological tests: Administration, norms, and commentary. American Chemical Society; 2006.

101. Lee G, Loring D, Newell J, McCloskey L. Figural fluency on the five-point test: preliminary normative and validity data. Int Neuropsychol Soc Program Abstr. 1994;1:51.

102. Leech NL, Onwuegbuzie AJ. An array of qualitative data analysis tools: a call for data analysis triangulation. School Psychology Quarterly. 2007;22(4):557.

103. Boyd H, Evans N, Cheston R, Noonan K, Harris N. Home Testing of a Digital Prompter for People with Dementia. Studies in Health Technology and Informatics. 2017;242:27-30.

104. Imbeault H, Bier N, Pigot H, et al. Electronic organiser and Alzheimer's disease: Fact or fiction? Neuropsychological Rehabilitation. 2014;24(1):71-100.

105. Lanza C, Knörzer O, Weber M, Riepe MW. Autonomous spatial orientation in patients with mild to moderate Alzheimer's disease by using mobile assistive devices: a pilot study. Journal of Alzheimer's Disease. 2014;42(3):879-884.

106. Robinson L, Brittain K, Lindsay S, Jackson D, Olivier P. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. International Psychogeriatrics. 2009;21(3):494-502.

107. Xenakidis CN, Hadjiantonis AM, Milis GM. A Mobile Assistive Application for People with Cognitive Decline. Paper presented at: 2014 International Conference on Interactive Technologies and Games (iTAG)2014.

108. Donnelly MP, Nugent CD, Craig D, Passmore P, Mulvenna M. Development of a cell phone-based video streaming system for persons with early stage Alzheimer's disease. Paper presented at: Engineering in Medicine and Biology Society, 2008. EMBS 2008. 30th Annual International Conference of the IEEE2008.

109. Hattink B, Meiland F, Overmars-Marx T, et al. The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact. Disability and Rehabilitation: Assistive Technology. 2016;11(1):61-71.

110. Meiland F, Hattink B, Overmars-Marx T, et al. Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European Rosetta project. International Psychogeriatrics. 2014;26(5):769-779.

111. Meiland FJ, Bouman AI, Sävenstedt S, et al. Usability of a new electronic assistive device for community-dwelling persons with mild dementia. Aging & Mental Health. 2012;16(5):584-591.

112. Meiland FJ, Reinersmann A, Bergvall-Kåreborn B, et al. COGKNOW: Development of an ICT device to support people with mild dementia. Journal on Information Technology in Healthcare. 2007;5(5):166-177.

113. Nugent C, O'Neill S, Donnelly M, et al. Evaluation of video reminding technology for persons with dementia. Paper presented at: International Conference on Smart Homes and Health Telematics2011.

114. Gibson G, Dickinson C, Brittain K, Robinson LA. Personalisation, customisation and bricolage: How people with dementia and their families make assistive technology work for them. Ageing & Society. 2018:1-18.

115. Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in the development of supportive IT applications: a systematic review. Ageing research reviews. 2013;12(2):535-551.

116. van Gemert-Pijnen L, Span M. CeHRes roadmap to improve dementia care. In: van Hoof J, Demiris G, Wouter EJM, eds. *Handbook of Smart Homes, Health Care and Well-Being.* Switzerland: Springer; 2017:133-146.

117. Winblad B, Amouyel P, Andrieu S, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. The Lancet Neurology. 2016;15(5):455-532.

118. Greaves F, Joshi I, Campbell M, Roberts S, Patel N, Powell J. What is an appropriate level of evidence for a digital health intervention? The Lancet. 2018.

119. Burns C. Human-centred design, book section 10. In: Routledge, Abingdon; 2018.

120. Gulliksen J, Göransson B, Boivie I, Blomkvist S, Persson J, Cajander Å. Key principles for user-centred systems design. Behaviour and Information Technology. 2003;22(6):397-409.

121. Scaife M, Rogers Y, Aldrich F, Davies M. Designing for or designing with? Informant design for interactive learning environments. Paper presented at: Proceedings of the ACM SIGCHI Conference on Human factors in computing systems1997.

122. Acuña ST, Castro JW, Juristo N. A HCI technique for improving requirements elicitation. Information and Software Technology. 2012;54(12):1357-1375.

123. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging & Mental Health. 2018;22(6):723-729.

124. Eysenbach G. The law of attrition. Journal of Medical Internet Research. 2005;7,1:e11.

125. Krebs P, Duncan DT. Health app use among US mobile phone owners: a national survey. JMIR mHealth and uHealth. 2015;3(4):e101.

126. Owen JE, Jaworski BK, Kuhn E, Makin-Byrd KN, Ramsey KM, Hoffman JE. mHealth in the wild: using novel data to examine the reach, use, and impact of PTSD coach. JMIR mental health. 2015;2(1):e7.

127. Baumeister H, Reichler L, Munzinger M, Lin J. The impact of guidance on Internet-based mental health interventions—A systematic review. internet Interventions. 2014;1(4):205-215.

128. Czarnuch S, Ricciardelli R, Mihailidis A. Predicting the role of assistive technologies in the lives of people with dementia using objective care recipient factors. BMC Geriatrics. 2016;16(1):143.

129. Clare L, Linden DE, Woods RT, et al. Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer disease: a single-blind randomized controlled trial of clinical efficacy. The American Journal of Geriatric Psychiatry. 2010;18(10):928-939.

130. Proud L, McLoughlin C, Kinghorn P. ICECAP-O, the current state of play: a systematic review of studies reporting the psychometric properties and use of the instrument over the decade since its publication. Quality of Life Research. 2019:1-11.

131. Handels RL, Sköldunger A, Bieber A, et al. Quality of Life, Care Resource Use, and Costs of Dementia in 8 European Countries in a Cross-Sectional Cohort of the Actifcare Study. Journal of Alzheimer's Disease. 2018(Preprint):1-14.

132. Makai P, Beckebans F, van Exel J, Brouwer WB. Quality of life of nursing home residents with dementia: validation of the German version of the ICECAP-O. PloS One. 2014;9(3):e92016.

133. Erzigkeit H, Lehfeld H, Peña-Casanova J, et al. The Bayer-Activities of Daily Living Scale (B-ADL): results from a validation study in three European countries. Dementia and Geriatric Cognitive Disorders. 2001;12(5):348-358.

134. Nagaratnam N, Nagaratnam K, O'Mara D. Bayer-activities of daily living scale in mild and moderate dementia of the Alzheimer type. American Journal of Alzheimer's Disease & Other Dementias®. 2013;28(8):784-789.

135. Hattink B, Meiland F, van der Roest H, et al. Web-based STAR E-learning course increases empathy and understanding in dementia caregivers: results from a randomized controlled trial in the Netherlands and the United Kingdom. Journal of Medical Internet Research. 2015;17(10):e241.

136. Pillai JA, Bonner-Jackson A. Review of Information and Communication Technology Devices for Monitoring Functional and Cognitive Decline in Alzheimer's Disease Clinical Trials. Journal of Healthcare Engineering. 2015;6(1):71-84.

137. National Institute for Health and care excellence 2019. https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/evidence-standards-framework/digital-evidence-standards-framework.pdf

# Appendixes

**Appendix A:** Paper I: Assistive technology designed to support self-management of people with dementia: User-involvement, dissemination and adoption. A scoping review

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# Assistive technology designed to support self-management of people with dementia: User-involvement, dissemination and adoption. A scoping review

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## Abstract

**Background:** Assistive technology is advocated as a key solution to the need for support among people living with dementia. There is growing awareness of the benefits of user-involvement in the design and test of these technologies and the need to identifying applicable and effective methods for implementation. This review was conducted to analyse the current state of research into assistive technology designed to be used by people with dementia for self-management. Further research aims were to explore if and how user-involvement, dissemination and adoption of assistive technology were addressed.

**Method:** Electronic databases were searched using specified search terms. Key publications and grey literature sources were hand-searched. Materials published until year-end 2018 were included. Results were summarised according to the research aims.

**Results:** Eleven papers derived from 8 studies were included. The studies presented data from prototype design and testing, and the review showed great variation in study scope, design and methodology. User-involvement varied from extensive involvement to no user-involvement. Methods for adoption also varied widely and only targeted prototype testing. None of the studies addressed dissemination.

**Conclusion:** The results of this review underline the need for well-designed high-quality research into all the aspects that are essential to deliver applicable, effective and sustainable assistive technology to support self-management of people with dementia. There is a need for evidence-based methods to promote and qualify user-involvement, dissemination and

adoption. The results also point to the need for standardised outcome measures and standards for conducting and reporting research to improve its quality and impact.

## Introduction

The number of people living with dementia world-wide is fast growing (World Health Organisation, 2017) and there is a strong demand to take action and move forward pervasive and innovative solutions to meet their needs for support and care. In recent years, the rapid advances in information technology and digitalization has attracted political attention as a key solution to these challenges (Alzheimer's Disease International 2016; World Health Organisation, 2017) and we see a rapid growth in assistive technology being promoted as suitable and effective solutions for people with dementia (Asghar *et al.*, 2017; Gibson *et al.*, 2016). Assistive technology (AT) is an umbrella term encompassing 'Any item, piece of equipment, software program, or product system that is used to increase, maintain or improve the functional capabilities of persons with disabilities' (Assistive Technology Industry Association, 2019). This review specifically addresses electronic AT.

One perspective given special attention is the potential of AT to promote the capacity of people with dementia, support them in coping with cognitive deficits and managing everyday life as independently as possible, e.g. electronic calendars, prompting and reminder devices, and navigation aids (Gibson *et al.*, 2015; Gillespie *et al.*, 2012; Kenigsberg *et al.*, 2017; Meiland *et al.*, 2017). These solutions can be conceptualised within the framework of self-management as defined by Barlow *et al.* (2002).

However, despite the optimism that AT is a core solution to the current and future challenges in dementia support and care, there is also increasing awareness of the challenges that impede significant progress within this field. For instance, many technologies are still underdeveloped (Knapp *et al.*, 2015; Meiland *et al.*, 2017) and the many psychosocial and societal factors that influence the adoption of AT are not addressed (Knapp *et al.*, 2015; Meiland *et al.*, 2017; Smith *et al.*, 2018). Lack of adoption or early abandonment of technology addressing health related issues is a well-known problem both in non-clinical and

clinical populations (Federici *et al.*, 2016; Krebs and Duncan, 2015; van Gemert-Pijnen *et al.*, 2014). It is therefore evident that a special effort is required when designing and implementing AT for people with dementia who have special needs due to cognitive decline, and who might also be experiencing age-related constraints such as hearing, visual and other physical disabilities. Generational factors can also influence response to AT solutions. To make progress within the field of AT supporting self-management of people with dementia we need to identify which factors facilitate or impede the adoption and continued use of AT.

Recent reviews and position papers, addressing AT for people with dementia from a broad perspective, generally come to concurrent conclusions regarding a range of topics to be addressed in order to make advances in research and bring to market evidence-based solutions that are usable and effective in everyday lives of people with dementia (Bächle *et al.*, 2018; Holthe *et al.*, 2018; Ienca *et al.*, 2017; Kenigsberg *et al.*, 2017; King and Dwan, 2017; Meiland *et al.*, 2017; Robillard *et al.*, 2018). Among the most evident is the recommendation to involve people with dementia in the design and testing of AT, to make sure that their needs, preferences and capacities are met and also to pursue this end-user perspective when developing applicable and effective methods for dissemination and adoption of AT.

These recent reviews and position papers also reveal that research addressing AT for people with dementia is still limited and rather heterogeneous and is generally not characterised by randomized controlled trials (van der Roest *et al.*, 2017). Based on these preconditions, a scoping review methodology was selected for this review.

This scoping review was not conducted to compile an exhaustive catalogue of the broad variety of AT promoted for people with dementia. Rather, our key focus was to explore in depth the characteristics of studies where AT was designed to be used by people with dementia for self-management in an autonomous and flexible manner. Furthermore, we

wanted to analyse if and how studies had involved users in the design and/or test of this AT, and the results of this involvement. We also wanted to investigate studies that had addressed methods for implementation of AT and/or adoption by the end-users.

Accordingly, the research aims of the scoping review were to:

1: Synthesise data from studies where AT had been designed to support self-management of people with dementia.
2: Explore if people with dementia had been included in the design and/or test of this AT and describe methods and results of this involvement.
3: Explore if issues of dissemination and adoption of AT had been addressed, and describe the methods used.

## Methods

The scoping review was conducted and reported according to the PRISMA Extension for Scoping Reviews (Tricco *et al.*, 2018) and guided by the recommendations on conducting systematic scoping reviews from Peters *et al.* (2015).

### Data sources and search strategy

First, data were derived from systematic searches in the electronic databases PubMed, PsycINFO, Web of Science, Scopus, Embase and CINAHL. A broad search strategy was designed to ensure that the inclusion of studies was as comprehensive as possible. Search terms were derived from titles, abstracts and keywords identified in key publications and from search terms used in previous reviews related to the scope of this review.

The following search terms were used: Dementia (Dementia or Alzheimer Disease) and assistive technology, supportive technology, self-help devices, information and communication technology, information technology, cognitive prosthetics, electronic memory aids, self-help devices, self-help technology or reminder systems. MeSH terms and truncation of search terms were used where appropriate.

To locate additional material, reference lists of key publications, e.g. reviews and position papers, were hand searched. In addition, to locate additional grey literature, Opengrey was searched by the keywords dementia and technology.

To avoid missing essential data at the stage of full text screening, an additional search was conducted if a reference was about to be excluded because of insufficient information to explore the review aims. In these cases, author names and study names/ acronyms were searched in Google and Google Scholar. If further publications were located these were included in the full text screening process.

The data search was conducted in December 2018 and all records published up until then were included, with no start date applied.

## Inclusion and exclusion criteria

### *Materials*

This scoping review was conducted to explore the present state of research; hence a wide range of data were accepted for inclusion covering all kinds of material published in peer-reviewed journals, book chapters, meeting abstracts and trial registrations. Literature not presenting original data from a research project, e.g. reviews and position papers were excluded. Only material published in English was included.

### *Population*

Studies related to people with dementia were included and there were no limits with regards to etiology or severity of disease. Studies involving people with mild cognitive impairment were only included if people with dementia were also included. Studies only addressing caregivers (family and/or professional) or other groups of end-users were excluded.

### *Interventions*

To investigate the first aim, studies eligible for this review included results from the design process and/or test of hardware or software designed for people with dementia and the main user of the technology was the person with dementia, with support from caregivers if needed. The scope of the technology was to support self-management of people with dementia, e.g. through support of cognitive functions (memory, spatial orientation, communication etc.), or through holistic solutions addressing support of self-management in various ways. Consequently, the following types of AT were excluded: AT supporting specific psychosocial intervention, e.g. reminiscence or cognitive stimulation therapy, AT used to support education or provide information, AT used for cognitive training and technology used for physical exercise. In addition, studies were also excluded if they only addressed one specific and predefined activity, e.g. medication management or handwashing. Technology that was only designed to support security by surveillance, e.g. GPS trackers or sensor technology, was also excluded. However, in many instances AT includes several features/functionalities and if the main scope for the AT was within the inclusion criteria of this review, and additional features were not, the study was included, e.g. in cases where GPS was an additional feature.

To further address the second aim, concerning the involvement of people with dementia in the design and/or test of AT, studies that fulfilled criteria for the first research aim were further reviewed. They were included in this part of the review if they addressed any kind of involvement of people with dementia in the scoping, design or test of the technology. To include the broadest possible range of data, studies were also included if they had by-proxy involvement of end-users, for instance involvement of caregivers.

Finally, exploring the third aim of the review, studies that fulfilled criteria of the first research aim were further reviewed and included in this part of the review if they involved activities addressing adoption and/or dissemination of AT to people with dementia.

**Study selection**

The search and selection procedures, and reasons for exclusion were recorded and are summarised in Figure 1. Two of the authors (first and second author) assessed the eligibility of all studies independently and in a standardized manner. Covidence (Covidence.org) was used for review management and the blinded review procedure. First, the 777 retrieved records from the search were screened by title and abstract. Second, 59 full texts were assessed for eligibility according to the criteria described above. Disagreements were discussed and resolved among the reviewers.

According to the nature of this scoping review, studies were not selected based on methodological quality, and no quality assessment was performed.

Figure 1: Prisma flow diagram illustrating the study selection process

**Data extraction**

As listed in Table 1, the following information was extracted from the included studies: Publication details (authors, year of publication, title and origin). To address research the first research aim, the aim and features of the assistive technology were recorded. To address the second research aim, characteristics of participants, methods for user-involvement, and evaluation methods and results were recorded. Finally, to address the third research aim, methods for adoption and/or dissemination were recorded.

Table 1: Characteristics and results from the studies included in the review

## Results

Eleven papers derived from 8 studies fulfilled the initial inclusion criteria and were included in the review. Three of the studies presented complementary data from the design and the test phase in two separate papers. The results are summarised in Table 1, including specific characteristics related to the three aims of this scoping review.

**Review aim 1: Assistive technology designed to support self-management of people with dementia.**

All studies included in this review addressed technology that was designed to support people with dementia in ways related to self-management. The aims and features of these technologies varied widely. Two studies, COGKNOW (Meiland *et al.*, 2012; Meiland *et al.*, 2007), and Rosetta (Hattink *et al.*, 2016; Meiland *et al.*, 2014) were comprehensive multidevice holistic solutions, addressing a variety of functional domains including memory, social contacts, daily activities and safety. These studies were also related, as the COGKNOW solution was integrated in the Rosetta solution. Two studies, AP@LZ (Imbeault *et al.*, 2014), and Alzminder (Xenakidis *et al.*, 2014), presented holistic app solutions comprising a variety of features that could support the user in everyday life, e.g. reminders, information on contacts, medication information or emergency contacts. In two other studies, Digital Prompter (Boyd *et al.*, 2017), and Video Reminding Technology (Donnelly *et al.*, 2010; Nugent *et al.*, 2011), the technology was designed with one main feature that was intended to support the user in various home-bound situations. The last two studies, KITE (Robinson *et al.*, 2009) and Autonomous Spatial Navigation (Lanza *et al.*, 2014) described technology solutions addressing one specific functional domain, in these cases support of independent outdoor navigation.

**Review aim 2: Involving people with dementia in the design and/or test of the assistive technology**

There was a great variety among studies when it came to involvement of people with dementia in the design phase. Three of the studies (Meiland *et al.*, 2014; Meiland *et al.*, 2007; Robinson *et al.*, 2009) based the design of technology on an extensive iterative design process involving people with dementia, family caregivers, dementia professionals, volunteers and other stakeholders. Methods used in these design phases were mainly

workshops, interviews and consultations. The number of people with dementia involved in these design phases varied between 10 and 27. Two studies (Boyd *et al.*, 2017; Donnelly *et al.*, 2010) referred to involvement of end-users and family caregivers in the design phase, but they did not provide any specific details on the number of participants or specific methods of involvement. However, Donnelly et al. involved a small group of end-users in a prototype pre-test. Xenakidis *et al.* (2014) designed their prototype app based on analysis of already existing technology and they consulted stakeholders and people with mild cognitive disorder. They did not report any specific details of this involvement or indicate if it had any impact on the design of their app. Two studies (Imbeault *et al.*, 2014; Lanza *et al.*, 2014) did not involve any end-users or other stakeholders in the design of their technology solutions.

Six of the studies involved people with dementia in a test phase. The methods applied, number of participants involved, and the duration of the test period varied greatly. Lanza *et al.* (2014) conducted a one-session outdoor laboratory test where they assessed the performance of 14 participants when they used technology to support navigation compared with when they used a map. Imbeault *et al.* (2014) included two participants in the testing phase, however they were involved in a quite extensive programme of laboratory and home testing for 11 and 14 months, respectively. Four other studies also involved home testing. Boyd *et al.* (2017) included 4 dyads of people with dementia and a family caregiver and Nugent et al. (2011) included 12 dyads. Both studies had a test period of 5 weeks. Meiland et al. (2012) included 42 dyads of people with dementia and a family caregiver in three test cycles that lasted between 0.5 days and 8 weeks. Hattink et al (2016) included 42 participants in a controlled trial where the Rosetta system was tested at home for a variable period ranging from 0.5 to 8 months.

Methods for data collection from these test phases varied among these six studies. Lanza et al. (2014) collected observational data describing participants behaviour during the

laboratory test. The remaining five studies (Boyd *et al.*, 2017; Hattink *et al.*, 2016; Imbeault *et al.*, 2014; Meiland *et al.*, 2012; Nugent *et al.*, 2011) all collected qualitative data mainly from interviews and questionnaires, but other methods were also used, e.g. observations or the use of a diary (Hattink *et al.*, 2016; Imbeault *et al.*, 2014). In addition, Imbeault et al. (2014), Meiland et al. (2012) and Nugent et al. (2011) used data-logs to register the use of technology. These data were generally used to assess usability and user-friendliness of the technology. Meiland et al. (2012) and Hattink et al. (2016) also used standardised outcome measures, addressing e.g. quality of life, coping and autonomy, to measure effectiveness of the technology. Meiland et al. (2012) compared pre- and post-test performance of a sub-group of participants and Hattink et al. (2016) compared between group differences on pre- and post-test performance in their controlled trial. Neither of the studies found statistically significant differences on any outcome measures.

Due to the heterogeneous nature of the outcome measures used and results presented in the studies, and according to the review aims of exploring methodological issues, the specific results of the studies are not summarised here.

Two studies (Robinson *et al.*, 2009; Xenakidis *et al.*, 2014) did not include a specific test phase in their publications, but Robinson *et al.* (2009) included feedback from two end-users and one family caregiver during the design of their prototypes. The Alzminder app (Xenakidis *et al.*, 2014) has been made available as open access on Google Play (2019) for prototype testing. We did not locate any scientific or other publications related to this test phase.

**Review aim 3: Dissemination and adoption of assistive technology for people with dementia**

Five of the studies provided information on methods used to support people with dementia in adopting the technology during the test phase. The most extensive method was applied by Imbeault et al. (2014), who conducted an individualised programme with training sessions based on established cognitive rehabilitation methods. Meiland et al. (2012) provided a user

manual and help-desk support. Two studies (Hattink *et al.*, 2016; Nugent *et al.*, 2011) conducted individual training sessions with participants and caregivers, and Lanza et al. (2014) gave participants a short instruction before conducting their outdoor laboratory tests. One study (Boyd *et al.*, 2017) only addressed caregivers with training sessions and telephone support. In addition, Xenakidis et al. (2014) included audio-based guidance as part of their design of the app.

All included studies described technology solutions that were developed to a prototype level and it was not possible to locate additional information that indicated whether these solutions had been further developed or disseminated. Even though the COGKNOW solution (Meiland *et al.*, 2012) was further developed to be included in the Rosetta project (Meiland *et al.*, 2014), this was still at a prototype level.

## Discussion

This scoping review was conducted to investigate the current state of research addressing AT designed to be used by people with dementia for self-management. It explored how user-involvement was addressed in the design and test of such user-centred technology and how dissemination and adoption of the solutions was approached.

The eight studies that fulfilled the inclusion criteria represented a broad and varied field of AT solutions, ranging from comprehensive multidevice holistic solutions, holistic app solutions, technology designed to support daily living through one main feature, and solutions addressing one specific functional domain. The limited number of studies identified reveal that a relatively little amount of the research activity within the field of AT and dementia is directed at creating solutions that can be used by people with dementia for self-management. It could also indicate that AT solutions promoted as applicable for self-management of people with dementia are not based on research.

**User-involvement**

User-involvement in the design and test of technologies varied greatly among the studies included in this review, ranging from no involvement of end-users or other stakeholders to extensive user-involvement throughout an iterative design process. The methods applied for user-involvement in testing and the extent of testing also differed greatly, ranging from a one-session outdoor laboratory testing to extensive single case studies. Most studies involved testing in the homes of end-users.

The heterogeneous approach to user-involvement, and in some cases lack of user-involvement has also been discussed in other reviews (Ienca *et al.*, 2017; Meiland *et al.*, 2017). Our results underline the need to validate methods and create guidelines for the involvement of people with dementia in designing, testing and conducting research on AT. Established models for user-centred design (Gulliksen *et al.*, 2003) should be adapted to be used with people with dementia. Previous examples of successful user-involvement should of course also be drawn on, as represented in this review by Meiland et al. (2007), Meiland et al. (2014) and Robinson et al. (2009). Alzheimer Europe's position paper on involving people with dementia in research through patient and public involvement (Gove *et al.*, 2018) highlights potential challenges and benefits associated with such involvement and could be a benchmark for developing such guidelines.

**Adoption and dissemination of assistive technology**

Adoption was generally addressed in the studies, but in very different ways, and the methods applied were only targeting the context of prototype testing. None of the studies reflected on the applicability and effectiveness of these adoption methods or how they could be used for future adoption of technology. Dissemination of technology was not discussed in any of the studies.

These results are in line with results from other studies demonstrating that dissemination and adoption of AT by people with dementia have only to a limited extent been addressed in

research (Gibson *et al.*, 2018; Knapp *et al.*, 2015), and it underlines the need to develop evidence-based methods for adoption and dissemination. Moreover, the results also demonstrate that this research field is characterised by a quite narrow focus on the design-process and lacks a holistic approach to the dynamic interrelationship between technology, user and context. Van Gemert-Pijnen *et al.* (2011) developed an evidence-based holistic framework which can serve as a guideline for development, implementation and evaluation of eHealth technologies. This framework incorporates user-centered design, participatory development and test, as well as dissemination, adoption and evaluation of the actual uptake of technologies. It also addresses the need to include business case models to reinforce viable technology solutions. The framework also underlines the obvious need to involve a variety of stakeholders to ensure that all these aspects are adequately included and operationalised when developing technologies. This holistic and agile framework seems highly suitable to be applied when developing AT for people with dementia (van Gemert-Pijnen and Span, 2017). It could reinforce the involvement of a variety of stakeholders and experts to ensure that all relevant aspects are met, including dissemination and adoption, and it could reinforce a more extensive user-involvement in the entire life cycle? of AT for people with dementia.

**Study design, methods and evidence**

As described, the results of this review were generally characterised by a considerable variability among studies on all parameters. These profound variations draw a picture of a heterogeneous and fragmented field of research, dominated by small scale studies that mainly address the design and test of AT prototypes. None of the studies were designed or powered to provide evidence for the effectiveness of technology. Hence, our results underline that there is a general need for suitable and applicable research methodology that can provide higher levels of evidence.

Within the related field of digital health technologies there is an ongoing debate on how to address research methodology and evidence (Greaves *et al.*, 2018). The dynamic and iterative nature of such technologies, and the cost of research compared with a product's perceived level of risk, are often used to argue against the use of traditional comparative methods to provide evidence, and to reject randomised controlled trials as the gold standard. Opposite to this, there is a growing demand that such technologies should not be excepted from providing evidence to document clinical- and cost-effectiveness, and standards relevant for this type of intervention, e.g. standards for data security, data management and ethics (Greaves *et al.*, 2018).

Several initiatives have addressed the need for standardised procedures when conducting and reporting research related to digital health technologies. Recently, the National Institute for Health and Care Excellence published a framework for evidence of effectiveness standards and economic impact standards for digital health technologies (The National Institute for Health and Care Excellence, 2018). We find that AT supporting self-management of people with dementia can be stratified within this framework, and the minimum evidence standards outlined in this framework can serve as guidelines when designing research within this field. The AT industry, which promotes solutions as applicable for people with dementia, should of course also comply with the standards. Incorporating such evidence standards would be a great benefit for this field of research and could promote a more transparent market of evidence-based AT solutions for people with dementia.

We also observed a lack of standards for conducting and reporting trials among the studies included in this review. An extension of the Consolidated Standards of Reporting Trials addressing e-health solutions, CONSORT- EHEALTH, was published in 2011 (Eysenbach and Consort-EHEALTH, 2011) and can be applied in this field of research. The implementation of standards on conducting and reporting research could also bring this field of research a great step forward.

Moreover, during the review of full text records,10 papers were excluded because only preliminary ideas or drafting of AT solutions were reported, no data documented the development or test of an operational prototype. Despite our effort to search additional information, including grey literature, no supplementary data were identified. There can of course be various reasons for this, e.g. lack of funding. Another possible reason is suppression or a tendency not to publish 'negative results' describing details of studies that did not result in successful design of an AT solution. Such possible publication bias is a severe limitation when comparing and synthesising data from various studies and aiming for a balanced perspective on this field of research. There is also a risk that it can influence funders, policymakers, and skew industry influence if all potential benefits and limitations of designing AT for people with dementia are not thoroughly disclosed.

**Outcome measures**

The results of this review also indicate that the low level of evidence is influenced by the lack of standardised outcome measures to assess usability, effectiveness and benefits of AT for people with dementia.

The studies included in this review mainly relied on qualitative results from workshops, interviews and questionnaires specifically developed for the study. Such methods are of course essential when collecting qualitative data and it can provide crucial data during a user-involving iterative design process as demonstrated by three of the studies in this review (Meiland *et al.*, 2014; Meiland *et al.*, 2007; Robinson *et al.*, 2009). However, the use of standardised outcome measures when testing technology and assessing usability and effectiveness would increase the reliability of results and enable comparison of studies and research results. The development and validation of such outcome measures could benefit from research in psychosocial interventions for people with dementia, where efforts are made to create outcome measures that capture the essence of such interventions (Øksnebjerg *et al.*, 2018). The development of AT outcome measures could find inspiration in the theoretical

and methodology advances within the field of psychosocial research, where there is a growing focus on positive psychology outcomes (Stoner *et al.*, 2015; Wolverson *et al.*, 2016), to introduce outcome measures that reflect interactions between AT use, positive psychology and self-management of people with dementia (Serino and Pedroli, 2016).

Another dimension of outcome measures in AT research is the potential of using log data to assess applicability, usability and adoption of technology. Three studies (Imbeault *et al.*, 2014; Meiland *et al.*, 2012; Nugent *et al.*, 2011) used log data among their outcome measures, but none of the studies gave any specific attention to these results and the potential of using such outcome measures. This is in contrast to the increasing use of log data and big-data within healthcare and disease management (Ienca *et al.*, 2018; Sieverink *et al.*, 2017), and the potential of using log data to assess usability, effectiveness and adherence to AT should be addressed in future studies.

## Conclusion and perspectives

The results of this scoping review underline the lack of well-designed high-quality research that can establish evidence-based methods on how to deliver user-centred AT solutions for people with dementia and provide evidence that AT can be effective to support self-management.

The results demonstrate that this field of research is in need of guidelines and evidence-based methods to promote and qualify user-involvement. The results also emphasise the need for research into all aspects that are essential to deliver applicable, effective and sustainable AT solutions to people with dementia. Future research has to go beyond the stages of design and testing to provide more knowledge and evidence-based methods for dissemination and adoption.

Moreover, it could be highly beneficial to implement standards for conducting and reporting research, to improve study design, level of evidence and impact of research results. It would also be highly beneficial for the quality of research and level of evidence if standardised outcome measures, that capture the interaction of AT and self-management of people with dementia, were developed and applied.

These perspectives should be further elaborated and incorporated in future studies addressing AT for people with dementia.

## Conflict of interest declaration

None

## Description of authors' roles

The first author was involved in all aspects of conceptualising and design the scoping review and the collection, analysis and interpretation of data. The second author was involved in data collection and analysis. All authors were involved in writing the manuscript and all authors have read and approved the final manuscript.

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# References

**Alzheimer's Disease International**. 2016. *Bibliography of References to National Plans.* Available at: https://www.alz.co.uk/sites/default/files/pdfs/national-plans-bibliography-2016.pdf. Accessed 1 February 2019.

**Asghar, I., Cang, S. and Yu, H.** (2017). Assistive technology for people with dementia: an overview and bibliometric study. *Health Information & Libraries Journal*, 34, 5-19. doi: 10.1111/hir.12173.

**Assistive Technology Industry Association**. 2019. *What is AT? - Assistive Technology Industry Association*. Available at: http://www.atia.org/at-resources/what-is-at/. Accessed 1 February 2019.

**Barlow, J., Wright, C., Sheasby, J., Turner, A. and Hainsworth, J.** (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48, 177-187.

**Boyd, H., Evans, N., Cheston, R., Noonan, K. and Harris, N.** (2017). Home Testing of a Digital Prompter for People with Dementia. *Studies in Health Technology and Informatics*, 242, 27-30. doi: 10.3233/978-1-61499-798-6-27.

**Bächle, M., Daurer, S., Judt, A. and Mettler, T.** (2018). Assistive technology for independent living with dementia: Stylized facts and research gaps. *Health policy and technology*, 7, 98-111. doi: 10.1016/j.hlpt.2017.12.002.

**Covidence.org**. Available at: https://www.covidence.org/home. Accessed 2018.

**Donnelly, M. P*., et al.*** (2010). A mobile multimedia technology to aid those with Alzheimer's disease. *IEEE multimedia*, 17, 42-51. doi: 10.1109/MMUL.2010.25.

**Eysenbach, G. and Consort-EHEALTH** (2011). CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. *Journal of Medical Internet Research*, 13. doi: 10.2196/jmir.1923.

**Federici, S., Meloni, F. and Borsci, S.** (2016). The abandonment of assistive technology in Italy: a survey of users of the national health service. *European Journal of Physical and Rehabilitation Medicine*, 52, 516-526.

**Gibson, G., Dickinson, C., Brittain, K. and Robinson, L.** (2015). The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. *BMC Geriatrics*, 15, 89. doi: 10.1186/s12877-015-0091-3.

**Gibson, G., Dickinson, C., Brittain, K. and Robinson, L. A.** (2018). Personalisation, customisation and bricolage: How people with dementia and their families make assistive technology work for them. *Ageing & Society*, 1-18.

**Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K. and Robinson, L.** (2016). The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, 15, 681-701. doi: 10.1177/1471301214532643.

**Gillespie, A., Best, C. and O'Neill, B.** (2012). Cognitive function and assistive technology for cognition: A systematic review. *Journal of the International Neuropsychological Society*, 18, 1-19. doi: 10.1017/S1355617711001548.

**GooglePlay**. 2019. Available at: https://play.google.com/store/apps/details?id=com.alzminder.mobilelite&hl=en. Accessed 1 February 2019.

**Gove, D.*, et al.*** (2018). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health*, 22, 723-729. doi: 10.1080/13607863.2017.1317334.

**Greaves, F., Joshi, I., Campbell, M., Roberts, S., Patel, N. and Powell, J.** (2018). What is an appropriate level of evidence for a digital health intervention? *The Lancet*. doi: 10.1016/S0140-6736(18)33129-5.

**Gulliksen, J., Göransson, B., Boivie, I., Blomkvist, S., Persson, J. and Cajander, Å.** (2003). Key principles for user-centred systems design. *Behaviour and Information Technology*, 22, 397-409. doi: 10.1080/01449290310001624329.

**Hattink, B.*, et al.*** (2016). The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact. *Disability and Rehabilitation: Assistive Technology*, 11, 61-71. doi: 10.3109/17483107.2014.932022.

**Holthe, T., Halvorsrud, L., Karterud, D., Hoel, K.-A. and Lund, A.** (2018). Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. *Clinical Interventions in Aging*, 13, 863. doi: 10.2147/CIA.S154717.

**Ienca, M.*, et al.*** (2017). Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. *Journal of Alzheimer's Disease*, 56, 1301-1340. doi: 10.3233/JAD-179005.

**Ienca, M., Ferretti, A., Hurst, S., Puhan, M., Lovis, C. and Vayena, E.** (2018). Considerations for ethics review of big data health research: A scoping review. *PloS One*, 13, e0204937. doi: 10.1371/journal.pone.0204937.

**Imbeault, H.*, et al.*** (2014). Electronic organiser and Alzheimer's disease: Fact or fiction? *Neuropsychological Rehabilitation*, 24, 71-100. doi: 10.1080/09602011.2013.858641.

**Kenigsberg, P.-A.*, et al.*** (2017). Assistive technologies to address capabilities of people with dementia: from research to practice. *Dementia*, 1471301217714093. doi: 10.1177/1471301217714093.

**King, A. C. and Dwan, C.** (2017). Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. *Dementia*, 1471301217735180. doi: 10.1177/1471301217735180.

**Knapp, M.*, et al.*** (2015).The case for investment in technology to manage the global costs of dementia.
http://eprints.lse.ac.uk/66482/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_LSEE_The%20case%20for%20investment%20in%20technology.pdf.

**Krebs, P. and Duncan, D. T.** (2015). Health app use among US mobile phone owners: a national survey. *JMIR mHealth and uHealth*, 3, e101. doi: 10.2196/mhealth.4924.

**Lanza, C., Knörzer, O., Weber, M. and Riepe, M. W.** (2014). Autonomous spatial orientation in patients with mild to moderate Alzheimer's disease by using mobile assistive devices: a pilot study. *Journal of Alzheimer's Disease*, 42, 879-884. doi: 10.3233/JAD-140063.

**Meiland, F.*, et al.*** (2014). Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European Rosetta project. *International Psychogeriatrics*, 26, 769-779. doi: 10.1017/S1041610214000088.

**Meiland, F.*, et al.*** (2017). Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. *JMIR rehabilitation and assistive technologies*, 4(1). doi: 10.2196/rehab.6376.

**Meiland, F. J.*, et al.*** (2012). Usability of a new electronic assistive device for community-dwelling persons with mild dementia. *Aging & Mental Health*, 16, 584-591. doi: 10.1080/13607863.2011.651433.

**Meiland, F. J.*, et al.*** (2007). COGKNOW: Development of an ICT device to support people with mild dementia. *Journal on Information Technology in Healthcare*, 5, 166-177.

**Nugent, C.*, et al.*** (2011). Evaluation of video reminding technology for persons with dementia. International Conference on Smart Homes and Health Telematics (pp. 153-160): Springer.

**Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D. and Soares, C. B.** (2015). Guidance for conducting systematic scoping reviews. *International journal of evidence-based healthcare*, 13, 141-146. doi: 10.1097/XEB.0000000000000050.

**Robillard, J. M., Cleland, I., Hoey, J. and Nugent, C.** (2018). Ethical adoption: A new imperative in the development of technology for dementia. *Alzheimer's & Dementia*. doi: 10.1016/j.jalz.2018.04.012.

**Robinson, L., Brittain, K., Lindsay, S., Jackson, D. and Olivier, P.** (2009). Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. *International Psychogeriatrics*, 21, 494-502. doi: 10.1017/S1041610209008448.

**Serino, S. and Pedroli, E.** (2016). Technology and cognitive empowerment for healthy elderly: the link between cognitive skills acquisition and well-being. In: D. Villani, P. Cipresso, A. Gaggioli and G. Riva (Eds.) Integrating Technology in Positive Psychology Practice (pp. 193-213) USA: IGI Global.

**Sieverink, F., Kelders, S., Poel, M. and van Gemert-Pijnen, L.** (2017). Opening the black box of electronic health: collecting, analyzing, and interpreting log data. *JMIR research protocols*, 6. doi: 10.2196/resprot.6452.

**Smith, R. O.*, et al.*** (2018). Assistive technology products: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. *Disability and Rehabilitation: Assistive Technology*, 1-13. doi: 10.1080/17483107.2018.1473895.

**Stoner, C. R., Orrell, M. and Spector, A.** (2015). Review of Positive Psychology Outcome Measures for Chronic Illness, Traumatic Brain Injury and Older Adults: Adaptability in Dementia? *Dementia and Geriatric Cognitive Disorders*, 40, 340-357. doi: 10.1159/000439044.

**The National Institute for Health and Care Excellence (NICE)**. 2018. *Evidence Standards Framework for Digital Health Technologies*. Available at: https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/evidence-standards-framework/digital-evidence-standards-framework.pdf. Accessed 1 February 2019.

**Tricco, A. C.*, et al.*** (2018). PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Annals of Internal Medicine*, 169, 467-473. doi: 10.7326/M18-0850.

**van der Roest, H. G., Wenborn, J., Pastink, C., Droes, R. M. and Orrell, M.** (2017). Assistive technology for memory support in dementia. *Cochrane Database of Systematic Reviews*, 6, Cd009627. doi: 10.1002/14651858.CD009627.pub2.

**van Gemert-Pijnen, J. E., Kelders, S. M. and Bohlmeijer, E. T.** (2014). Understanding the usage of content in a mental health intervention for depression: an analysis of log data. *Journal of Medical Internet Research*, 16. doi: 10.2196/jmir.2991.

**van Gemert-Pijnen, J. E.*, et al.*** (2011). A holistic framework to improve the uptake and impact of eHealth technologies. *Journal of Medical Internet Research*, 13. doi: 10.2196/jmir.1672.

**van Gemert-Pijnen, L. and Span, M.** (2017). CeHRes roadmap to improve dementia care. In: J. van Hoof, G. Demiris and E. J. M. Wouter (Eds.) Handbook of Smart Homes, Health Care and Well-Being (pp. 133-146) Switzerland: Springer.

**Wolverson, E. L., Clarke, C. and Moniz-Cook, E. D.** (2016). Living positively with dementia: a systematic review and synthesis of the qualitative literature. *Aging & Mental Health*, 20, 676-699. doi: 10.1080/13607863.2015.1052777.

**World Health Organisation (WHO)**. 2017. *Global action plan on the public health response to dementia 2017–2025.* Available at: http://apps.who.int/iris/bitstream/handle/10665/259615/?sequence=1. Accessed 1 February 2019.

**Xenakidis, C. N., Hadjiantonis, A. M. and Milis, G. M.** (2014). A Mobile Assistive Application for People with Cognitive Decline. 2014 International Conference on Interactive Technologies and Games (iTAG) (pp. 28-35): IEEE.

**Øksnebjerg, L.*, et al.*** (2018). Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expectations*, 21, 1056-1065. doi: 10.1111/hex.12799

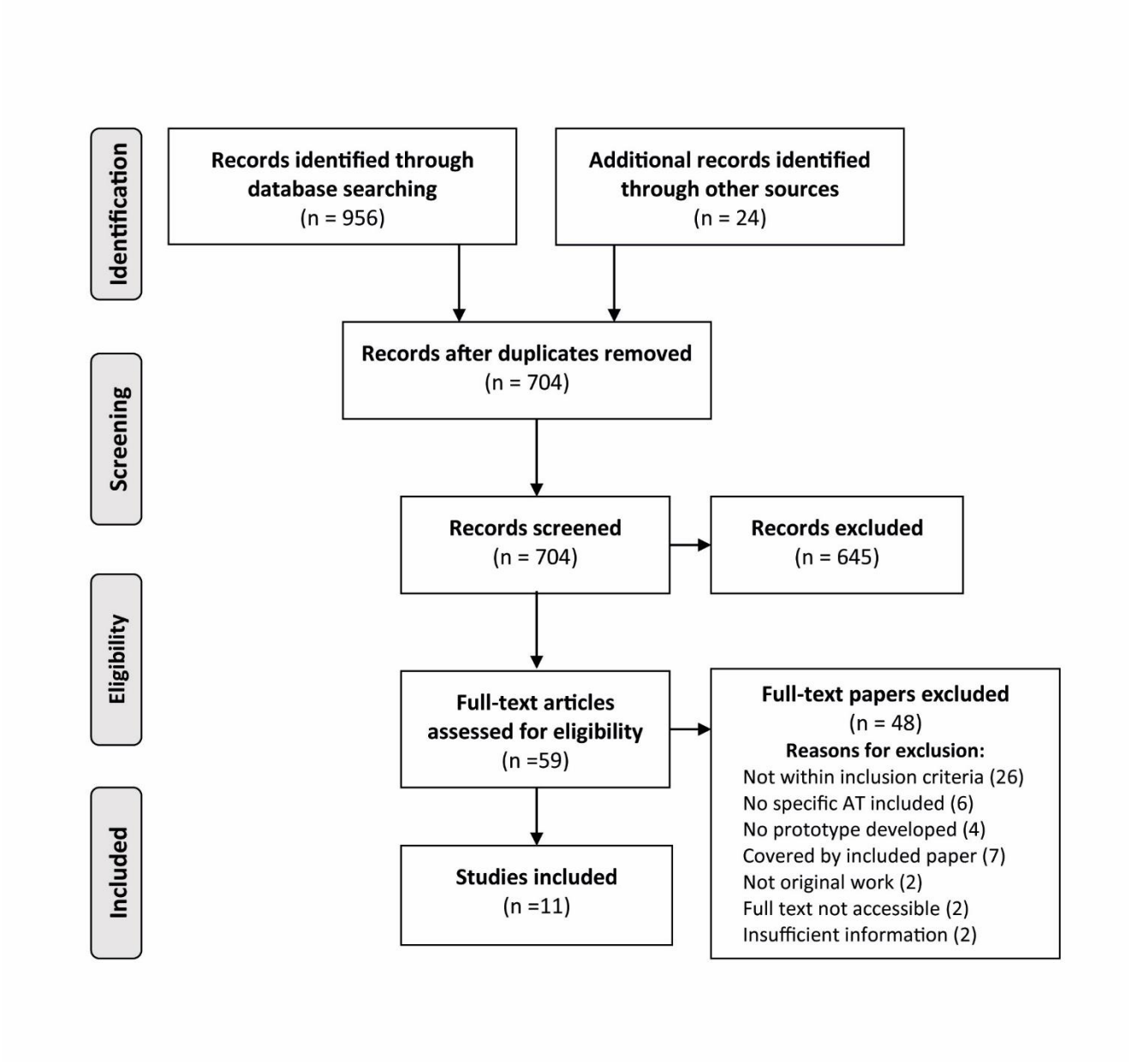


Figure 1: Prisma flow diagram illustrating the study selection process

**Table 1: Characteristics and results from the studies included in the review**

| | | **Review aim 1: Assistive technology used by people with dementia for self-management** | | **Review aim 2: Involvement of end-users in design and/or test phases** | | | **Review aim 3: Methods addressing adoption and dissemination** | |
|---|---|---|---|---|---|---|---|---|
| **Study** | **Publication and origin** | **Aim of technology and target users** | **Features** | **Participants[#]** | **Methods for user- involvement** | **Evaluation methods and results** | **Adoption** | **Dissemination** |
| **COGKNOW** | Meiland et al. (2007)<br>Origin: The Netherlands, Ireland and Sweden | Aim: Supporting daily function through support of memory, social contacts, daily activities and safety.<br>Target users: People with mild dementia | The holistic solution included two user-devices:<br>– Stationary touch screen<br>– Mobile device<br>And:<br>– Home-based sensors<br>– Actuators | Design phase:<br>17 dyads: people with AD and FC.<br>Details verifying diagnosis: Yes. | Design phase:<br>Workshops and interviews. | Design phase:<br>A prototype was designed based on results from workshops and interviews. | N/A | N/A |
| | Meiland et al. (2012)<br>Origin: The Netherlands, Ireland and Sweden | | | Test phase:<br>42 dyads: People with AD and FC.<br>Details verifying diagnosis: Yes. | Test phase:<br>Home testing.<br>Duration: 3 successive test-cycles: 0.5 days, 1 week and 3-8 weeks. | Test phase:<br>– Interviews<br>– Questionnaires<br>– Observations<br>– Diaries<br>– Data-log<br>– Standardised outcome measures e.g.: autonomy, coping and quality of life.<br>Results:<br>No statistically significant differences on standardised outcome measures.<br>Authors conclude: The solution was overall rated as user-friendly and useful. Effectiveness of the system in daily life could not be evaluated due to insufficient duration of the test period. | User manual and helpdesk. | N/A |
| **Rosetta** | Meiland et al. (2014)<br>Origin: The Netherlands and Germany | Aim: Supporting daily function through support of memory, social contacts, daily activities and safety.<br>Target users: People with dementia | The holistic solution included three kinds devices/hardware:<br>– Day Navigator: Video home terminal and mobile device supporting memory, social contacts, daily activities and safety.<br>– Detection System: monitor the status of the user. | Design phase:<br>11 PwD, 3 MCI, 13 FC, 23 professionals.<br>Specific details verifying diagnosis: No, but from dementia care organisations. | Design phase:<br>Workshops, individual interviews, expert meetings, consultations and prototype testing. | Design phase:<br>A prototype was designed based on the results from the iterative design process. | N/A | N/A |

[#]Participants: Alzheimer's disease (AD), mild cognitive impairment (MCI), people with dementia (PwD, not specified), family caregiver (FC)

N/A: Not available, the study does not provide information on this topic.

***Table 1 continued***

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Rosetta** (continued) | Hattink et al. (2016)<br>Origin: The Netherlands, Germany and Belgium | | – Surveillance system: detecting emergency situations.<br>The system was an adapted combination of three previously developed assistive technology systems including the COGKNOW. | Test phase:<br>42 PwD or MCI<br>32 FC, 6 professionals.<br>Specific details verifying diagnosis: yes | Test phase:<br>Home test: controlled trial: partly randomised controlled trial and partly matched groups design.<br>Duration: ½ - 8 months.<br>Focus group interview with a subgroup of family caregivers.<br>Online questionnaire for professional caregivers. | Test phase:<br>– Interviews<br>– Questionnaires<br>– Standardised outcome measures, e.g. perceived autonomy, quality of life, care needs and caregivers feeling of competence.<br>Results:<br>No statistically significant differences on standardised outcome measures.<br>Drop-out rate: 18<br>Authors conclude: Participants generally found the system useful for future care, but user-friendliness was generally perceived low. | Short individual introduction. | N/A |
| **AP@LZ** | Imbeault et al. (2014)<br>Origin: Canada | Aim: Compensation for memory problems in day-to-day activities.<br>Target users: People with Alzheimer's disease. | The holistic app was designed for smartphones and included:<br>– Appointments<br>– Personal information<br>– Medical information<br>– Contacts<br>– Notepad | Design phase:<br>No end-users were involved.<br>Test phase:<br>2 people AD.<br>Specific details verifying diagnosis: Yes. | Design phase:<br>N/A<br>Test phase:<br>Laboratory and home testing.<br>Duration: 11 and 14 months. | Design phase:<br>N/A<br>Test phase:<br>– Questionnaires<br>– Observation/experimenter log journal<br>– Data-log<br>Results:<br>Authors conclude: Participants were able to use the app efficiently and it facilitated their day-to-day activities. | Individualised programme with training session based on cognitive rehabilitation methods. | N/A |
| **Alzminder** | Xenakidis et al. (2014)<br>Origin: Cyprus | Aim: Support various needs across multiple cognitive domains.<br>Target users: People with cognitive decline, including people with dementia. | The holistic app was designed for smartphones and included:<br>– Reminders<br>– Music therapy and entertainment<br>– Photos with narratives<br>– Games<br>– Contact details<br>– Automatic call and SMS to emergency contacts | Design phase:<br>Professionals, stakeholders and people with MCI (numbers not specified).<br>Specific details verifying diagnosis: No<br>Test phase:<br>Prototype testing was planned (access to the app on Google Play). | Design phase:<br>A prototype was design based on analysis of already existing technologies promoted for people with dementia.<br>The prototype was demonstrated during consultations.<br>Test phase:<br>N/A | N/A | Audio based guidance was included in the app. | N/A |

***Table 1 continued***

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Digital Prompter** | Boyd et al. (2017)<br>Origin: United Kingdom | Aim: Guide the independent performance of multi-step tasks at home.<br>Target users: People with dementia. | The app was designed for a tablet computer. It provided personalised prompts (text, audio messages and photos) on how to perform daily tasks.<br>The prompts were loaded into the system by the family caregiver through separate software. | Design phase:<br>Authors refers to user engagement (not specified).<br>Test phase:<br>12 dyads: PwD and FC.<br>Specific details verifying diagnosis: No. | Design phase:<br>N/A<br>Test phase: Home testing.<br>Duration: 5 weeks | Test phase:<br>Semi-structured interviews<br>Results:<br>Authors conclude: Participants and caregivers could o some extend able to operate the system, but with varied success in the home-based setting. | Training session and a manual for caregivers. Telephone support and hoc hotline. | N/A |
| **Video Reminding Technology** | Donnelly et al. (2010)<br>Origin: Northern Ireland | Aim: Provide individualised video-based reminders to support memory.<br>Target users: People with dementia. | The personalised video-based reminders were delivered on a modified mobile phone.<br>The video reminders were created by caregivers and loaded through separate software. | Design phase:<br>PwD and FC<br>Pre-trial test for adoption of the AT:<br>4 dyads: PwD and FC, 5 controls.<br>Specific details verifying diagnosis: Yes | Design phase:<br>Interviews<br>Pre-trial test phase:<br>Home testing<br>Duration: 3 days | Pre-trial test phase:<br>Interviews.<br>Results:<br>The prototype was refined based on the results from this test- phase. | N/A | N/A |
| | Nugent et al. (2011)<br>Origin: Northern Ireland | | | Test phase:<br>4 dyads: PwD and FC.<br>Specific details verifying diagnosis: No. but from a memory clinic. | Test phase:<br>Home testing<br>Duration: 5 weeks. | Test phase:<br>– Questionnaires.<br>– Data-log registering the use of the system<br>Results:<br>Authors conclude: The technology was usable, and caregiver's involvement was essential. | One individualised training session for participant and caregiver dyads. | N/A |
| **KITE** | Robinson et al. (2009)<br>Origin: United Kingdom | Aim: Facilitate independence.<br>Target users: People with dementia. | Prototypes of two individualised technologies:<br>– Electronic reminder including GPS tracking.<br>– Armband with pedometer and GPS tracking. | Design phase:<br>10 PwD, 11 FC, 4 volunteers.<br>Specific details verifying diagnosis: No, but from dementia care organisations.<br>Test phase: N/A | Design phase:<br>Workshops and consultations.<br>Test phase: N/A | Design phase:<br>End-users feedback on prototypes. | N/A | N/A |

***Table 1 continued***

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Autonomous Spatial Navigation** | Lanza et al. (2014)<br><br>Origin: Germany | Aim: Support autonomous spatial navigation.<br><br>Target users: People with dementia. | The navigation system integrated photo-based navigation with acoustic and optic feedback. It was designed to be used on a smartphone. | Design phase:<br>No involvement of people with dementia.<br><br>Test phase:<br>14 participants with Alzheimer's disease.<br><br>Specific details verifying diagnosis of participants: Yes | Design phase: N/A<br>.<br><br>Test phase:<br>Outdoor laboratory pilot test at a hospital campus.<br>Duration: 1 test session | Registration of participants' behavior: e.g. time to complete navigation task and number of errors.<br><br>Results:<br>Authors conclude:<br>Participants perform better when using the navigation technology. | Short individual instruction. | N/A |

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# Designing the ReACT App to Support Self-Management of People with Dementia: An Iterative User-Involving Process

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**Keywords**
Dementia · Assistive technology · Self-management · Rehabilitation · User-involving design

**Abstract**
***Background:*** Assistive technology (AT) has the potential to support and enhance self-management of people living with dementia. However, a range of special and heterogeneous needs must be considered when designing and deploying AT for people with dementia, and consequently the involvement of end-users throughout the design process is essential to provide usable and effective AT solutions. ***Objective:*** The ReACT study was conducted to investigate how a tailor-made app, the ReACT app, can be designed and deployed to meet the needs of people with dementia in relation to self-management. ***Methods:*** This paper presents 4 steps of an iterative user-involving app design process. In the first step, a pilot study was conducted to explore the potential benefits and challenges of using existing off-the-shelf apps to support self-management when living with early-stage dementias. In the second step, focus group interviews provided in-depth understanding of the perspectives and needs of potential end-users of the app. The third step was a product benchmarking process, which served to further qualify the design process. Finally, results from these first 3 steps were included in the fourth step where the ReACT app was designed through an iterative codesign process. In total, 28 people with dementia, 17 family caregivers, and 10 professional caregivers were involved through these 4 iterative steps. ***Results:*** The functionalities and the design of the ReACT app directly reflect the perspectives and needs of end-users in relation to self-management. Support of memory and structure in daily living were identified as main needs, and the ReACT app was designed as a holistic and adaptable solution with a tailor-made calendar as a key feature. ***Conclusion:*** Based on this extensive iterative user-involving design process, the ReACT app has great potential to support and enhance self-management of people living with dementia. Further studies are needed to test and validate the usability and impact of the app, and methods for deployment and adoption of AT for people with dementia also need to be considered.



## Introduction

Societies worldwide are faced with the challenge of providing suitable and affordable support and care for the fast-growing number of people living with dementia [1, 2]. Crucial breakthroughs are still awaited in the effort to find pharmaceutical treatments for the range of dementia diseases [2], but there is growing emphasis on how other

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methods and approaches, for example, psychosocial interventions, can play a crucial role in reducing the impact of dementia symptoms, and enable people with dementia and their supporters to cope and live with dementia [3, 4]. One of the advancing approaches is the use of assistive technology (AT) to support and enhance the capacity of people living with dementia, and this potential impact of technology is emphasized in international initiatives to counteract dementia [1, 5].

AT can be defined as "Any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities" [6], and it spans a wide variety of solutions, ranging from basic everyday low-tech devices to advanced high-tech hardware or software technology [6].

Both the technology industry and dementia researchers have growing interest in AT for people with dementia [7, 8], and AT is applied to meet a range of needs of people with dementia, for example, assisting management of everyday life, engagement in meaningful and pleasurable activities, and supporting professionals and organizations who provide health and social care for people with dementia [9]. However, as much as there is optimism that AT can be a key solution in the support, rehabilitation and care for people with dementia, there is also a growing awareness of the lack of high-quality research to provide evidence-based solutions and methods within this field [9, 10]. Recent reviews and position papers point to various topics that are not adequately met in current development and research into AT and dementia: for example, the benefits of end-user involvement in the design of AT, exploration of barriers to deployment and adoption, the need for high-quality research on usability and effectiveness of AT, and ethical considerations [7, 9, 11–14].

The ReACT study (Rehabilitation in Alzheimer's disease using Cognitive support Technology) is based on the promising perspectives of using AT to support people with dementia in coping with the consequences of cognitive symptoms and thereby support self-management in everyday life [9, 15].

The first aim of the study was to design an app (the ReACT app) as an easily accessible AT, which can meet the heterogeneous needs of people with mild to moderate dementia in relation to self-management. The second objective was to develop and assess methods, which can reinforce deployment and adoption of this kind of AT. The third objective was to explore relevant outcome measures for capturing the possible benefits of using AT to support self-management of people with dementia.

The ReACT study comprises a range of interacting components and its design is therefore based on the principles of the Medical Research Council framework for development and evaluation of complex interventions [16], as illustrated in Figure 1.

## Methods

This paper describes the initial theoretical phase of the ReACT study, which led to the design of the ReACT app. The iterative process of designing the ReACT app comprised 4 steps, which are illustrated in Figure 1. They include an explorative pilot study, focus group interviews, a product benchmarking process, and the final codesign process. To provide a clear overview of this iterative stepwise process, the methods and results of these 4 steps are presented separately in this paper, and subsequently compiled and elaborated in the discussion.

The initial step, the explorative pilot study, was conducted in 2014, and the following 3 steps were conducted from January to June 2016.

### Step 1: Explorative Pilot Study

A pilot study was conducted to explore the potential benefits and challenges of applying apps to support self-management of people with early-stage dementia.

The apps were provided on tablet computer (iPad), and they were introduced as part of a group-based self-management programme for people with early-stage Alzheimer's disease, where participants were introduced to various compensatory strategies, aids and tools that could support self-management in everyday life (unpublished data). It was not mandatory for participants to use the tablet and specific apps, but they were encouraged to try these solutions. At the time, no apps were available that were specifically designed for people with dementia, so other readily accessible off-the-shelf apps were selected for this pilot study. Selection criteria were that the app was in Danish, and that it was considered the best possible app solution to meet the participants' needs, preferences, and technology skills. Examples of apps were a calendar app, an Internet search app, an app for e-mail communication, and a news app.

*Step 1: Methods*

Participants and Setting

Fourteen participants were recruited from the Memory Clinic at Danish Dementia Research Centre, where the pilot-study was also conducted. All participants had a clinical diagnosis of probable Alzheimer's disease, ac-

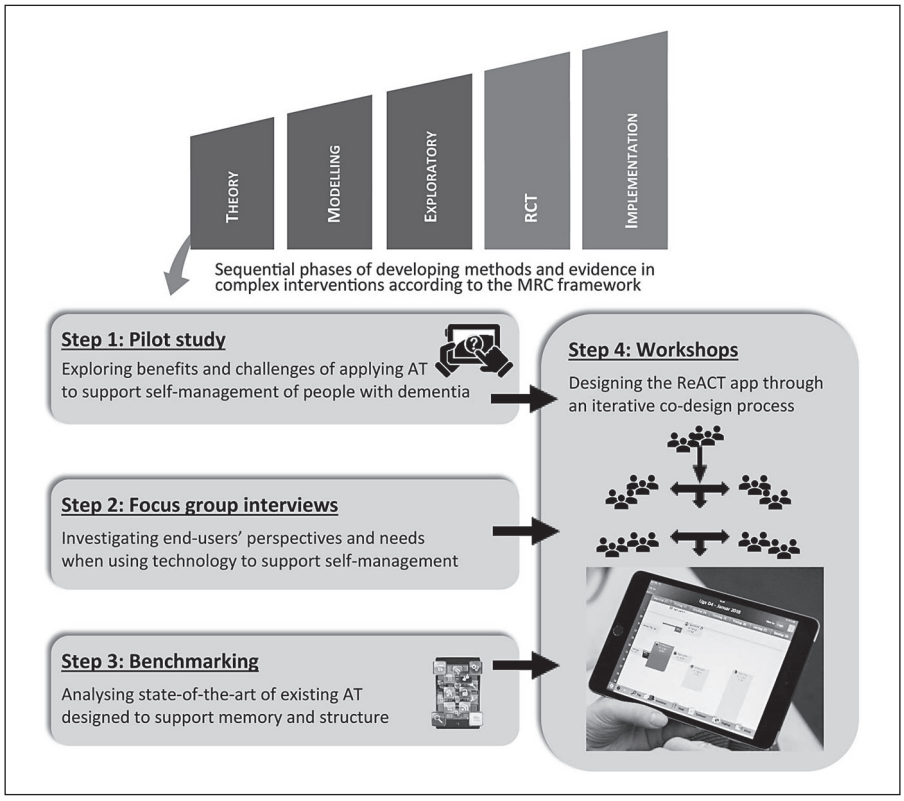


**Fig. 1.** The 4 steps of the theoretical phase of the ReACT study.

cording to the NINCDS-ADRDA criteria for Alzheimer's disease [17]. Based on clinical evaluation, they were assessed to be at an early stage of the disease.

The study ran as a group intervention with 2 consecutive groups of 7 participants. The participant's baseline characteristics are summarised in Table 1. One aim of the pilot was to explore if inexperienced users of touchscreen technology could also benefit from the intervention, and therefore it was not mandatory for participants to be previous user of a touchscreen device (smartphone or tablet). All participants were provided with an iPad during the intervention. The study was conducted by the first author (specialist in clinical neuropsychology with expertise in cognitive rehabilitation) and a psychology assistant.

Procedure

The programme comprised 1 weekly 2-h session for a period of 10 weeks. Prior to the group programme, the participant and a family caregiver came to an individual session with staff conducting the intervention to discuss and specify the participants' needs and preferences in relation to self-management and compensatory means. During the group intervention, the compensatory strategies and tools, including the apps, were gradually introduced, practiced, and adapted to meet the user's individual needs and preferences.

Data Collection

The intervention was evaluated through individual semi-structured interviews with the participants and caregivers separately at the end of the programme. The interviews were based on 2 rather open-ended questions addressing the overall experience of participating in the programme and the use of touchscreen technology and apps to support self-management. Data from these interviews were collected by note-taking.

Three participants were excluded from the data set; 1 participant dropped out during the intervention after 3 sessions, she expressed discomfort with the group-based intervention, and 2 participants were absent at the time of post-intervention evaluations.

Data Analysis

Results from the interviews were coded by hand and processed and interpreted according to the principles of the general inductive approach [18]. The data analysis was conducted by the first author. To target the aim of this paper, only the results related to the use of technology are included.

**Table 1.** Participant characteristics in step 1 (pilot study), step 2 (focus-group interviews), and step 4 (workshops)

| Participants[1] | 1. Pilot study | | 2. Focus group interviews | | | 4. Workshops | | |
|---|---|---|---|---|---|---|---|---|
| | PwD | FCG | PwD | FCG | PCG | PwD | FCG | PCG |
| Number | 11 | 11 | 13 | 2 | 6 | 4 | 4 | 4 |
| Gender (male/female) | 5/6 | 6/5 | 7/6 | 1/1 | 1/5 | 2/2 | 2/2 | 0/4 |
| Age, years, mean (SD, range) | 66.3 (9.7, 53–82) | | 61.5 (11.6, 41–86) | 60 (4.2, 57–63) | 49 (8.67, 40–64) | 72 (5.7, 65–78) | 71 (2.5, 68–73) | |
| Diagnosis, *n*[2] | AD: 11 | | AD: 7<br>VaD: 1<br>Mixed: 1<br>Other: 4 | | | AD: 4 | | |
| Time since diagnosis, years, mean (SD, range) | All <1.5 years | | 2.4 (1.71, 1–6) | | | 1 (1.4, 0.5–1.5) | | |
| Previous user of touchscreen technology (user/nonuser)[3] | 5/6 | | 10/3 | 2 | 6 | 4/0 | 4/0 | 4/0 |
| Caregiver relation | | Spouse: 9<br>Parent: 1<br>Son/ daughter: 1 | | Spouse: 1<br>Parent: 1 | | | Spouse: 4 | |
| Professional caregiver[4] | | | | | Teacher: 3<br>OT: 1<br>CCW: 1<br>Nurse: 1 | | | OT: 2<br>CCW: 2 |

[1] Participants: PwD, person with dementia; FCG, family caregiver; PCG, professional caregiver. [2] Diagnosis: AD, Alzheimer's disease; VaD, vascular dementia; Mixed, mixed AD and VaD. [3] Previous user of touchscreen technology: Tablet computer and/or smartphone. [4] Professional caregiver: Teacher (adult education), OT, occupational therapist; CCW, community care worker.

*Step 1: Results*

Both participants and their caregivers reported benefits of using apps to support cognitive functions and self-management. A calendar app was used by 5 participants, and in these cases, all participants and caregivers pointed out advantages of using an electronic calendar compared to a paper version, for example, the use of notifications and the possibility for caregivers to support the use of the web-based calendar by having access to it from their own device. An e-mail app was used by 7 participants, and they all reported that using an e-mail app on a touchscreen device was a more accessible and convenient way to communicate by e-mail, compared to using a computer. Caregivers supported this observation. Three of the participants specifically reported that they felt more included in technology-based communication with friends and family after being introduced to the e-mail app. Nine of the participants used an app for Internet search and they all mentioned that this gave them the advantages of a more effortless and independent access to information, compared to the often troublesome use of a computer.

However, the use of technology also presented obstacles. All participants expressed frustration with the need to set up and maintain software, for example, updating apps. It was generally perceived as difficult, and in many cases, impossible to accomplish for the person with dementia, even for participants who were experienced users of touch-screen technology. Moreover, all participants and caregivers requested apps that were tailor-made to the needs of people with dementia. They generally did not find the off-the-shelf apps sufficiently adaptable, well designed, or reliable.

### Step 2: Focus Group Interviews

In the second step, people with dementia, family caregivers, and professional caregivers participated in focus group interviews. Adding to the results of step 1, the aim of the

**Table 2.** Emerging themes and subthemes in the focus group interviews

| Emerging themes | Subthemes |
|---|---|
| Individual approaches to the use of technology | Common use of technology as an integrated part of modern life<br>Preference for nontechnological solutions |
| Technology's influence on self-management | Positive influence on self-management<br>Reduced access to society caused by the mandatory use of technology<br>Feeling of inadequacy caused by technology use<br>Stigmatizing caused by technology tailor-made for people with special needs |
| Special needs when using technology | People with dementia's need for education and support when using technology<br>Caregivers' needs for education on how to support the use of technology<br>Needs caused by cognitive symptoms |
| Special features of technology | Individualized and adaptable technology<br>Reliable and efficient technology |
| Perspectives and wishes for future technology | Holistic solutions that provide user-friendly technology<br>Features that can ease the use of technology and support cognition |
| Ethical and human right issues | Privacy<br>Equal rights and access to technology |

second step was to conduct an in-depth investigation of needs and wishes regarding the use of technology to support and enhance self-management of people with dementia.

*Step 2: Methods*

Participants and Setting

To include a broad range of perspectives, participants were recruited through purposive sampling. Interviews were conducted at 2 different established group settings for community-dwelling people with dementia: a meeting center and an adult education center offering tailor-made activities for people with dementia. To recruit participants, written information was handed out by staff to people attending activities at the settings. Those who showed interest were invited to participate in the interviews. People with dementia and staff participated at both settings, and at the meeting center family caregivers were also present. All participants clearly indicated that they were comfortable with giving their opinion in a joint group. Prior experience with technology was not mandatory to join the interviews. A total of 13 people with dementia, 2 family caregivers, and 6 professional caregivers participated in the interviews. Characteristics of participants are presented in Table 1.

Procedure

The focus group interviews were facilitated by the first author. To embrace all participants' experiences and views in the most flexible manner, interview questions were prepared as rather general questions addressing: positive experiences with technology, challenges in relation to technology, and wishes for future technology. It was specified that the focus of the interview was the use of technology to support self-management. To guide the interviews, and to support the participants' attention and memory, the interview questions were presented on posters. The questions were addressed in a flexible manner during the interviews to adapt to the pace and atmosphere of the specific group. The length of the focus group sessions varied between 1 and 2 h and were audio recorded in full agreement with all participants.

Data Analysis

Recordings from the focus group interviews were transcribed verbatim, and the data were subsequently processed and summarized in emerging themes, based on the principles of the Constant Comparison Analysis [19]. Analysis and coding were done by hand by the first author, and the themes, subthemes, and related quotes were subsequently translated into English to be included in this publication.

*Step 2: Results*

The themes that emerged in the focus group interviews covered a wide range of perspectives on the use of technology when living with dementia. For an overview of these themes and subthemes, see Table 2. These themes

serve as headlines of the results and related quotes below and it is indicated whether a person with dementia (P) family caregiver (C) or staff (S) is quoted.

Individual Approaches to the Use of Technology

Various approaches to the use of technology were discussed, underlining the broad range of individual preferences and needs. Both the common need and wish to use technology as an integrated part of modern life and the opposite, a preference for nontechnological solutions, was discussed.

P: "I try to use technology in the same as I have always done, it is necessary in so many ways nowadays." (The participant explains that it is necessary to use technology for example to communicate with public authorities and to access e-banking.)

P: "With a paper diary it is easier to get an overview – you can sort of see everything at the same time … whereas with technology … you have to shut down and open up (programmes and apps) ... and you forget what you were doing."

Technology's Influence on Self-Management

Participants gave examples of how technology can positively influence coping and self-management when living with dementia:

P: "I often forget to take my pills in the evening. Or I did … now I set an alarm in my phone…it reminds me."

P: "You can put the appointment in (the calendar) … then you can always find it. Those calendars are quite smart."

There were also examples of how a mandatory use of technology can limit access to society and services, and how specific technology features can obstruct access. For instance, the use of access codes seemed generally frustrating:

P: "You have access codes for everything ... even if I just want to look at special offers at the supermarket website … it's a nightmare. And then if you forget the code … you can ask for a new password, but you then have to remember your username, and if you can't you're lost."

The growing demand to use web-based solutions to access services was also part of these discussions:

P: "My sister tells me that I should order my medicine through the web-site instead of calling (the doctor's secretary) and being on hold for ages. But I can't, and I'm just not able to learn how to do it."

Some participants explained how these experiences often led to the feeling of inadequacy and incompetence when using technology:

P: "I get so frustrated … I cannot learn how to do it … I have tried, but it just goes into a muddle."

P: "… then I tell my brain to slow down and not get too confused…but it doesn't understand … and it just gets worse. Then I turn it against myself ... and I withdraw."

Some also gave examples of how technology tailor-made for people with cognitive disability had features that made them feel stigmatized:

P: "I was so happy when I found out how to turn off the sound on my GPS … for a long time the whole village could hear when I came riding on my bike…arguing with that nagging woman." (Referring to the device voice).

C: (Talking about using cognitive training games on a touch-screen computer, participants describe them as oversimplified and childish) " … there is a need for some (games) that are relevant for adults."

Special Needs when using Technology

Education and support when using technology was one of the special needs of people with dementia that was highlighted during the discussions:

P: "It would be nice to have somewhere to go when things don't work, some person you could go to."

P: "I have a son who can fix these things, he can sort things, so I cannot fiddle with it and that makes me feel comfortable."

P: "Then you know … your community support worker comes in 2 weeks, and she can help you, but that is not useful. There has to be someone who can help right now."

Also, family caregivers put forward their needs for education on how to assist and support the use of technology:

C: "… it is important that you know what to do … when you are so close (to the person with dementia) it can be difficult … So, I would find it useful to have someone explain exactly how to do it."

The special needs of people with dementia caused by cognitive symptoms were stated as an essential issue to address if technology should be usable.

P: "We need something that isn't too confusing, things that are manageable."

P: "It is important … to maintain your identity … that you have a calendar which you can manage."

Special Features of Technology

The request for individualized and adaptable technology was highlighted when talking about designing technology for people with dementia:

P: "I think a good calendar is a calendar which can be set-up to be exactly how you want it."

S: "The possibility to choose solutions … that is what's important."

The need for reliable and efficient technology was also stressed:

P: "I love my GPS, but it is terrible when it crashes … it is so important that it is reliable."

P: "It has to be working from day one and it must be flawless … I know it's a high demand."

Perspectives and Wishes for Future Technology

Participants put forward specific ideas and wishes for future technology. Among these were various examples stressing the wish for more user-friendly technology. One example of user-friendly technology was to have holistic solutions that could combine multiple functionalities. It was also suggested that integration of various functionalities between apps could relieve the troublesome process of transferring information, for example, when looking up a contact person's address in a contact app and having to manually add this to an appointment in a calendar app, it was suggested that technology could provide a smarter solution. More specific ideas were also put forward. One example was the use of photos as a supplement to text and thereby support memory and communication. It was also suggested that integrating voice recognition could relieve users of typing text. Another idea was that technology could provide alternative ways to indicate time of the day that would be easier to understand for a person with dementia, for example, monitoring time of the day on a line.

Ethical and Human Right Issues

Ethics and human right issues were also discussed. Privacy was a main subject, and the wish for privacy was discussed in contrast to exposing private matters, for instance in situations where they needed assistance and support from professionals to use technology. This dilemma was considered unavoidable, but the participants in general relied on the ethics and confidentiality of professionals.

P: "… we have this disease, and we need help … that's the way it is, so we have to give permission that someone comes and helps us with our calendar … and the people who come and do this … well, they are bound to maintain privacy."

Issues on equal rights and access to technology were also discussed, and participants argued for the request to give technology the same status as other assistive devices when it comes to accessibility and support:

P: "If you have a wheelchair and it breaks down you get a new one (assistive devices are provided by the public sector in Denmark). When my GPS broke down I could not get a new one. So, I was lost, and I could just sit back home and do nothing for 3 weeks."

### Step 3: Benchmarking Existing AT Solutions

The third step was a product benchmarking process, which was conducted to gain an overview and analyze state-of-the art of existing solutions. Benchmarking is a multifaceted technique widely used in many organizational and business contexts to support innovation and enhance operational efficiency and effectiveness [20]. In this study, the benchmarking process was conducted to identify potential advantages and gaps of current solutions to further qualify the app design process.

In steps 1 and 2, end-users had emphasized the need to support memory as essential to self-management, and consequently products promoted to meet such needs were the focus of this benchmarking process.

*Step 3: Methods*

Procedure

An explorative search was conducted in January 2016 to identify apps and other software products that were accessible in Denmark and therefore could be reviewed. A search was conducted in Apple's App Store [21] and Google Play [22], and a Danish online catalogue of assistive technologies was searched [23] to explore other software solutions that were not designed as apps.

The following search terms were used independently: Dementia, memory, and calendar. Both English terms and the equivalent Danish terms were used in both app stores. Only products that were promoted to support memory and mentioned people with dementia as potential users were included. Products that were not within this scope, for example, products targeting cognitive training, testing of cognitive functions, information about dementia, or support for caregivers, were excluded. The benchmarking process was not intended to be a systematic review, but an overview of features and designs in current solutions promoted for people with dementia. However, a Google Scholar search was conducted to explore if any of the identified solutions were associated with any research activity.

Data Analysis

The solutions that were identified were analyzed based on information that was provided by developers in the app stores and the online catalogue at the current time. If

available, websites describing the solutions were also accessed, to collect additional information. Due to copyright issues and later modification of products and product information, it is not possible to include specific references.

*Step 3: Results*

The search in app stores and the online catalogues of assistive technologies did not identify any solutions that were specifically designed for people with dementia. However, we did identify 3 solutions that were promoted as applicable for people with dementia, but not exclusively. They were also promoted as suitable for other groups of people with cognitive symptoms (e.g., caused by ADHD, autism, or brain injury). These were an app and 2 series of tailor-made software packages that could be applied on a small variety of smart phones and tablets.

A calendar was a key functionality in these 3 solutions, and other features were, for instance, reminders, individualized activity guiding, and picture messages. The design of these products was in general characterized by simple layouts, use of symbols, pictograms, photos, and a few contrasting colors. There was no documentation available to specify if and how the solutions were designed, tested, or validated in relation to people with dementia or other potential end-users, and the Google Scholar search did not identify any scientific publications in relation to the solutions.

### Step 4: The Iterative User-Involving Design Process

In the fourth and final step, the ReACT app was designed based on an iterative user-involving design process. As illustrated in Figure 1, the perspectives and ideas for functionalities and design were based on the results of the previous 3 steps, and in this fourth step, the functionalities and the layout of the app were discussed and gradually developed during the workshops.

The app was produced in a public–private innovation partnership-involving professionals with expertise on dementia from the public partner and experts on app development from the private partner.

To reach a manageable diversity in the design scope, it was decided to focus on the needs and perspectives of community-dwelling people with early-stage Alzheimer's disease as the primary target group for the app. Consequently, people matching this profile and their family caregivers were recruited to participate in the design process. Also, the professional caregivers participating in the process were instructed to base their views and advice on this subgroup.

*Step 4: Methods*

Participants

Four dyads of people with early-stage Alzheimer's disease and their closest relative were recruited from the memory clinic at Danish Dementia Research Centre, and 4 professional caregivers were recruited from the research center's network of dementia specialists. To have the richest possible dialogue and feedback during the design process, it was essential for all participants to be familiar with the use of touch screen technology. The characteristics of participants are included in Table 1.

Procedure

The 5 workshops that were conducted during the iterative design process are illustrated in Figure 1.

The first workshop only involved the professionals. The aim of this workshop was to initiate the design process by identifying user scenarios, user journeys, flows, and scopes and limits of the app. To introduce the perspectives and needs of end-users, and to the begin narrowing down the scope and features of the ReACT app, the workshop was initiated with a condensed overview of the results from steps 1, 2, and 3. Material for the successive workshops was based on the results of this workshop.

This first workshop was followed by 2 sets of parallel workshops with separate groups of end-users: 1 group included people with early-stage Alzheimer's disease and family caregivers and the other group included professionals. The workshops were conducted with separate groups to adapt the setting and discussion to the needs of the participants. The workshops with professionals were more extensive and included discussions on complex design and technical issues that were difficult to access for nonspecialists. The first set of parallel workshops focused on user-flows and ideas for design. In the second set of parallel workshops, the design of the app was discussed and validated.

The workshops were conducted at the Danish Dementia Research Centre and were facilitated by the first author and a coworker (expert on communication and technology).

Data from the workshops were collected as notes and illustrations on flip charts. The workshops were also audio recorded, but recordings were not transcribed, they were used to support note-taking if necessary.

*Step 4: Results*

The result of the iterative innovation process is the ReACT app, and the design and functionalities of the app are illustrated in Figure 2. The app is a holistic solution with a calendar as a main framework for the multiple integrated and interacting functionalities: diary, checklists, and contacts. As described in Figure 2 the various special features of the app are tailor-made to meet the needs of end-users that were pointed out by participants during the various steps of this study. Moreover, the app can be adapted to individual preferences, needs, and skills; this is done by editing various features in the "Settings" menu. This includes the possibility to select individualized default settings and selecting/deselecting the various functionalities of the app. The app works in overlays and animations were added to support memory, structure, orientation to current time, and the flow within and between functionalities.

The ReACT app is a native cloud-based app that enables caregivers to have parallel access to the app, and both view, add and edit information, and thereby giving people with dementia access to support from caregivers when using the app.

## Discussion

The ReACT app was designed to comply with the request for AT that genuinely reflects and meets the self-management needs of people with dementia.

The perspectives and needs of the end-users were essential throughout the 4 iterative steps presented in this paper, which led to the final design of the app: In the initial step, the explorative pilot study revealed the potential benefits and challenges of using apps to support self-management when living with early-stage dementias. In the second step, focus-group interviews provided varied perspectives on the use of technology to support self-management of people with dementia. In the third step, a product benchmarking process served to further qualify the design process. Finally, the results from these first 3 steps served as a basis for the fourth step, where the ReACT app was designed through an iterative process with direct user-involvement. The 4 steps are illustrated in Figure 1.

Results from the pilot study in step 1 and the focus group interviews in step 2 underlined the request for AT, for example, apps, tailor-made for people with dementia and this was supported by the results from the product benchmarking process in step 3, where very few existing solutions promoted as suitable for people with dementia were identified. These solutions were not specifically developed for people with dementia and no specified information was provided regarding end-user involvement in the design process and testing. This lack of user-involvement when designing and testing AT for people with dementia has been highlighted in several position papers and reviews, all advocating the strong need for user-involvement to promote applicability and acceptability of AT [9, 13, 24, 25].

The solutions that we identified in the benchmarking process were also promoted without any evidence for effectiveness and applicability for people with dementia, and this is in line with the observation of a general lack of evidence for the effectiveness and cost-effectiveness of AT solutions for community-dwelling people with dementia [8, 9]. Designing and deploying AT solutions for people with dementia is a new and fast expanding field, and large investments are being made, but this is apparently based on very limited evidence, which is in striking contrast with the demand for evidence-based solutions when considering pharmacological and other nonpharmacological solutions for people with dementia [2].

The involvement of end-users in the ReACT study facilitated various decisions during the study. Initially, the decision to develop software technology for an off-the-shelf touchscreen device in the ReACT project was based on the positive results from both steps 1 and 2. Participants and caregivers in the explorative pilot study generally appreciated the accessibility and usability of the touchscreen devices and the apps. Accessibility and usability were also discussed as essential for initiating and maintaining use of technology in the focus-group interviews. This preference for touch-screen devices is in line with the results of other studies, emphasizing the intuitive interface, user-friendliness, adaptability, and multifunctional nature of such devices [26, 27].

The results from steps 1 and 2 also led to the selection of the specific touch-screen device used in the study. For practical reasons, it was necessary to build the ReACT app for one specific hardware device during the design and test phase. The selection of hardware device was not based on actual tests comparing different hardware solutions; however, the Apple tablet (iPad) was found user-friendly both by people with dementia and caregivers in step 1, and users who had no previous experience with tablet computers learned to use an iPad in this pilot study. This selection of device was also supported by the fact that iPads are the most commonly used tablets in Denmark [28]. Based on these findings, it was decided that the Re-

## FUNCTIONALITIES AND FEATURES OF THE ReACT APP

### CALENDAR

**Orientation to time:** Current time is always indicated by a pulsating "now" in the calendar and the user can go back to current time by pushing "show now".

**Several adaptable reminders:** Three reminders can be added and adapted: time to get ready, time to leave the house, time when the appointment starts.

**Easy access to contact details:** Contact details can automatically be added from existing contact. This also includes access to maps, enabling navigating to the contact persons address.

### DIARY

**Supporting retrograde memory of activities and people involved in these activities:** Photos, text and contact details can be added in diary notes.

### CHECKLISTS

**Personalised checklists to support memory of both routine and new tasks:** Photos and a 'tick off list' of items can be created, e.g. 'What do I need to remember when I leave my house?'

These check-lists can be added to appointments in the calendar and pops up with the first reminder.

### MEMOS

**A memo list supports anterograde memory for various to-do's and things to remember in the future.**

**Retrograde memory is also supported:** When pushing "done" the memo goes into the calendar to visualise that it has been completed.

### CONTACTS

**Easy access to contacts details:** Contacts can be added with all relevant details, including photos to support memory.

**Overview of activities with a contact person:** All activities with a contact can be viewed on a timeline.

**Reminders of birthdays and other special days:** These special days are automatically added and marked in the calendar for contact persons, including a photo of the person.

### SETTINGS

**Tailoring the app:** Various functionalities of the app can be tailored. In settings the preferred default settings can be selected individually to fit the user, e.g. calendar view (8 hour or week), time intervals for reminders and which functions in the app should be used and hence visible on the menu-bar.

**Simplifying the app:** All functions on the menu-bar can deselected. Then the user can just view the information in the app and leave editing to caregivers.

**Caregiver support:** The app is web-based, and a caregiver can add and edit information when accessing the user's personal app-account from their own device.

**Fig. 2.** Functionalities and features of the ReACT app.

ACT app should be built for iPads. The preference for iPads by people with dementia is also supported by other studies [27, 29], emphasizing the user-friendliness and intuitive interface of these specific devices. In future dissemination of the app, it should of course be provided for a variety of touchscreen hardware, to meet the individual preferences of end-users.

Results from both the pilot-study and focus group interviews in steps 1 and 2 indicated the potential benefits of using apps to support self-management when living with dementia. More specifically, the need to support both prospective and retrospective memory in daily living was put forward as essential to self-management by both people with dementia and caregivers. This is in line with other studies documenting that people with dementia experience unmet needs in relation to memory support [30, 31], and support of memory and other cognitive functions have been described as essential in relation to the wish for self-management [29]. The potential of using AT to support people with dementia when coping with the consequences of cognitive symptoms, and thereby support self-management in everyday life, has also been discussed and confirmed by others [9, 15, 29].

Based on the results from our pilot study and focus group interviews a calendar seemed to be the essential part of the solution that most end-users requested. The products that were identified in the benchmarking process were also based on various approaches to designing a calendar solution. In addition to a calendar system, the need for a holistic solution was also pointed out in both steps 1 and 2. In the focus-group interview, it was discussed how features of various programmes/apps could be integrated and thereby relieve the troublesome process of manually transferring information, which sometimes led to abandonment of technology. It was also suggested that solutions which could integrate various features such as personal photos and voice recognition were useful to support memory and other cognitive functions. The advantages of designing holistic solutions for people with dementia have also been emphasized in other studies [32, 33]. As a result, the ReACT app was designed as a holistic solution, using a calendar as a main framework and integrating a variety of functionalities that were emphasized by end-users as essential to support self-management in their everyday life. This led to the functionalities, and interaction between functionalities, that are described in Figure 2.

However, the effects of using electronic memory aids for people with dementia have until now been sparsely explored by a small number of studies with limited generalizability [15, 34]. Further studies in the ReACT project will address the usability and effect of applying this kind of AT to people with dementia.

Our initial explorative pilot study revealed that apps that are tailor-made and adaptable to fit individual needs and preferences for people with dementia are requested. The debates in the focus-group interviews also underlined the broad range of individual preferences and needs that should be addressed when designing AT for people with dementia. The adaptability of AT to meet the heterogeneousness of people living with dementia has also been requested by others [26, 35, 36]. Ideally, the adaptability should comply both with the varied needs and individual preferences of people with dementia and with the change in these individual needs caused by the nature of progressive dementia diseases. To meet these requirements, the ReACT app was made adaptable by enabling individualized default settings in various features of the app and by the option to deactivate functions, as described in Figure 2.

Results from both steps 1 and 2 underlined the general need for education and support of people with dementia when using technology. In the pilot study, participants generally found setting up and updating software unmanageable, and requested support for this, and the need for continued education and support was also discussed in the focus-group interviews. These need for support and education have also been discussed by others [9, 37, 38]. To meet these needs, the ReACT app was designed as a web-based solution, which allows access to a user's personal app account from various devices, and this can facilitate caregiver support, even at a distance. Furthermore, the needs for education and support will be addressed in the subsequent studies of the ReACT project, which will address the equally important issues of deployment and adoption of AT to people with dementia [13, 39].

The design and methods of this study caused some limitations. One limitation was that participants in the sub-studies were recruited through convenience sampling. The intention was to include a wide variety of people with early-stage dementia from various settings, but this resulted in a neglect of people with dementia who do not take active part in regular activities for people with dementia or are not in close contact with a memory clinic. Processing of data also implied potential limitations. Coding of data, checking of coding, analysis, and translation of interviews were conducted by only one researcher and this could have been added more rigor if additional

researchers had been involved. Also, the splitting of workshops into 2 parallel groups in step 4 could be a potential limitation, since the benefits of directly combining views of end-users and professionals could be missed. The groups were split during the workshops to adapt the codesign process to the participants' needs, for example, spare the end-users the more extensive discussions on complex design and technical issues. The ReACT study was not designed to be a participatory study, but we found it highly beneficial to have end-users participating as codesigners in the iterative design phase [24]. We find that general principles of user-centered system design [40] can be directly applied when designing AT for people with dementia and should be applied. This framework considers end-users at each stage of the design process and actively involves users throughout the entire development process and system lifecycle [40]. However, conducting research in relation to design and creation of technology such as apps does imply issues that are highly complex, and it can be challenging to modify and adapt all research issues to be adequately dementia friendly. Based on these considerations, we find that conducting genuine participatory research when designing AT for people with dementia does imply specific challenges that have to be addressed in future studies.

## Conclusion

The ReACT app was designed to support the needs of people with dementia in relation to self-management. The app was designed through an extensive iterative user-involving process where we identified a request for a holistic and adaptable solution with main features supporting memory in daily living.

The usability and applicability of the app are promising, since the app functionalities and design are directly based on user needs and perspectives. However, the app will be tested by end-users in further studies of the ReACT project, to see if adaptions are needed. Further studies will also address the equally important request for methods to promote deployment and adoption of AT tailor-made for people with dementia.

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## Statement of Ethics

The study protocol was evaluated by the regional scientific ethical committees of The Capital Region of Denmark (protocol number H-15005558), where it was decided the study did not need approval, since it was not considered to be within the framework of biomedical research.

All participants received oral and written information about the overall study objectives and the details of the specific step they participated in. They all gave written informed consent.

## Disclosure Statement

The authors have no conflicts of interest to declare.

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## Author Contributions

The corresponding author was involved in all aspects of conceptualizing and designing the study, the acquisition of data, and the analysis and interpretation of data. All authors made substantial contributions to designing the study and were involved in writing the manuscript. All authors have read and approved the final manuscript.

## References

1 WHO. Global action plan on the public health response to dementia 2017–2025. 2017. [Cited Dec 3, 2018]. Available from: http://apps.who.int/iris/bitstream/handle/10665/259615/?sequence=1.
2 Winblad B, Amouyel P, Andrieu S, Ballard C, Brayne C, Brodaty H, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. Lancet Neurol. 2016 Apr;15(5):455–532.
3 Moniz-Cook E, Vernooij-Dassen M, Woods B, Orrell M; Interdem Network. Psychosocial interventions in dementia care research: the INTERDEM manifesto. Aging Ment Health. 2011 Apr;15(3):283–90.

4 Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. Dement Geriatr Cogn Disord. 2010;30(2):161–78.
5 ADI. Bibliography of References to National Plans. 2016 [Cited Dec 3, 2018]. Available from: https://www.alz.co.uk/sites/default/files/pdfs/national-plans-bibliography-2016.pdf.
6 Assistive Technology Industry Association. 2018 [Cited 2018 Dec 3]. Available from: http://www.atia.org/at-resources/what-is-at/.
7 Asghar I, Cang S, Yu H. Assistive technology for people with dementia: an overview and bibliometric study. Health Info Libr J. 2017 Mar;34(1):5–19.
8 Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia. 2016 Jul;15(4):681–701.
9 Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR Rehabil Assist Technol. 2017 Jan;4(1):e1.
10 Van der Roest HG, Wenborn J, Pastink C, Dröes RM, Orrell M. Assistive technology for memory support in dementia. Cochrane Database Syst Rev. 2017 Jun;6:CD009627.
11 Bennett B, McDonald F, Beattie E, Carney T, Freckelton I, White B, et al. Assistive technologies for people with dementia: ethical considerations. Bull World Health Organ. 2017 Nov;95(11):749–55.
12 Ienca M, Jotterand F, Elger B, Caon M, Pappagallo AS, Kressig RW, et al. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. J Alzheimers Dis. 2017;56(4):1301–40.
13 Kenigsberg PA, Aquino JP, Bérard A, Brémond F, Charras K, Dening T, et al. Assistive technologies to address capabilities of people with dementia: from research to practice. Dementia. 2017 Jan:1471301217714093.
14 Zwijsen SA, Niemeijer AR, Hertogh CM. Ethics of using assistive technology in the care for community-dwelling elderly people: an overview of the literature. Aging Ment Health. 2011 May;15(4):419–27.
15 King AC, Dwan C. Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. Dementia. 2017 Jan:1471301217735180.
16 Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M; Medical Research Council Guidance. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008 Sep;337:a1655.
17 McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. Neurology. 1984 Jul;34(7):939–44.
18 Thomas DR. A general inductive approach for analyzing qualitative evaluation data. Eval Pract. 2006;27(2):237–46.
19 Leech NL, Onwuegbuzie AJ. An array of qualitative data analysis tools: a call for data analysis triangulation. Sch Psychol Q. 2007;22(4):557–84.
20 Yasin MM. The theory and practice of benchmarking: then and now. Benchmark Int J. 2002;9(3):217–43.
21 Apple Itunes App store. [Cited June 1, 2016]. Available from: https://itunes.apple.com/dk/genre/ios/id36?mt=8.
22 Google Play Apps. [Cited June 1, 2016]. Available from: https://play.google.com/store.
23 Denmark AT. [Cited June 1, 2016]. Available from: https://hmi-basen.dk/en/.
24 Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in the development of supportive IT applications: a systematic review. Ageing Res Rev. 2013 Mar;12(2):535–51.
25 Topo P. Technology studies to meet the needs of people with dementia and their caregivers: a literature review. J Appl Gerontol. 2009;28(1):5–37.
26 Joddrell P, Astell AJ. Studies involving people with dementia and touchscreen technology: a literature review. JMIR Rehabil Assist Technol. 2016 Nov 4;3(2):e10.
27 Lim FS, Wallace T, Luszcz MA, Reynolds KJ. Usability of tablet computers by people with early-stage dementia. Gerontology. 2013;59(2):174–82.
28 World C. Nye danske data afslører: Her er de mest populære smartphones i Danmark 2016. [Cited Dec 1, 2016]. Available from: https://www.computerworld.dk/art/238637/nye-danske-data-afsloerer-her-er-de-mest-populaere-smartphones-i-danmark.
29 Kerkhof Y, Bergsma A, Graff M, Dröes R. Selecting apps for people with mild dementia: identifying user requirements for apps enabling meaningful activities and self-management. J Rehabil Assist Technol Eng. 2017;4:2055668317710593.
30 Miranda-Castillo C, Woods B, Orrell M. The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey. BMC Health Serv Res. 2013 Feb;13(1):43.
31 van der Roest HG, Meiland FJ, Comijs HC, Derksen E, Jansen AP, van Hout HP, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. Int Psychogeriatr. 2009 Oct;21(5):949–65.
32 Boman IL, Persson AC, Bartfai A. First steps in designing an all-in-one ICT-based device for persons with cognitive impairment: evaluation of the first mock-up. BMC Geriatr. 2016 Mar;16(1):61.
33 Meiland FJ, Hattink BJ, Overmars-Marx T, de Boer ME, Jedlitschka A, Ebben PW, et al. Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European Rosetta project. Int Psychogeriatr. 2014 May;26(5):769–79.
34 Imbeault H, Gagnon L, Pigot H, Giroux S, Marcotte N, Cribier-Delande P, et al. Impact of AP@LZ in the daily life of three persons with Alzheimer's disease: long-term use and further exploration of its effectiveness. Neuropsychol Rehabil. 2018 Jul;28(5):755–78.
35 Ancient C, Good A. Considering people living with dementia when designing interfaces. In: Marcus A, editor. Design, User Experience, and Usability. User Experience Design Practice. DUXU 2014. Lecture Notes in Computer Science. Volume 8520. Cham: Springer; 2014. pp. 113–23.
36 Egan KJ, Pot AM. Encouraging innovation for assistive health technologies in dementia: barriers, enablers and next steps to be taken. J Am Med Dir Assoc. 2016 Apr;17(4):357–63.
37 Dewar BK, Kapur N, Kopelman M. Do memory aids help everyday memory? A controlled trial of a Memory Aids Service. Neuropsychol Rehabil. 2018 Jun;28(4):614–32.
38 Kerkhof YJ, Graff MJ, Bergsma A, de Vocht HH, Dröes RM. Better self-management and meaningful activities thanks to tablets? Development of a person-centered program to support people with mild dementia and their carers through use of hand-held touch screen devices. Int Psychogeriatr. 2016 Nov;28(11):1917–29.
39 Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. J Med Internet Res. 2017 Nov;19(11):e367.
40 Gulliksen J, Göransson B, Boivie I, Blomkvist S, Persson J, Cajander Å. Key principles for user-centred systems design. Behav Inf Technol. 2003;22(6):397–409.

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# Self-management and cognitive rehabilitation in early stage dementia – merging methods to promote coping and adoption of assistive technology. A pilot study

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**ABSTRACT**

**Objectives:** It is essential to develop interventions that meet individual needs for coping and self-management of people with dementia. This study explored the feasibility and applicability of an intervention merging methods of cognitive rehabilitation and self-management groups for people with early stage dementia. The potential of this intervention to promote adoption of assistive technology was also explored.

**Method:** People with early stage Alzheimer's disease (N = 19) participated in the programme comprising both individual and group sessions. Caregivers were involved in the individual session and a separate group meeting. The intervention both addressed individual goals and more general self-management approaches. In addition, both participants and caregivers were introduced to the ReACT app, a holistic solution tailormade to meet self-management needs of people with early stage dementia.

**Results:** There was significant improvement in the participants' attainment of individual goals and satisfaction with goal attainment from pre- to post-intervention. Participants and caregivers generally reported a positive attitude towards the intervention, attendance rate was high, and all participants completed the intervention. Qualitative results also indicated that the intervention promoted awareness, acceptance and coping among participants. The specific benefits of using the ReACT app for self-management were also emphasised. Forty-two percent of the participants adopted the app and continued using it after completing the intervention.

**Conclusion:** Results from this pilot study indicated that the intervention is both feasible and applicable and can be an effective method to promote coping and adoption of assistive technology among people with early stage dementia.

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## Introduction

The number of people living with dementia world-wide is fast growing and this generates an increasing demand for adequate and affordable solutions to meet the needs for support and care of those affected by dementia. Neurodegenerative dementia diseases cause progressive cognitive and functional decline, but the consequences of these symptoms can be reduced through timely and suitable interventions (Olazarán et al., 2010). It is essential that we develop and adopt interventions to support independence, quality of life and well-being of people living with dementia and to reduce the impact on supporters and society in general.

Various forms of assistive technology (AT) have potential to support cognitive functions and thereby promote self-management and functional independence of people living with dementia (King & Dwan, 2017; Meiland et al., 2017; Van der Roest, Wenborn, Pastink, Droes, & Orrell, 2017), and the number of AT solutions offered to people with dementia is fast increasing (Asghar, Cang, & Yu, 2017; Gibson et al., 2016). However, to provide adequate, efficient and evidence-based AT solutions for people with dementia there are several issues that need to be further addressed through research. Among these is the crucial need to find applicable and effective methods to deploy and adopt AT, bringing it into people's everyday life (Kenigsberg et al., 2017; Meiland, et al., 2017).

To identify such applicable and effective methods, we can consider other successful methods of promoting self-management and coping among people with dementia and here both self-management groups (Quinn, Toms, Anderson, & Clare, 2016) and individualised reablement programmes (Poulos et al., 2017) seem relevant and applicable. They each represent different approaches to positive support and empowerment of people with dementia. Self-management groups target self-efficacy in a broader sense, addressing cognitive, psychological and social functioning,

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by combining elements like psychoeducation, problem solving and coping skills training (Mountain & Craig, 2012; Quinn et al., 2016). The group setting also promotes the benefits of sharing, socializing and learning from people in a similar situation, which is often put forward by people with dementia when expressing their preferences in relation to psychosocial interventions (Toms, Quinn, Anderson, & Clare, 2015; Øksnebjerg et al., 2018). Compared to this, reablement interventions, e.g. programmes of goal-oriented cognitive rehabilitation, target self-management from a person-centred and individualised approach (Clare, 2017; Poulos, et al., 2017). Both Self-management groups (Laakkonen et al., 2016; Martin et al., 2015; Quinn et al., 2016) and individualised reablement programmes (Clare, 2017; Clare et al., 2010; Hindle et al., 2018) have proven to be well suited as post-diagnostic interventions for people with early stage dementia, and effective ways to adopt coping strategies and compensatory aids and tools.

To the best of the authors' knowledge, the potential of combining methods from group-based self-management programmes and individualised reablement methods into a group-based cognitive rehabilitation programme for people with early stage dementia has not been explored in any intervention studies. Integrating these methods could promote self-management, empowerment and coping skills by combining a person-centred and individualised approach with the benefits of peer-support and meaningful social activities. Furthermore, the possible benefits of deploying and adopting the use of AT though such a programme has not been explored. Such an integrated programme could reinforce the use of AT by offering a structured intervention involving both education and support from staff, and inspiration and support from peers.

The pilot study described in this paper is part of the research project ReACT (Rehabilitation in Alzheimer's disease using Cognitive support Technology), which comprises a range of interacting components (Øksnebjerg, Woods, & Waldemar, in press). Consequently, the study design is based on the principles of the Medical Research Council (MRC) framework for the development and evaluation of complex interventions (Craig et al., 2008).

The development of the specific AT used here, the ReACT app, has been reported elsewhere (Øksnebjerg et al., in press). It was tailormade through an iterative user-involving process to meet the self-management needs of the end-users, people with early stage Alzheimer's disease. The app was designed as a holistic solution, with a calendar system as a main feature, and combines a range of functionalities, mainly supporting various aspects of prospective and retrospective memory (ibid). The app was designed to be used on a touch screen tablet computer (iPad).

The aim of the current pilot study was to examine the feasibility and applicability of a group-based goal-oriented rehabilitation programme for people with early stage Alzheimer's disease, and to explore if such a programme can be a suitable and effective way to deploy and adopt AT. In addition, the study also aimed to explore outcome measures that capture the aims of the intervention, to inform planning of future large-scale studies.

## Methods

### Participants

The study was conducted in three Danish memory clinics and participants were recruited from these clinics. Potential eligible participants who met the inclusion criteria were offered a short oral introduction to the study and written information when visiting the memory clinic, and they were subsequently contacted by telephone and invited to a screening interview with the staff conducting the intervention. Inclusion criteria were a clinical diagnosis of Alzheimer's disease according to the NIA-AA criteria for probable Alzheimer's disease (McKhann et al., 2011) within the last 12 months, a Mini-Mental State Examination (MMSE) score of 23 or above (Folstein, Folstein, & McHugh, 1975) to include those with a mild degree of dementia, stability of prescribed anti-dementia or anti-depressant medications (stable doses at least one month prior to the start of the intervention), and they should be Danish-speaking. Exclusion criteria were severe psychiatric symptoms (e.g. severe depressive or psychotic symptoms), substance abuse, or a visual or hearing disability that could impede participation in the group-based activities or the use of a tablet computer. Participants were also required to have a caregiver who could support their participation in the programme. A caregiver was defined as a family member or a friend with whom they had face-to-face contact at least once a week. Since people with dementia were the primary participants in the intervention they are subsequently referred to as participants and the co-participating family caregivers are referred to as caregivers.

Twenty-four potential participants and their caregivers accepted the invitation to the screening interview. One participant withdrew after the screening interview and three more withdrew after the consecutive baseline visit. They all stated that they found the intervention programme too extensive. Twenty participants were enrolled, and all completed the intervention programme, but one participant died from an unrelated acute disorder before the final assessment. Hence data from nineteen participants could be analysed after the conclusion of the study. The study was conducted between December 2016 and June 2017.

### Procedure

As illustrated in Figure 1, the intervention programme included both individual and group-based activities and it was conducted over a period of 13 weeks.

Group sizes varied between three to seven participants. All activities were conducted by a clinical neuropsychologist, and two neuropsychologists were present at the group session, except in one group, where a neuropsychologist was assisted by a nurse specialised in dementia care.

There were two individual sessions with patient-caregiver dyads at the start of the programme and one individual session at the end of the programme. The two initial sessions were conducted with two objectives. The first objective was to identify the participants' individual goals for the rehabilitation programme, in a collaboration between the participant, caregiver and staff. As outlined in

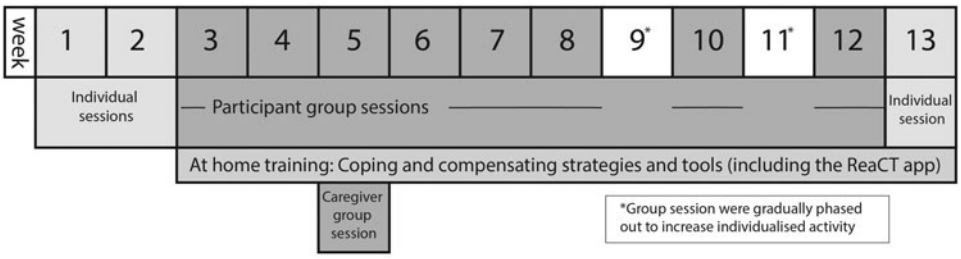


**Figure 1.** Activities during the intervention programme.

the outcome measures section, a Danish version of the Bangor Goal Setting Interview (Clare et al., 2012) was used to define and assess these individual goals. The participant was encouraged to select a minimum of one and a maximum of three individual goals to be addressed during the programme. Participants and caregivers were of course informed that they would be introduced to the use of the ReACT app during the programme, but it was emphasised that it was not mandatory to define individual goals related to the use of the app. During the sessions there was also discussion of how the individual goals could be supported and achieved during the programme. The second objective of the individual sessions was to provide an introduction to the tablet and the ReACT app for the participant and the caregiver, and to provide initial instructions, support and inspiration of how to use the app.

At the individual session at the end of the programme the objectives were to carry out a final evaluation of the participants' individual goals and to support continued activities related to these goals if relevant. The participants and caregivers who wanted to continue using the ReACT app after the programme were also given advice on this and information on post-intervention support. Between these individual sessions the participants attended eight two-hour weekly group sessions and caregivers attended one two-hour group session for caregivers.

The group sessions for participants comprised components from self-management group interventions (Quinn et al., 2016) including psychoeducation related to living with early stage Alzheimer's disease and solution focused approaches to challenges in everyday life, including training of coping and compensation skills. The themes and activities were planned to target the participants' individual goals, and the sessions included both group discussions and individualised activities. The use of the ReACT app as a compensatory tool was introduced as a potential solution when relevant, but using the app was not mandatory for participants. Between sessions participants were encouraged to practise coping and compensation skills at home, including the use of the app when relevant.

The session for caregivers provided information on the topics included in the group sessions for participants, and caregivers were also given advice on how to support transfer of knowledge and skills from the programme into home activities. During the entire programme the information presented to participants and caregivers was also made available in writing.

Both participants and caregivers had a tablet during the intervention programme with the ReACT app installed on it. Some off-the-shelf apps were also installed on the tablets, e.g. a news app, a weather forecast app, and an app for internet search. These were selected based on participants' preferences and results from a previous pilot study, where criteria for selecting dementia friendly off-the-shelf apps were addressed (Øksnebjerg et al., in press). To reduce the complexity of operating the tablet a tailored device management system was installed on all the tablets, enabling the study team to simplify the layout of the screens and manage updates of the devices and apps. Participants and caregivers who wanted to continue using the app after the programme could choose whether to continue using the device from the study or have the ReACT app installed on a private device.

## Outcome measures

Baseline and post-intervention outcome measures were obtained before and after the intervention programme. Post-intervention measures were obtained within two weeks after finalising the programme. Demographic information for both participants and caregivers was collected at baseline. Outcome measures were selected to capture the potential impacts of the intervention programme and to identify possible differences between participants who adopted the ReACT app during the intervention and continued using the app after the intervention (adoptors) and those who did not adopt the app (non-adoptors). Adoptors were defined as participants who continued using the app after finishing the intervention programme.

### *Primary outcome*

Goal attainment was evaluated using a Danish translation of the Bangor Goal Setting Interview (BGSI) (Clare et al., 2012). Participants' and caregivers' evaluation of goal attainment was assessed on a Likert scale ranging from 1 to 10, with 1 representing "Unable to carry out or perform task" and 10 representing "Able to carry out or perform task without difficulty". Participants' rating of satisfaction with goal attainment was also assessed on a Likert scale ranging from 1 to 10, with 1 representing "Extremely dissatisfied with attainment" and 10 representing "Extremely satisfied with attainment".

### *Secondary outcomes*

Capability-related well-being was measured with the ICECAP-O (Coast et al., 2008). Scores range from 0 to 1, with higher scores indicating better well-being.

Activities of Daily Living were assessed using the Bayer Activities of Daily Living Scale (B-ADL) (Hindmarch, Lehfeld, de Jongh, & Erzigkeit, 1998). The main target group of this scale is community dwelling patients who have mild cognitive impairment or mild-to-moderate dementia and the

scale is designed to be completed by a caregiver. The scale comprises 25 items and the caregiver was asked to rate if the participant had difficulty performing various daily activities on a 10-point Likert scale ranging from 1 "Never" to 10 "Always". The total score was divided by the number of items rated, to correct for items replied to as irrelevant, and the score was rounded to two decimal places, giving total scores ranges between 1.00 and 10.00.

Health-related quality of life was measured by the EQ-5D-5L (EuroQol Group, 1990) and responses were converted to an index value between –0.624 and 1 (Van Hout et al., 2012), with 1 representing best possible health-related quality of life. The visual analogue scale (EQ-5D VAS) was also included. It has a range of 0 to 100, with 100 representing best-imagined health. These two health-related quality of life scales were both administered to participants and, as a proxy, to caregivers.

Cognitive outcome measures included the Mini-Mental State Examination (MMSE) (Folstein, et al., 1975), Addenbrooke's Cognitive Examination ACE (Mathuranath, Nestor, Berrios, Rakowicz, & Hodges, 2000), list learning and visual memory tests from the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) (Randolph, Tierney, Mohr, & Chase, 1998). Symbol Digit Modalities Test (SDMT) (Smith, 1982), Trail A and B tests (Reitan, 1992), verbal fluency (number of animals and words beginning with S for 1 min) (Strauss, Sherman, & Spreen, 2006), and non-verbal fluency measured with the Five Point test (Lee, Loring, Newell, & McCloskey, 1994).

To obtain a nuanced evaluation of the feasibility and acceptability of the intervention programme a short semi-structured interview was conducted with both participants and caregivers during the final assessment. They were asked to give feedback on their experience of participating in the programme, and they were encouraged to give examples of both possible gains and needs or wishes that had perhaps not been met during the interventions. They were also invited to suggest changes to the programme that could be addressed in future studies. The data from the interviews were collected by note-taking.

Attendance rate was registered to support the assessment of acceptability.

To monitor the use of the ReACT app during the intervention log data was collected to monitor the operations in the app performed by both participants and caregivers.

The usability and applicability of the ReACT app was rated with a modified version of the USE Questionnaire (Usefulness, Satisfaction, and Ease of use) (Lund, 2001). To make the scale applicable for people with dementia it was adapted and reduced from 30 to 12 items. Scores on each item range from 1 to 5 on a Likert scale, with higher scores indicating higher ratings of usability and applicability. In this paper this version of the scale is referred to as the USE-dem questionnaire.

## Data analyses

Quantitative data were analysed using IBM SPSS Statistics v.22. Baseline characteristics were explored with descriptive statistics. Possible changes in outcome measures were investigated through non-parametric analysis of change scores (Wilcoxon signed rank test).

Possible differences between baseline characteristics of adoptors and non-adoptors of the ReACT app were analysed using the non-parametric Mann–Whitney U test or Fisher's exact test as appropriate. The variation in the two groups' use of the app during the intervention, assessed through log data, and their evaluation of the usability of the app, measured with the USE-dem questionnaire, were analysed using the Mann–Whitney U test. In addition, the changes in the two groups' outcomes on the BGSI from baseline to post-intervention were analysed using mixed-design analysis of variance (split-plot ANOVA).

Tests of significance were performed two-tailed, with a significance level of 0.05 and a Bonferroni correction was applied to correct for multiple comparisons. Imputed values for missing data were calculated following standard procedures for multiple regression modelling.

The qualitative data from the interviews was inductively processed and summarised in emerging themes and sub-themes, according to the principles of the Constant Comparison Analysis (Leech & Onwuegbuzie, 2007).

## Results

### *Participants*

The baseline characteristics for participants and caregivers are presented in Table 1. Most participants were female, their mean age was 67.5 years and their average education was 14.3 years. They were on average diagnosed 5.5 months before entering the study. Fifteen of the participants were living with their spouse, who participated as caregivers in the study. Four participants were living alone. One of them had a non-cohabiting partner and three of them had a friend who supported their participation in the study. Except for one participant, all the participants and caregivers were previous users of a smartphone and 12 of the participants and 11 of the caregivers were previous user of a tablet computer.

### *Impacts of the intervention programme*

Table 2 presents scores on outcome measures at baseline and post-intervention. Results show that there was a significant change in the participants' evaluation of goal attainment ($p < .001$) and satisfaction with goal attainment ($p = .001$), whereas the caregivers' evaluation of goal attainment did not change to a level that was statistically significant.

There were no statistically significant differences on the secondary outcome measures addressing well-being and level of performance in activities of daily living, however data did show a tendency towards an increase in participants' self-

**Table 1.** Baseline characteristics of participants and caregivers.

| | |
|---|---|
| Participants | |
| Age years, mean (SD) (range) | 67.5 (8.4) (52-79) |
| Sex female n (%) | 15 (79) |
| Years of education mean (SD) (range) | 14.3 (2.4), 8-17 |
| Time since diagnosis months, mean (SD) (range) | 5.5 (3.3) (1-12) |
| Previous smartphone user yes/no | 18/1 |
| Previous tablet user yes/no | 12/7 |
| Caregivers | |
| Age years, mean (SD) (range) | 67.3 (8.5) (51-83) |
| Sex (female n, %) | 8, 42% |
| Previous smartphone user yes/no | 19/0 |
| Previous tablet user yes/no | 11/8 |

**Table 2.** Changes in outcome scores from baseline to post-intervention.

| Measure (max score) | Baseline Mean (SD) (range) | Post intervention Mean (SD) (range) | *p*-value |
|---|---|---|---|
| BGSI attainment participants (10)[#] | 4.05 (1.51) (1–7.7) | 6.64 (2.26) (2.5–10) | .000* |
| BGSI attainment caregivers (10)[#] | 4.83 (2.35) (1-9.3) | 5.47 (2.43) (1–10) | .530 |
| BGSI satisfaction (10)[#] | 4.58 (2.06) (1-8.5) | 7.22 (1.97) (3-10) | .001* |
| ICECAP-O (1)[#] | 0.87 (0.08) (0.75-1) | 0.86 (0.07) (0.73-0.96) | .642 |
| B-ADL (10)[Δ] | 3.57 (1,96) (1.36-8.96) | 4.71 (2.48) (1.18-8.76) | .042 |
| EQ-5D-5L Index value (1)[#] | 0.83 (0.12) (0.58-1) | 0.88 (0,11) (0.67-1) | .033 |
| EQ-5D-5L Index value by-proxy (1)[#] | 0.76 (0.20) (0.33-1) | 0.75 (0.17) (0,22-1) | .737 |
| EQ-5D VAS (100)[#] | 81.74 (14.78) (50-100) | 79.78 (17.15 (40-100) | .774 |
| EQ-5D VAS by proxy (100)[#] | 81.21 (19.33) (25-100) | 77.26 (17.45 (40-100) | .156 |
| MMSE (30)[#] | 26.47 (2.01) (23-30) | 26.47 (2.55) (22-30) | .954 |
| ACE (100)[#] | 80.63 (8.26) (63-97) | 79.79 (8.74) (60-92) | .265 |
| RBANS list learning, recall (40)[#] | 1.41 (1.75) (0 – 6) | 0.55 (0.83) (0 -2) | .018 |
| RBANS figure learning, recall (22)[#] | 4.95 (4.67) (0 – 16) | 5.17 (4.41) (0 – 14) | .753 |
| SDMT (N/a)[# ¥] | 28 (10.54) (10-45) | 28,53 (9.67) (11-46) | .602 |
| Trail A (N/a)[Δ €] | 55.37 (30.55) (23-140) | 59.90 (38.69) (23-184) | .231 |
| Trail B (N/a)[Δ €] | 171.93 (130.45) (69-643) | 151.24 (61.79) (80-309) | .856 |
| Verbal fluency (animals) (N/a)[#] | 18.37 (4.66) (9-25) | 16.90 (4.95) (8-31) | .027 |
| Verbal fluency (S-words) (N/a)[#] | 12.68 (5.70) (4-26) | 12.16 (5.05) (3-21) | .685 |
| Non-verbal fluency (N/a)[#] | 18.95 (7.17) (8-32) | 20.28 (7.37) (8-34) | .111 |

*Statistically significant after Bonferroni correction.
[#]Higher scores indicate higher attainment, satisfaction or level of function.
[Δ]Lower scores indicate better function.
[¥]SDMT score is number of combinations correctly processed within the time limit of 90 seconds.
[€]Trail A and Trail B scores are total time (seconds) to complete the tests.

**Table 3.** Results from interviews with participants and caregivers.

| Themes | Sub-themes | Quotes – participants (P) and caregivers (C) |
|---|---|---|
| Benefits and shortcomings | Acceptance of the method in general | P: *'It was very detailed, and things were repeated.'* |
| | | P: *'It worked very well … and not too much. It was manageable.'* |
| | | P: *'Staff were good at noticing the participants and their different needs.'* |
| | | P: *'The structure was a good thing.'* |
| | Positive emotional reactions | P: *'There was a positive and open atmosphere.'* |
| | | P: *'I was always in a good mood afterwards.'* |
| | | C: *'There was a positive experience, they had a nice time together, also with the staff.'* |
| | | C: *'She has met some very nice people … enjoyed talking.'* |
| | Sharing with peers | P: *'It touched me a lot to meet the others. We're in the same boat … You didn't feel wrong … I could be more relaxed.'* |
| | | P: *'It was really nice. Just knowing that you're not alone. Others have the same problems.'* |
| | | C: *'It was nice for them to meet each other and learn from each other.'* |
| | | C: *'X found it nice talking to peers in a similar situation.'* |
| | Creating new relationships | P: *'We have planned to meet again.'* |
| | | P: *'I went to the meetings with one of the others [by car]. I think we're going to meet again.'* |
| | | C: *'She has become quite close with X.'* |
| | Shortcomings | P: *'I didn't feel that I gained a lot from the group, but it was nice meeting the others.'* |
| | | P: *'Participants were quite different.'* |
| | | P: *'The group should have been matched by level of ability.'* |
| Suggested changes | Breaks | P: *'I would prefer more breaks, it was difficult for me to stay focused for such a long time.'* |
| | | P: *'Staff could suggest topics that participants could discuss during breaks.'* |
| | More time for informal talks | P: *'We had too little time to just talk … but the education shouldn't be shorter. Perhaps the meetings should be longer.'* |
| | | P: *' … perhaps more buzz groups … to engage participants and give them more time to talk.'* |
| Impact | Increased acceptance and openness about living with dementia | P: *'You gain more respect for yourself and others … knowing about dementia makes it less secret. We are all human beings. I have started telling more people that I have a dementia disease. It's more OK.'* |
| | | P: *'I told my friends that I have dementia after I started here.'* |
| | | P: *'I feel that I have more knowledge about myself and my situation. It makes it easier to feel more open about it.'* |
| | | C: *'It made her feel more self-confident.'* |
| | Self-management coping and support activities | P: *'I more often stop to think. It has implicitly been put into our minds how we can cope with things … organize things, write things down etc.'* |
| | | P: *'It has made me consider how I can be more active … made me more aware that I can use these things.'* |
| | | C: *'The individual goals are important to her and they were achieved.'* |
| | | C: *'It has helped her become better at organizing her appointments.'* |
| | Benefits from the use of tablet and ReACT app | P: *'It gave me a lot of experience of how to use the tablet and app.'* |
| | | P: *'I mainly use the calendar, but also the diary* [specific features in the ReACT app].' |
| | | C: *'She uses the app independently. The shared calendar is a good feature.'* |
| | | C: *'She uses the app everyday … has become a skilled user.'* |

rating of health-related quality of life at the end of the intervention, indicated by the EQ-5D-5L Index value (p = .033).

Among the secondary outcome measures addressing cognitive functions there were no significant changes, but a tendency to reduction on two of the tests, measuring categorial verbal fluency (p = .027) and list learning (p = .018).

### *Interviews*

Results from the semi-structured interviews are summarized in Table 3, presenting themes, subthemes and related quotes. Both participants and caregivers generally gave positive feedback on participating in the programme. Many emphasised

**Table 4.** Baseline differences between adoptors vs. non-adoptors of the ReACT app.

| Measure | Adoptors (n = 8) | Non-adoptors (n = 11) | p-value |
|---|---|---|---|
| Age years, mean (SD) (range) | 63.3 (9.3) (52-74) | 70.6 (6.4) (58-79) | .068 |
| Sex female/male | 7/1 | 8/3 | .603 |
| Years of education mean (SD) (range) | 14.5 (3.0) (8-17) | 14.2 (2.0) (11-17) | .524 |
| Time since diagnosis (months) | 6.1 (3.9) (2-12) | 5.0 (2.9) (1-10) | .530 |
| Previous smartphone user yes/no | 7/1 | 11/0 | .421 |
| Previous tablet user yes/no | 6/2 | 6/5 | .633 |
| MMSE[#] mean (SD) (range) | 27.1 (2.0) (25-30) | 26 (2.0) (23-29) | .256 |

[#]Higher scores indicate higher level of function.

**Table 5.** Change in scores on the BGSI from baseline to post-intervention for adoptors and non-adoptors.

| | Adoptors | | Non-adoptors | | | |
|---|---|---|---|---|---|---|
| Measure | Baseline Mean (SD) | Post-intervention Mean (SD) | Baseline Mean (SD) | Post-intervention Mean (SD) | F | p-value |
| BGSI attainment[#] all goals - participant rating | 4.66 (1.87) | 8.69 (1.27) | 3.60 (1.06) | 5.14 (1.49) | 11.47 | .004* |
| BGSI attainment[#] app-related goals - participant rating | 4.01 (2.14) | 8.65 (1.46) | 2.60 (1.55) | 5.15 (2.11) | 3.80 | .068 |
| BGSI attainment[#] non-app related goals - participant rating | 6.63 (1.25) | 7.66 (1.61) | 5.07 (2.46) | 5.38 (2.16) | .272 | .610 |
| BGSI attainment[#] all goals - caregiver rating | 6.04 (2.77) | 7.53 (2.10) | 3.99 (1.86) | 4.17 (1.76) | 1.31 | .270 |
| BGSI attainment[#] app-related goals - caregiver rating | 6.30 (2.94) | 7.55 (2.31) | 3.75 (2.41) | 3.46 (1.83) | 1.15 | .300 |
| BGSI attainment[#] non-app related goals - caregivers rating | 6.39 (2.48) | 6.70 (2.22) | 4.70 (2.50) | 4.77(2.65) | .02 | .735 |

[#]Higher scores indicate higher level of attainment.
*$p < .05$.

positive emotional reactions to participating, including the encouraging experience of meeting people in a similar situation, sharing their experience of living with dementia. Some participants also mentioned new relationships with other group members as a benefit. The shortcomings were related to the differences between group participants and some felt that the group did not match their personal skills. Participants also drew attention to issues that should be considered when developing further interventions, some of them requested longer breaks and more time for informal talks among participants.

Most participants underlined that they had profited from gaining knowledge of their disease and for some this had led to increased awareness of symptoms and being more open to others about living with dementia. The interviews also indicated that participants and their caregivers had noticed specific activities related to self-management, coping and support that had been encouraged or promoted through the intervention programme, e.g. communicating with family and friends and being more organised with notetaking and reminders. In addition, specific benefits from learning how to use the tablet and the ReACT app was also discussed, e.g. using the electronic calendar and diary to support memory. However, some participants and caregivers also found it difficult or less beneficial to use the tablet and the app. The feedback that was specifically related to the app and suggested changes were collected and, if expedient, used to further optimize the app. This specific user feedback on app design and functionalities are not included in this paper.

### *Attendance during the programme*

The attendance rate was in general high among both participants and caregivers. All participants attended the individual sessions. All the caregivers attended at least one of the initial individual sessions. In the group setting all participants attended at least six sessions, 14 of the participants participated in all sessions. The most common reasons for non-attendance were holidays and shorter periods of illness.

### *Differences between adoptors and non-adoptors of the ReACT app*

As summarised in Table 4 the quantitative data did not reveal any statistically significant differences in baseline characteristics between adoptors and non-adoptors of the ReACT app.

As mentioned it was not mandatory for participants to use the app or to define individual goals related to the use of the app. In total, 32 individual goals were defined among the participants. Nineteen of these goals were related to the use of the ReACT app (app-related goal), e.g. using the app to manage appointment and to-do lists or using the app to recollect precious moments with a grandchild by using photos and text in diary notes. Thirteen goals addressed other themes (non-app related goals), e.g. methods to support memory for choir lyrics or finding a system to support memory for various access codes. All participants defined at least one app-related goal, and four participants only defined app-related goals (three of them became adoptors and one of them a non-adoptor).

Table 5 summarises the change in the two groups' outcomes on the BGSI from baseline to post-intervention, including separate analyses for app-related goals and non-app related goals. These data show that the adoptors had a significantly larger change in rating of goal attainment for all goals compared to non-adoptors ($p = .004$). When separating these goals into app-related and non-app

**Table 6.** Number of operations in the ReACT app and rating of the app.

| Measure | Adoptors Mean (SD) (range) | Non-adoptors Mean (SD) (range) | p-value *<0.005 |
|---|---|---|---|
| **Number of operations in the ReACT app during intervention – participants** | 1740 (1113) (481 -3708) | 284 (149) (118 - 501) | .001* |
| **Number of operations in the ReACT app during intervention – caregivers** | 309 (290) (0 – 773) | 177 (123) (27 – 399) | .457 |
| **USE-dem participants** | 56.5 (2.619) (54-60) | 36.90 (14,45) (14 – 53) | .000* |
| **USE-dem by-proxy** | 49.38 (8.017) (37 – 60) | 31 (13.35) (14 – 49) | .006* |
| **USE-dem caregivers** | 48.43 (7.807) (37 – 60) | 37.43 (14.22) (12 – 52) | .397 |

#Higher scores indicating higher ratings of usability and applicability of the ReACT app.
*$p < .05$.

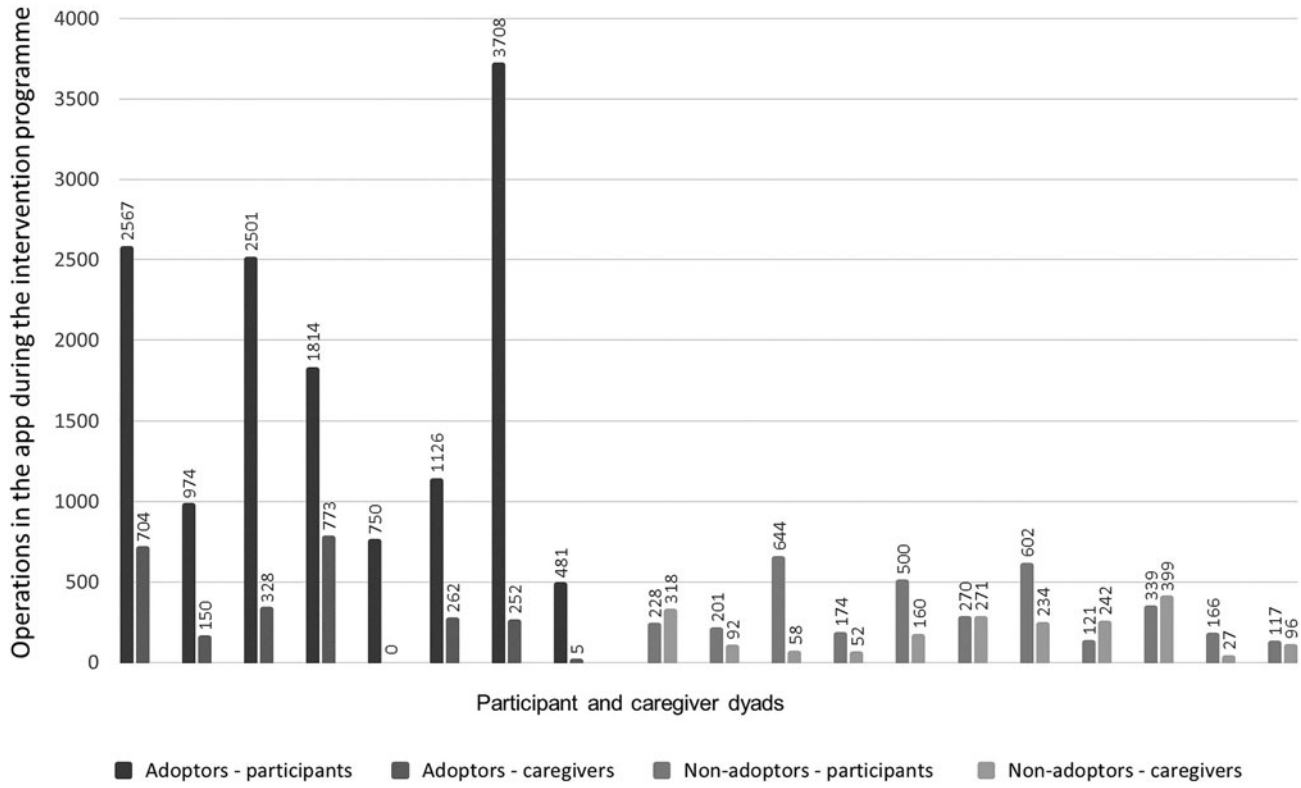


**Figure 2.** Participant and caregiver dyads: Number of operations in the app during the intervention programme.

related goals there was no significant difference between the two groups, though there was a tendency for the app-related goal attainment to have a larger change from baseline to post-intervention for the group of adoptors ($p = .068$).

The differences between adoptors' and non-adoptors' use and rating of the ReACT app is summarised in Table 6. These data show that there was a significant difference in the number of operations in the app during the intervention performed by participants who adopted the app compared to those who did not adopt the app ($p = .001$), whereas there was no significant difference between the caregiver's number of operations in the two groups ($p = .741$). These differences are also illustrated in Figure 2 where the total number of actions in the app during the intervention programme is summarised for each participant and caregiver dyad, and for adoptors and non-adoptors separately. The rating of usefulness, satisfaction, and ease of use the ReACT app as measured with the USE-dem questionnaire is also presented in Table 6. These data illustrate that adoptors rate the app significantly higher compared to non-adoptors ($p < .001$) and this is in line with the by-proxy rating conducted by the caregivers ($p = .006$), whereas the between group difference in the caregivers' own rating of the app is not significant ($p = .397$).

## Discussion

This pilot study aimed to explore the feasibility and applicability of an intervention merging methods of cognitive rehabilitation and self-management groups for people with early stage dementia to gain the best of both worlds and, in addition, to explore if this structured intervention is a feasible and effective way to encourage adoption of AT by people with dementia. To the best of the authors' knowledge this study is the first to explore such a combined intervention and relating it to AT adoption.

The results demonstrated that our programme was generally feasible. Attendance rates were high and none of the participants dropped out after the initiation of the intervention.

The combination of methods from individual cognitive rehabilitation and group based self-management programmes appeared applicable. The qualitative data from interviews with participants and caregivers showed that they were generally positive towards the activities and methods applied during the programme.

Quantitative data confirmed that the programme was an applicable method to address individual goals of rehabilitation. The Bangor Goal Setting Interview (BGSI) (Clare et al., 2012) was used to define and assess the

individual goals during the intervention. In line with other studies involving people with early stage dementia (Clare, 2017; Hindle, et al., 2018) participants in our study were in general able to identify individual goals in collaboration with caregivers and professionals and results confirmed that they experienced a significant improvement in their achievement of these goals during the intervention.

Qualitative data also supported the successful implementation of self-management features in the programme. Results from the interviews demonstrated that participants emphasised the benefits of meeting and sharing with peers in a similar situation. The utility of group-based psychoeducation, providing knowledge of disease and possible ways to cope with symptoms, was also highlighted. These results are in line with other studies published on self-management underlining the feasibility of such programmes to promote knowledge, independence and support, and having a positive impact on self-esteem (Martin, et al., 2015), quality of life (Sprange et al., 2015) and self-efficacy (Quinn, Toms, Jones, et al., 2016). Our results showed a tendency towards improvement in the participants' rating of health-related quality of life.

Other small-scale studies have explored the adoption of cognitive supportive AT solutions similar to the ReACT app to people with dementia, both in a group-based setting (Dewar, Kapur, & Kopelman, 2018) and through individualised rehabilitation approaches (Imbeault et al., 2018), but with varied success. In our study, the combination of individual and group-based activities proved to be a feasible, applicable and efficient method to deploy AT. All participants accepted some degree of introduction to the app and forty-two percent of the participants adopted the app. The adoptors performed significantly more operations in the app during the intervention and they rated the app higher in usefulness, satisfaction, and ease of use compared to non-adoptors.

To be able to target future adoptors of this kind of AT, and to avoid adverse effects, e.g. non-adoptors feeling defeat or incompetence, we explored data to detect possible differences between adoptors and non-adoptors. The baseline characteristics did not reveal any significant differences between the two groups, though there was a tendency for adoptors to be slightly younger. The adoptors also had a significantly larger change in goal attainment during the intervention compared to non-adoptors. This could be ascribed to a larger success with app-related goals, which was of course unintended, as the intervention aimed to give equal attention to app-related and non-app related goals. These results and tendencies could indicate that there might be some factors that influence successful adoption of AT by people with dementia that were not fully captured in the outcome measures that were applied in this study. However, being an uncontrolled pilot study, the study was not designed or powered to detect significant differences in outcome measures, the assessments were conducted to explore outcome measures that could capture the aims of the intervention. Further large-scale studies are needed to identify possible predictive factors of AT adoption.

### *Study limitations and implications*

In contrast to the participants' evaluation of goal attainment, the caregiver's evaluation did not change significantly during the intervention. The caregivers' rating of goal attainment was relatively high at baseline, perhaps reflecting that participants were all newly diagnosed, and caregivers were maybe more optimistic about levels of functional ability at this time point. In order to provide psychoeducation and to promote coping and compensation, the consequences of living with dementia were highlighted during the intervention programme. It is possible that this increased focus on the participants' ability to perform tasks and the assessment of ability and skills during the programme had a negative influence on caregiver's evaluations, accentuating their focus on disabilities. This is also supported by the post-intervention increase in scores on the B-ADL, indicating that caregivers rated the participants to have a lower level of performance in activities of daily living. This could be viewed as an adverse effect of the intervention on caregivers. On the other hand, it also highlights the need to explore if the caregivers were adequately involved in the intervention and if they were provided enough information and support on how to be involved in coping and self-management as a caregiver. These questions must of course be addressed when planning future studies.

Another limitation is the skewed recruitment of participants. Despite efforts to recruit a varied group of people with early stage Alzheimer's disease from the three memory clinics, a disproportionate part were woman. and they were all fairly well-educated. This might influence the generalizability of the results and a broader recruitment of participants should also be addressed in future studies.

In addition, the relevance of using cognitive tests among secondary outcomes in a self-management intervention programme can be questioned (Mountain, 2017), since the main goal of the intervention was to promote self-management and empowerment through positive support, including coping strategies and tools. However, in line with the MRC framework for the development and evaluation of complex interventions (Craig, et al., 2008) both the feasibility and applicability of intervention methods and outcome measures were explored in this pilot study. Cognitive outcome measures were applied to explore possible baseline differences among participants, and if possible to detect factors that could predict adoption of AT, but for future studies it should be considered to omit these cognitive outcome measures post-intervention to reduce the assessment burden for participants.

## Conclusion

The results of this study demonstrated that a structured intervention programme addressing both individual goal-based rehabilitation and more general self-management approaches is feasible and applicable for people with early stage Alzheimer's disease. In addition, results indicated that such a programme can be an effective method to promote adoption of AT. However, large-scale studies are needed to explore effective measures that capture the impact of the programme. Methods for deployment of the intervention at a larger scale and across multiple settings also need to be explored.

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## Disclosure statement

The authors report no conflict of interest.

## Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available because they contain information that could compromise research participants' privacy and consent.

## Ethics approval and consent to participate

The study protocol was evaluated by the regional scientific ethical committees of The Capital Region of Denmark (protocol number H-15005558), where it was decided the study did not need approval, since it was not considered to be within the framework of biomedical research.

All participants received oral and written information about the study objectives and methods. They all gave written informed consent.

## References

Asghar, I., Cang, S., & Yu, H. (2017). Assistive technology for people with dementia: an overview and bibliometric study. *Health Information & Libraries Journal*, *34*(1), 5–19.

Clare, L. (2017). Rehabilitation for people living with dementia: A practical framework of positive support. *PLoS Medicine*, *14*(3), e1002245

Clare, L., Hindle, J. V., Jones, I. R., Thom, J. M., Nelis, S. M., Hounsome, B., & Whitaker, C. J. (2012). The AgeWell study of behavior change to promote health and wellbeing in later life: study protocol for a randomized controlled trial. *Trials*, *13*(1), 115.

Clare, L., Kudlicka, A., Oyebode, J. R., Jones, R. W., Bayer, A., Leroi, I., … Pool, J. (2019). Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial. ). *International Journal of Geriatric Psychiatry*, *34*(5), 709–721.

Clare, L., Linden, D. E. J., Woods, R. T., Whitaker, R., Evans, S. J., Parkinson, C. H., … Rugg, M. D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer disease: a single-blind randomized controlled trial of clinical efficacy. *The American Journal of Geriatric Psychiatry*, *18*(10), 928–939.

Coast, J., Flynn, T. N., Natarajan, L., Sproston, K., Lewis, J., Louviere, J. J., & Peters, T. J. (2008). Valuing the ICECAP capability index for older people. *Social Science & Medicine*, *67*(5), 874–882.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *Bmj*, *337*, a1655.

Dewar, B.-K., Kapur, N., & Kopelman, M. (2018). Do memory aids help everyday memory? A controlled trial of a Memory Aids Service. *Neuropsychological Rehabilitation*, *28*(4), 614–632.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*(3), 189–198.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K., & Robinson, L. (2016). The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, *15*(4), 681–701.

EuroQol Group. (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy (Amsterdam, Netherlands)*, *16*(3), 199.

Hindle, J. V., Watermeyer, T. J., Roberts, J., Brand, A., Hoare, Z., Martyr, A., & Clare, L. (2018). Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. *International Journal of Geriatric Psychiatry*, *33*(5), 718–728.

Hindmarch, I., Lehfeld, H., de Jongh, P., & Erzigkeit, H. (1998). The Bayer activities of daily living scale (B-ADL). *Dementia and Geriatric Cognitive Disorders*, *9*(2), 20–26.

Imbeault, H., Gagnon, L., Pigot, H., Giroux, S., Marcotte, N., Cribier-Delande, P., … Bier, N. (2018). Impact of AP@ LZ in the daily life of three persons with Alzheimer's disease: long-term use and further exploration of its effectiveness. *Neuropsychological Rehabilitation*, *28*(5), 755–778.

Kenigsberg, P.-A., Aquino, J.-P., Bérard, A., Brémond, F., Charras, K., Dening, T., …., Innes, A. (2017). Assistive technologies to address capabilities of people with dementia: from research to practice. *Dementia*, *18*(4), 1568–1595.

King, A. C., & Dwan, C. (2017). Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. *Dementia*, 1–14. doi:10.1177/1471301217735180.

Lee, G., Loring, D., Newell, J., & McCloskey, L. (1994). Figural fluency on the five-point test: preliminary normative and validity data. *International Neuropsychological Society Program Abstract*, *1*, 51.

Leech, N. L., & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: a call for data analysis triangulation. *School Psychology Quarterly*, *22*(4), 557

Lund, A. M. (2001). Measuring usability with the use questionnaire. *Usability Interface*, *8*(2), 3–6.

Laakkonen, M. L., Kautiainen, H., Hölttä, E., Savikko, N., Tilvis, R. S., Strandberg, T. E., & Pitkälä, K. H. (2016). Effects of self-management groups for people with dementia and their spouses—Randomized controlled trial. *Journal of the American Geriatrics Society*, *64*(4), 752–760.

Martin, F., Turner, A., Wallace, L. M., Stanley, D., Jesuthasan, J., & Bradbury, N. (2015). Qualitative evaluation of a self-management intervention for people in the early stage of dementia. *Dementia*, *14*(4), 418–435.

Mathuranath, P., Nestor, P., Berrios, G., Rakowicz, W., & Hodges, J. (2000). A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. *Neurology*, *55*(11), 1613–1620.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Jr, Kawas, C. H., … Mayeux, R. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 263–269.

Meiland, F., Innes, A., Mountain, G., Robinson, L., van der Roest, H., García-Casal, J. A., …., Dröes, R.-M. (2017). Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. *JMIR Rehabilitation and Assistive Technologies*, *4*(1), 1.

Mountain, G. A. (2017). Self-management programme for people with dementia and their spouses demonstrates some benefits, but the model has limitations. *Evidence Based Nursing*, *20*(1), 26–27.

Mountain, G. A., & Craig, C. L. (2012). What should be in a self-management programme for people with early dementia?. *Aging & Mental Health*, *16*(5), 576–583.

Øksnebjerg, L., Diaz-Ponce, A., Gove, D., Moniz-Cook, E., Mountain, G., Chattat, R., & Woods, B. (2018). Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expectations*, *21*(6), 1056–1065.

Øksnebjerg, L., Woods, B., & Waldemar, G. (in press). Designing the ReACT app to support self-management of people with dementia: An iterative user-involving process. *Gerontology*, doi:10.1159/000500445.

Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., del Ser, T., … Muñiz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, *30*(2), 161–178.

Poulos, C. J., Bayer, A., Beaupre, L., Clare, L., Poulos, R. G., Wang, R. H., … McGilton, K. S. (2017). A comprehensive approach to reablement in dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *3*(3), 450–458.

Quinn, C., Toms, G., Anderson, D., & Clare, L. (2016). A review of self-management interventions for people with dementia and mild

cognitive impairment. *Journal of Applied Gerontology*, *35*(11), 1154–1188.

Quinn, C., Toms, G., Jones, C., Brand, A., Edwards, R. T., Sanders, F., & Clare, L. (2016). A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). *International Psychogeriatrics*, *28*(5), 787. p

Randolph, C., Tierney, M. C., Mohr, E., & Chase, T. N. (1998). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): preliminary clinical validity. *Journal of Clinical and Experimental Neuropsychology*, *20*(3), 310–319.

Reitan, R. M. (1992). *Trail Making Test: Manual for administration and scoring*. Tucson, AZ: Reitan Neuropsychology Laboratory.

Smith, A. (1982). *Symbol digit modalities test*. Los Angeles, CA: Western Psychological Services Los Angeles.

Sprange, K., Mountain, G. A., Shortland, K., Craig, C., Blackburn, D., Bowie, P., … Spencer, M. (2015). Journeying through Dementia, a community-based self-management intervention for people aged 65 years and over: A feasibility study to inform a future trial. *Pilot and Feasibility Studies*, *1*(1), 42.

Strauss, E., Sherman, E. M., & Spreen, O. (2006). *A compendium of neuropsychological tests: Administration, norms, and commentary*. New York, NY: American Chemical Society.

Toms, G. R., Quinn, C., Anderson, D. E., & Clare, L. (2015). Help yourself: perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research*, *25*(1), 87–98.

van der Roest, H. G., Wenborn, J., Pastink, C., Droes, R. M., & Orrell, M. (2017). Assistive technology for memory support in dementia. *Cochrane Database of Systematic Reviews*, *6*, Cd009627.

van Hout, B., Janssen, M. F., Feng, Y.-S., Kohlmann, T., Busschbach, J., Golicki, D., … Pickard, A. S. (2012). Interim scoring for the EQ-5D-5L: mapping the EQ-5D-5L to EQ-5D-3L value sets. *Value in Health : The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, *15*(5), 708–715.

# A tablet app supporting self-management of people with dementia: Analysis of adoption and use patterns

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## Abstract

**Background:** Assistive technology (AT) is fast emerging within dementia care and support. One area of application is AT to support people with dementia in compensating for cognitive symptoms and thereby promote their self-management. There is, however, generally little evidence for the applicability, usability and effectiveness of AT for people with dementia and a need to identify factors that can promote adoption.

**Objective:** The aims of this study were (1) to evaluate the applicability and usability of an app, tailormade for people with dementia, (2) to explore factors affecting adoption, (3) to explore the possible influence of caregiver involvement and (4) contribute to process evaluation of the intervention.

**Methods:** The ReACT app had been designed as a holistic solution to support memory and structure in daily living. The person with dementia had access to a personal user-account and family caregivers were given a parallel login. Written and online materials were provided to support self-applied implementation. A mixed methods design was applied to explore adoption and use-patterns, including background and disease-related data, qualitative data from a survey and log data. Adoption was defined as use of the app over a period of 90 or more days.

**Results**: Data from 112 participants and 98 caregivers were included. Shorter time from diagnosis (U=595 P=0.046, r=.19) and caregiver having activated the app (p=.02; FET) had a significant impact on participant adoption status. Logistic regression analysis showed that if caregivers had activated the app the participant was 5 times more likely to become an adoptor (OR 5.1; 95% CI 1.29-19.99; P=.02). The overall predictive power was however low and there was quite wide variation in background and disease-related characteristics among adoptors. Level of experience and skills in tablet-use were not significantly different between adoptors and non-adoptors. Adoptors generally rated the app high on usefulness, satisfaction, and ease of using (rated on the USEdem questionnaire). Their scores were significantly higher compared to non-adoptors (U=5.5 P=0.02, r=.64). Analysis of use-patterns showed that all functionalities of the app were used among adoptors.

**Conclusions:** Results confirmed the applicability and usefulness of the ReACT app and self-applied methods for implementation in a mixed group of people with dementia. The study provided insight into the importance of timely introduction and caregiver support for adoption of AT among

people with dementia. It also underlined the high complexity of personal and contextual factors that influence adoption. These complex factors need to be considered when designing and implementing AT for people with dementia.

**Keywords:** Dementia, Assistive technology, App, Self-management, Memory, Caregivers, Adoption, Usability, Mixed methods, Log data.

## Introduction

The number of people living with dementia worldwide is fast growing [1] and it is a global concern that in the near future we may not have enough resources to meet their need for support and care [2]. These challenges call for efficient and flexible solutions and the progressive digitalisation and use of technology are seen as promising solutions [2, 3]. During the last decade there has been a steadily growing emphasis on assistive technology (AT) in dementia care and support, both from industry, governments, organisations and in research [4-6]. One perspective is that AT has great potential to support cognition and can be used to compensate for cognitive decline, which is a core symptom across dementia diseases, and thereby promote self-management of people living with dementia [7-9].

AT comprises a variety of solutions, ranging from basic everyday low-tech devices to advanced technology [10]. In the field of dementia especially AT based on information and communication technology (ICT), such as apps applied on touchscreen devices, has expanded [6]. The focus of this study is ICT based AT and for the remainder of the paper this will be the kind of AT referred to.

The optimism on the potential of AT to support people with dementia is unfortunately not based on strong evidence. There is a great need for research addressing applicability, usability and effectiveness of AT for people with dementia [8, 11, 12], and when designing and conducting research within this field a complex set of preconditions must be considered. First of all, this field of research is subject to the same challenges as other digital health interventions. The relatively high rate of non-adoption and non-adherence, referred to as 'the law of attrition' [13], is a natural and typical feature of digital health interventions in all medical fields [14, 15]. Consequently, the pattern of drop-out rates in research addressing these kinds of interventions are quite distinct from e.g. drug trials or studies of psychosocial interventions. This requires a different approach to research methodology, e.g. by including detailed log data analysis to explore user-patterns and analyse characteristics of individuals who successfully adopt and adhere to the technology [13]. Such perspectives and methodology are often not included in research addressing AT for people with dementia, where more traditional quantitative and qualitative outcome measures have often been applied to assess usability and impact of AT [8]. Another precondition is that the progressive cognitive symptoms of dementia diseases impair the ability of people with dementia to adopt and

adhere to AT. Therefore, it is essential to explore factors that can support and promote their adoption and adherence, e.g. caregiver support and tailormade interventions. Consequently, to explore the potential of AT for people with dementia, and to provide evidence for specific solutions, study designs have to incorporate these complex preconditions. An essential step is the use of mixed methods when accessing applicability, usability and effectiveness, including log data analysis.

This paper presents data from the third sub-study of the research project ReACT (Rehabilitation in Alzheimer's disease using Cognitive support Technology). In the first sub-study the ReACT app was created through an iterative user-centred design process [16]. The app was tailormade to support self-management of people with dementia, mainly by supporting various aspects of prospective and retrospective memory and structuring of daily activities. People with early stage Alzheimer's disease were considered the main group of end-users during the design phase, and the applicability and usability of the app for people with Alzheimer's disease has been investigated in a second sub-study [17]. The present third sub-study was conducted to investigate the applicability and usability of the app in a large mixed cohort of people with dementia, representing various etiologies and backgrounds. To the best of the authors knowledge this paper is the first to present detailed data, including analysis of log data, from a study where AT tailormade for people with dementia has been disseminated to a large heterogenous group of people with dementia.

Accordingly, the aims of the study were:

1. Investigate the applicability and usability of the ReACT app to a mixed population of people with dementia.
2. Investigate user-patterns and factors influencing adoption and non-adoption.
3. Explore the possible influence of caregiver involvement on participants' adoption of the app.
4. Contribute to process evaluation of the app and methods used for deployment and adoption, to guide future adaption of the app and methods of implementation.

# Methods

## Participants

Participants were recruited from 9 Danish memory clinics. The aim was to recruit a broad variety of people with dementia and therefore few inclusion criteria were specified. Participants were eligible if they were patients in the memory clinic, were motivated to try using the app and had access to a tablet where the app could be installed (iPad). It was not mandatory to have a caregiver as co-participant, but if they were accompanied by a family caregiver when visiting the clinic, the caregiver was invited as co-participant. There were no inclusion criteria related to age, language or other personal or disease-related characteristics, and participants were not required to have had a final diagnosis at the time of inclusion. Since the intervention addressed people with dementia as primary participants they are referred to as participants in this paper and the co-participating caregivers are referred to as caregivers.

Information about the study was presented to patients in the memory clinics. Posters and flyers presenting the app and the study were available in waiting areas and introduced by staff. Eligible participants who showed interest in the study were given a detailed oral introduction and additional written material describing the details of the study. Participants and caregivers were then given opportunity for deliberation before deciding whether to participate in the study and give written informed consent.

Participants were recruited from June 2017 to February 2018 and during this period 116 participants were enrolled.

## Intervention

Participants and caregivers were given access to the ReACT app after being included in the study. The specific features of the ReACT app are illustrated in Figure 1. As described, the app was a holistic solution, comprising a calendar which interacts with other features, e.g. diary notes, contacts, check-lists and memos. It was designed as a cloud-based native app for a tablet computer and could be accessed from an iPad. As described in Figure 1, the participant had access to a personal user-account and the caregiver could support the use of the app via a parallel login to this account, allowing both adding and editing content. Usernames and access codes were provided separately to participants and caregivers to enable monitoring of log data from both. For

data protection, these codes were provided in sealed envelopes to the participant and caregiver, and staff at the memory clinics had no access to this information. In case of need for backup information on usernames and access codes these could only be provided if a participant or caregiver contacted the study PI directly.

Participants and caregivers were provided written material to support their self-applied implementation of the app. This written material had been validated as applicable for a person with early stage dementia during the second sub-study in the ReACT research project [17], where people with early stage Alzheimer's disease and caregivers were consulted when developing these materials. Two leaflets were provided. One leaflet gave instructions on how to download and activate the ReACT app to a tablet. Another leaflet gave a brief introduction to the functionalities of the app and gave advice on how the app could be used in various everyday situations, including how caregivers could support the use of the app. Details on telephone and e-mail hotline support were also included. Hotline support was accessible within working hours throughout the study period.

A help-feature was also built into the app, as illustrated in Figure 1. When tapping this icon on the app's menu bar the user was directed to a website with information, video tutorials and hotline details.

Figure 1. Features of the ReACT app

## Assessments

### *Baseline characteristics*

Demographic information for both participants and caregivers was collected at the time of inclusion, data included participant's age, gender and education, caregiver's gender and the relation between participant and caregiver. In addition, data from participants' medical records were included to document diagnosis, time of diagnosis and the most recent score on the Mini-Mental State Examination (MMSE) [18], a brief cognitive assessment of cognitive function.

### *Log data*

App usage was monitored through data logs from each participant's and caregiver's use of the app. The log files provided data on participant's and caregiver's actions in the app and provided

information on action types and timestamps for these actions. The action types that were logged were: activating the app, using adaptive features, and activities related to appointment, diary note, memos, check list and search features.

Adoption of the app was defined as minimum period of 90 days between the first and the last use of the app. This criterion was set based on results from the previous sub-study [17], showing that a person with early stage dementia could adopt the app and use it independently after a period of 90 days of introduction and familiarising with it.

### *Survey*

An online survey was conducted to collect additional background information and to collect feedback on the app. It was distributed via e-mail three to four months after inclusion in the study. In cases where e-mail correspondence was unsuccessful a printed version of the survey was sent out by mail.

Two versions of the survey were distributed, one for participants and a by-proxy version for caregivers. It was constructed in an adaptable manner, enabling specific questions being directed at those who had used the app and those who had not. The survey included questions with a fixed set of possible answers. For non-users the questions addressed level of skills to use a tablet and reasons for not using the app. For users the questions addressed methods used when learning how to use the app and level of skills to use a tablet. Two optional text boxes were also included, allowing additional comments on reasons for not using the app and general feedback on the app. The general feedback mainly addressed specific technical and functional issues of the app which is not within scope of this paper.

In those cases where the participant had tried using the app the USEdem questionnaire [17] was included in the survey and a by-proxy version was delivered to caregivers. The USEdem is a modified version of the USE Questionnaire [19]. It was designed to assess usefulness, satisfaction, and ease of use of technology and the modified version contains 12 items [17]. Scores on each item range from 1 to 5 on a Likert scale, with a total score between 12 and 60, higher scores indicating higher ratings.

### *Data Analysis*

Quantitative data were analysed using IBM SPSS Statistics v.22. Baseline characteristics and log data from adoptors were explored with descriptive statistics. Possible between group differences on baseline characteristics, log data and data from the surveys were analysed using non-parametric chi-square tests for categorical variables, and for continuous variables Kruskal-Wallis tests, Mann–Whitney U tests or Fisher's exact tests were used as appropriate. Logistic regression was conducted to explore whether baseline characteristics predicted adoption status.

Tests of significance were performed two-tailed, with a significance level of .05. Imputed values for missing data on background characteristics were calculated following standard procedures for multiple regression modelling.

Qualitative data from surveys, from the textbox allowing feedback on reasons for not using the app, were processed and summarised in themes, as outlined in constant comparison analysis [20].

## Results

Data from 112 participants were included in data analysis. No participants or caregivers withdrew their consent to participate in the study, but due to insufficient background information 4 cases were excluded from the original sample of 116 participants.

Log data monitoring use of the app was collected for all participants and caregivers for a maximum of 90 days, hence the inclusion period for this study was 90 consecutive days after activating the app or 90 days from inclusion for those who did not activate the app. Additional follow-up data is not within the scope of this paper.

Data from the surveys were obtained from 35 participants and 30 caregivers and 19 of these cases were overlapping, with a reply from both. Fourteen participants had support from a caregiver when answering the survey and in two cases a caregiver had answered the participant survey on behalf of the participant; these two were excluded, leaving 33 participant and 30 caregiver replies for data analysis. Included in this was data on the USEdem questionnaire from 14 participants and 9 caregivers from cases where the participant had tried using the app.

## Participant characteristics

The characteristics of participants and caregivers are summarised in Table 1. These data show that participants were quite heterogeneous with regards to age, education level, months since diagnosis and most recent MMSE score. Most participants were diagnosed with Alzheimer's disease, people with vascular dementia were also represented as well as other less common dementia diagnoses such as frontotemporal dementia. Participants diagnosed with mild cognitive impairment were also among the participants. A quite large group of participants were categorised as other and included e.g. participants with an unspecified dementia diagnosis or cognitive symptoms caused by stroke. Gender was almost equally represented, but with a slightly greater proportion of men among participants. A dyad of participant and caregivers were included in 88 percent of the cases and most of these caregivers were spouses.

Table 1. Characteristics of participants and caregivers, and differences between adoptors and non-adoptors

| **Characteristics** | **All participants** (N=112) | **Adoptors**[a] (N=18) | **Non-adoptors**[a] (N=94) | **P** |
|---|---|---|---|---|
| | | | | |
| Age (years)<br>mean (SD, range) | 68 (8.8) (39-86) | 69 (10) (52-82) | 68 (8.6) (39-86) | .86 |
| Gender (women)<br>n (%) | 49 (44) | 9 (50) | 40 (43) | .51 |
| Education level[b]<br>n (%) | 1: 16 (14)<br>2: 23 (21)<br>3: 25 (22)<br>4: 29 (26)<br>5: 19 (17) | 1: 3 (17)<br>2: 3 (17)<br>3: 2 (11)<br>4: 8 (44)<br>5: 2 (11) | 1: 13 (14)<br>2: 20 (21)<br>3: 23 (25)<br>4: 21 (22)<br>5: 17 (18) | .36 |
| Diagnosis[c]<br>n (%) | AD: 65 (58)<br>VaD: 2 (2)<br>DLB: 1 (1)<br>FTD: 3 (3)<br>MCI: 9 (8)<br>Other: 27 (24)<br>Unresolved: 5 (4) | AD: 12 (67)<br>VaD: 0<br>DLB: 1(6)<br>FTD: 0<br>MCI: 2 (11)<br>Other: 2 (11)<br>Unresolved: 1 (6) | AD: 53 (56)<br>VaD: 2 (2)<br>DLB: 0<br>FTD: 3 (3)<br>MCI: 7 (8)<br>Other: 25 (26)<br>Unresolved: 4 (4) | .29 |
| Months since diagnosis<br>mean (SD, range) | 12 (15) (0-73) | 6 (7) (0-25) | 16 (14) (0-73) | .046 |
| MMSE score[d]<br>mean (SD, range) | 25 (4.2) (11-30) | 25 (5) (11-30) | 25 (4) (11-30) | .69 |
| Caregiver included (yes)<br>n (%) | 98 (88) | 15 (83) | 83 (88) | .70 |
| Caregiver gender (women) | 58 (59) | 8 (44) | 50 (60) | .78 |

| | | | | |
|---|---|---|---|---|
| n (%) | | | | |
| Caregiver relation[e] n (%) | Spouse: 81 (83) Son/daughter: (13) Other: 4 (4) | Spouse: 11 (73) Son/daughter: 4 (27) Other: 0 | Spouse: 70 (84) Son/daughter: 9 (11) Other: 4 (5) | .30 |
| Caregiver adoptor or non-adoptor of the app[a] (adoptor) n (%) | 7 (6) | 3 (17) | 4 (4) | .08 |
| Caregiver activated the app[f] (yes) n (%) | 21 (19) | 8 (44) | 13 (14) | .02 |

[a]Adoptors/Non-adoptors: Adoption was defined use of the app for ≥ 90 days.
[b]Education level: 1: Primary school/≤10 years, 2: Vocational education/11-12 years, 3: Short higher education/13-14 years, 4: Bachelor's degree/15-16 yeas, 5: Master's degree or more/≥17 years.
[c]Diagnosis: AD: Alzheimer's disease, VaD: Vascular dementia, DLB: dementia with Lewy bodies, FTD: Frontotemporal dementia, MCI: Mild Cognitive Impairment, Other: e.g. Stroke, Huntington's Disease and unspecified dementia diagnosis. Unresolved: Participants who were not diagnosed at the time of inclusion.
[d]MMSE: higher scores indicate higher attainment. The scores on MMSE are the most recent score documented in the participants' medical record. Data on months between latest MMSE score and study inclusion showed MMSE were on average conducted 9 months prior to inclusion (SD=10 , range 0-47), and 79 % of the MMSEs were conducted less than 12 months prior to inclusion.
[e]Caregiver relation: Other e.g. sibling or friend.
[f]Caregiver activated the app: Includes all levels of caregiver adoption status.

## Adoption

The details of adoption status and period of adherence are specified in Table 2, showing that 18 participants (16 %) and 7 (7 %) of the caregivers became adoptors. Forty-seven (42%) participants and 78 (80 %) caregivers never activated the app. However, if adoption status was based only on those who had activated the app, 28 percent of participants and 35 percent of caregivers became adoptors. The aim of this study was to explore both non-use, abandonment and adoption and therefore data from the entire population are included in data analysis when applicable. Caregivers had also activated the app in 44 percent of the 18 cases where the participants became adoptors, and in three of these cases both the participant and caregiver were adoptors. In 4 additional cases the caregiver became adoptor without the participant becoming adoptor.

Table 2. Adoption status and period of adherence among participants and caregivers

| | **Adoption status** | **Participants** N=112 | **Caregivers** N=98 |
|---|---|---|---|
| | | | |
| | Never used the app (0 days), n (%) | 47 (42) | 78 (80) |
| **Activated the app** | Short use (1-10 days), n (%) | 19 (17) | 7 (7) |
| | Early abandonment (11-31 days), n (%) | 11 (10) | 2 (2) |
| | late abandonment (32-89 days), n (%) | 17 (15) | 4 (4) |
| | Adoptor (≥90 days), n (%) | 18 (16) | 7 (7) |

As summarised in Table 1, when comparing adoptors with non-adoptors results showed that time from diagnosis was significantly lower for adoptors (Mdn=4 months) than for non-adoptors (Mdn=8 months) U=595 P=0.046, r=.19. There was also a significant association between participants' adoption status and whether caregivers had activated the app (p=.02; FET). There were no significant associations for other characteristics.

An exploratory logistic regression analysis was performed to assess the impact of baseline characteristics and caregiver's app activities on participant adoptor status. As shown in Table 3 caregivers having used the app was a significant predictor of a participant's adoption status (OR 5.1; 95% CI 1.29-19.99; P=.02). Results indicated that a participant was 5 times more likely to become an adoptor when a caregiver had engaged in activating the app.

Table 3. Logistic regression: The impact of baseline characteristics and caregiver's app activities on participant adoption status

| **Included** | **β (SE)** | **P** | **OR** | **(95% CI)** | |
|---|---|---|---|---|---|
| | | | | | |
| | | | | Lower | Upper |
| Participant age | -.03 (.03) | .29 | .97 | .91 | 1.03 |
| Participant gender | -.27 (.60) | .65 | .76 | .24 | 2.47 |
| Months since diagnosis | -.01 (.02) | .74 | .99 | .96 | 1.03 |
| MMSE score | -.09 (.06) | .17 | .92 | .81 | 1.04 |
| Caregiver adoption status | .13 (1.01) | .90 | 1.1 | .16 | 8.24 |
| Caregiver activated the app | 1.6 (.70) | .02 | 5.1 | 1.29 | 19.99 |
| Constant | 2.5 (2.83) | .29 | 12.4 | | |

Data from the survey provided additional information on adoptors versus non-adoptors. As summarised in table 4 there were no significant differences in either disease-related or background characteristics between participants who replied to the survey and those who did not reply. However, months since diagnosis was close to significance (p=.06).

Table 4. Baseline characteristics of participants who replied to survey compared to participants who did not reply to the survey

| **Characteristics** | **Participant Reply to survey** (N=35) | **Participant No reply to survey** (N=77) | **P** |
|---|---|---|---|
| | | | |
| Age (years) mean (SD, range) | 68 (9.7) (52-86) | 69 (8.5) (39-83) | .65 |
| Gender (women) n (%) | 15 (46) | 33 (43) | .84 |
| Education level[a] n (%) | 1: 6 (18)<br>2: 6 (18)<br>3: 6 (18)<br>4: 9 (27)<br>5: 6 (18) | 1: 10 (13)<br>2: 16 (21)<br>3: 19 (25)<br>4: 19 (25)<br>5: 13 (17) | .92 |
| Diagnosis[b] n (%) | AD: 21 (64)<br>VaD: 0<br>DLB: 1(3)<br>FTD: 0<br>MCI: 4 (12)<br>Other: 6 (15)<br>Unresolved: 2 (6) | AD: 43 (56)<br>VaD: 2 (3)<br>DLB: 0<br>FTD: 3 (4)<br>MCI: 5 (7)<br>Other: 21 (27)<br>Unresolved: 3 (4) | .33 |
| Months since diagnosis mean (SD, range) | 9 (12) (0-61) | 14 (15) (0-73) | .06 |
| MMSE score[c] mean (SD, range) | 26 (4.1) (11-30) | 24 (4.4) (11-30) | .12 |

[a]Education level: 1: Primary school/≤10 years, 2: Vocational education/11-12 years, 3: Short higher education/13-14 years, 4: Bachelor's degree/15-16 yeas, 5: Master's degree or more/≥17 years.
[b]Diagnosis: AD: Alzheimer's disease, VaD: Vascular dementia, DLB: Lewy Body Dementia, FTD: Frontotemporal dementia, MCI: Mild Cognitive Impairment, Other: e.g. Huntington's Disease or stroke. Unresolved: Participants who were not diagnosed at the time of inclusion.
[c]MMSE: higher scores indicate higher attainment. The scores on MMSE are the most recent score documented in the participants' medical record.

The survey gave opportunity to further explore reasons why participants did not use the app or become an adoptor. As outlined in table 5 there were no significant differences between adoptors

and non-adoptors regarding their level of experience, skills and need for help when using a tablet, both when rated by the participant and by caregivers.

Table 5. Data from survey: participant's and caregiver's rating of the participant's level of experience, skills and need for help when using a tablet

| **Participant and caregivers' by-proxy rating**[a] | | **Adoptor**[b] | **Non-adoptor**[b] | **P** |
|---|---|---|---|---|
| | | | | |
| Participant:<br>Level of experience as tablet user<br>n (% within group) | Much experience:<br>Some experience:<br>Little experience:<br>Novel user: | 2 (15)<br>7 (54)<br>1 (8)<br>3 (23) | 5 (28)<br>5 (28)<br>4 (22)<br>4 (22) | .49 |
| Participant:<br>Skills as tablet user<br>n (% within group) | Uncomplicated:<br>A little difficult:<br>Quite difficult:<br>Very difficult: | 7 (54)<br>5 (38)<br>1 (8)<br>0 | 7 (44)<br>2 (12)<br>5 (31)<br>2 (12) | .15 |
| Participant:<br>Help from others when using tablet<br>n (% within group) | No help:<br>A little help:<br>Some help:<br>A lot of help: | 5 (38)<br>6 (46)<br>1 (8)<br>1 (8) | 6 (33)<br>5 (28)<br>3 (17)<br>4 (22) | .54 |
| Caregiver/by-proxy:<br>Level of experience as tablet user<br>n (% within group) | Much experience:<br>Some experience:<br>Little experience:<br>Novel user: | 3 (38)<br>3 (38)<br>1 (12)<br>1 (12) | 4 (19)<br>7 (33)<br>7 (33)<br>3 (14) | .41 |
| Caregiver/by-proxy:<br>Skills as tablet user<br>n (% within group) | Uncomplicated:<br>A little difficult:<br>Quite difficult:<br>Very difficult: | 3 (37)<br>3 (37)<br>2 (35)<br>0 | 6 (30)<br>3 (15)<br>6 (30)<br>5 (25) | .38 |
| Caregiver/by-proxy:<br>Help from others when using tablet<br>n (% within group) | No help:<br>A little help:<br>Some help:<br>A lot of help: | 2 (25)<br>4 (50)<br>2 (25)<br>0 | 3 (14)<br>8 (36)<br>4 (18)<br>7 (32) | .28 |

[a]Ratings cannot be compared between participants and caregivers since participant's and caregiver's rating does not refer to parallel cases.
[b]Answers were not complete to all questions, hence the total number of answers on each question varies for both participants and caregivers

In those cases where the app had not been activated by the participant or the person had stopped using it, the survey gave opportunity to comment on reasons for not using or adopting the app. These comments are summarised in themes (Textbox 1). The results indicated that both among participants and caregivers common reasons were that the app either did not fit their needs, some

indicated the using the app was 'too early' from the perspective of living with a progressive dementia disease, and others found it too difficult to use. Some indicated that they preferred using standard off-the-shelf software, e.g. the calendar app that is pre-installed in the device, others preferred to continue using a paper diary. Reasons for not using the app were in some cases also related to cognitive symptoms caused by the dementia disease, e.g. some participants forgot to use the app or had lost the ability to use a tablet, indicating that this kind of AT was introduced too late for the person with a progressive disease.

Textbox 1. Participants' and caregivers' reasons for not using the app

**Theme: Participant intend to start using the app:**

**Quotes participants:** *I want to use the app, I just need to learn how to use it*
*I will try to install the app*
*I think I will start using it, the calendar would be nice to have.*

**Theme: Using the app was found premature:**

**Quotes participants:** *It's not relevant for me...yet.*
*It was too simple for him.*

**Quotes caregivers:** *I think we will wait until it is the right time to use it.*

**Theme: Participant do not use the app due to dementia symptoms:**

**Quotes participants:** *I forget to use it.*
*I don't think about using it…I forget.*
*Frankly, I have forgotten that I have ever heard of it.*

**Quotes caregivers:** *He is not able to use the iPad anymore.*
*She has opened the app a few times, she but does not understand how to use it. It is too late to introduce it.*
*The problem is my wife forgets to use it.*
*Our X probably got the app too late.*
*X feels under surveillance when using the app.*

**Theme: Participant prefer to use other technology solutions:**

**Quotes participants:** *I am happy with the things I use already.*
*I use a computer for e-mails, calendar and things like that…I have an iPad, but I haven't started using it yet.*
*When I read more about what the app could do I realised that I was covered by the things I already use, and I like using the things that I already know.*
*I prefer to use the calendar that is installed on my phone.*

**Quotes caregivers:** *X prefers to use the calendar which is installed on the iPad.*

**Theme: Participant prefer to non-technology solutions:**

**Quotes participants:** *It is easier for me to use a paper diary.*
*I prefer my paper diary.*

**Quotes caregivers:** *X finds it easier to use an ordinary paper diary.*

### Use patterns and usability

To enable a more detailed analysis of use patterns of those participants who activated the app (N=65) they were split into four groups based on number of days they had been users of the app (number of days from first to last activity in the app, with a maximum of 90 days): Short use (1-10 days), Early abandonment (11-31 days), late abandonment (32-90 days), adoptor (≥90 days). These are summarised as part of Table 2.

The number of activities in the app for the four groups of participants who had activated the app is summarised in Figure 2, which illustrates a clear tendency that a longer period of using the app generated more activities in the app, however there was a quite large within-group variation.

Figure 2. Number of activities in the app (max. 90 days) for all participants who activated the app

To further assess if the content of the app was relevant to users, or if adaptions were needed, data from adoptors were further analysed. The number of times each functionality was used by a participant or caregiver is illustrated in Figure 3.

Figure 3. Log data from adoptors illustrating what app-functionalities were used.

The level of satisfaction with the app could be analysed based on data from USEdem questionnaire. Analysis of results (not illustrated) showed an overall average score of 40 (SD 9.4, range 21-55) for participants and 34 (SD 12, range 18-51) for caregivers, which indicated a generally positive rating of the app with regards to usefulness, satisfaction, and ease of use, but with large variation. For the participants the score on the USEdem questionnaire was significantly higher for adoptors (Mdn=46) compared to non-adoptors (Mdn=38) U=5.5 P=0.02, r=64. There was also a tendency towards higher scores on by-proxy replies from caregivers to participants who became adoptors, but this difference did not reach statistical significance (p=0.14).

## Discussion

The aims of this study were to investigate the applicability and usability of the ReACT app in a mixed group of people with dementia and to investigate user-patterns, factors influencing

adoption and possible impact of caregiver involvement. The study also served as a process evaluation of both the app and methods for implementation.

## Participant profiles

According to study objectives a heterogeneous sample of people referred to a memory clinic were included in the study. As expected from a mixed population of people with dementia, most of the participants were diagnosed with Alzheimer's disease, however the frequency was higher among participants in this study compared to a general Danish population of people referred to a memory clinic [21], and participants were also on average younger compared to a general population of people referred to a memory clinic [21].

The relatively low age of participants could reflect an age/generation related higher frequency of using tablets and apps among middle-aged and younger seniors compared to older generations [22]. However, it is also important to notice the relatively wide age-range among participants and that there was no significant age difference between adoptors and non-adoptors, underlining the importance of not letting age be a determinant when presenting AT to people with dementia.

## Disease-related factors had influence on adoption

The MMSE scores, indicating level of cognitive function, were generally higher among participants than in a general Danish population of people referred to a memory [21]. These results indicate that participants who were interested in using the app, and hence included in the study, were generally at an early stage of dementia, and this was consistent with the target group of the app. There was no significant difference on MMSE scores for adoptors versus non-adoptors, indicating that AT should not be guided by results from cognitive screening tests. However, time since diagnosis was statistically significant and can be considered a pseudo marker for disease severity. This finding shows that timely introduction of AT can be of great importance for successful adoption. Comments from the survey indicated that reasons for non-adoption in some cases were that it was considered too early to use AT tailormade for people with dementia and standard off-the-shelf software met the participant's current needs. This preference to use off-the-shelf technology to support people with dementia and family caregivers has also been observed in other studies [23, 24]. In other cases, comments revealed that the app was introduced too late, at

a stage where the participant was no longer able to learn how to use it or had lost the ability to use a touch-screen device. This notion of timely introduction of technology is in line with the general emphasis on the importance of timely delivery of support and interventions for people with dementia [25, 26] and it underlines the importance of providing clear and user-centred labelling of AT for people with dementia, enabling users and caregivers to choose a solution that fits their current needs and resources, and professionals to give individualised advice on the use of AT, and thereby provide genuinely person-centred AT to people with dementia.

As illustrated in Figure 1 the app was designed to be adaptable and could be tailored to fit individual preferences and skills. The idea was the app could either from the start be adapted to a person with a more advanced stage of dementia, or over time gradually be adapted to fit the changing needs due to progressive cognitive symptoms. As summarised in Figure 3 analysis of log data from adoptors showed that adaptive features of the app were only activated 12 times for participants and 15 times by caregivers, indicating that perhaps there is a need to promote these features more strongly. Future studies will be needed to explore if these adaptable features are suitable to fit the changing needs of a user, or if such features should be further adapted.
In general, research is needed to explore how long-term adherence to technology can be supported among people with dementia and to define realistic goals for long-term adherence among this group. It is also important to consider whether progressive cognitive symptoms might imply that aiming for long-term adherence is too ambitious. Various models and frameworks have been proposed for successful innovation, design and implementation of AT [27] and eHealth solutions [28, 29]. The holistic framework to improve the uptake and impact of eHealth technologies proposed by Van Gemert-Pijnen et al. [29] has been applied within the field of dementia [30]. It is clearly important to consider the progressive nature of dementia diseases and how it affects AT needs and skill over time and to include such variable disease-related factors in these frameworks when guiding the innovation and implementation life-cycles of AT for people with dementia.

## Caregiver involvement

Our results clearly indicated that caregiver involvement in using the app could influence participants' adoption of it. These results are in line with other studies finding caregiver engagement important for the everyday use of technology among people with dementia [23]. The benefits of caregiver involvement have implications for the design and implementation of AT for people with dementia. AT should be designed to promote convenient and flexible caregiver support in a way that is feasible and acceptable for both the person with dementia and the caregiver. There are however important issues of privacy and ethics that need to be addressed when designing and implementing AT [31]. The ReACT app was designed as a web-based app, it could be accessed from several devices simultaneously, and this allowed flexible caregiver support. Our design also allows the person with dementia to decline caregiver support, since caregiver access could be de-activated, this option was however never used during the study. In many cases the caregiver undoubtedly also supported the use of the app alongside the participant without accessing their parallel login, but our data does not provide enough insight into this use-pattern.

The benefits of caregiver involvement also highlight the need to provide information and guidance to caregivers on how they can best support people with dementia in using AT. In this study this was done by providing written and online-material giving advice on caregiver involvement. The need to consider methods to support caregiver involvement has also been discussed by others [23], stressing the need to address both the person with dementia and caregivers, and their mutual cooperation on AT use, when designing methods for implementation of AT.

It is important to notice however, that in some cases participants adopted the app and were high-frequency users with minimal or no caregiver involvement, again indicating a large variation among adoptors, and stressing that the person with dementia should be addressed as the main user of AT for people with dementia.

The regression analysis showed that none of the participants' background characteristics could predict participant's adoption status and overall the regression to predict adoption was relatively low in predictive power (Nagelkerke $R^2$= ,173) underlining that a complex set of personal and contextual features influence adoption of AT, making it difficult to predict adoption and

adherence. It also underlines the limited applicability of models trying to predict use of AT among this group of users which have been proposed by others [32].

### Usability and use-patterns

Data from the surveys revealed that there were no significant differences between adoptors and non-adoptors when it came to how much experience they had using a tablet, their skills when using it and how much help they needed to use it. Some of the adoptors were even characterised as novel users, indicating the app is applicable for a varied group of users and can be used despite a low level of tablet skills, which has also been demonstrated in a previous pilot study [16]. This finding is similar to other studies demonstrating the accessibly and user-friendliness of tablet computers and app-based interventions for people with dementia [33, 34].

Use-patterns among all participants who activated the app is illustrated in Figure 2 showing considerable variation in how intensively the app is used in all groups. Interestingly, among non-adoptors who abandoned the app late (after 32 to 89 days of use) there were users who used the app quite intensively. The reasons for their late abandonment of the app was not revealed by our data, since most were lost to follow-up in the survey. These log data indicates that it can be of great importance that both people with dementia and caregivers are provided support not just at the beginning of a self-applied intervention like this, but also during the intervention to support continued use of the app. Further studies are needed to address what kind of support is needed and how it is best delivered.

The results from the USEdem questionnaire revealed a relatively high satisfaction with the app among participants and caregivers, but with some variation, and participants who became adoptors rated it significantly higher than non-adoptors. Results from caregivers were generally less positive, this should of course be investigated further. However, data quality on this questionnaire was limited due to the small numbers of replies.

Log data showed that all functionalities in the app were used, as illustrated in Figure 3. There was of course variation, reflecting that some functionalities were by nature more frequently used, e.g. appointment and memos, compared to others, e.g. search. Consequently, this part of the process evaluation did not imply major changes of the app.

## Limitations

This study has several limitations which should be acknowledged. Participants were recruited from memory clinics and consequently only people who have sought a diagnosis and had contact with a memory clinic were included. This limitation will be addressed in a subsequent study with open access to the app. In addition, staff could have been biasing inclusion. Even though information on the study was generally available in the clinics, inclusion was also promoted by staff and they could have been directing information to sub-groups of participants, based on common ideas of who can benefit from using AT, e.g. younger participants or those with mild cognitive symptoms. In addition, a number of participants did not have a dementia diagnosis, hence describing participants as a group of people with dementia could be considered imprecise. There was also a quite large proportion of participants who were categorised as 'other', e.g. having a non-specific dementia diagnosis or stroke, and many of these did not become adoptors. This could indicate a risk of bias from participants being included whose needs did not match the design and functionalities of the app. The study did however aim to apply the intervention to a broad group of potential end-users, allowing their own need and motivation to guide inclusion, rather than specific disease-related factors. Though the relatively large proportion of 'others' who were non-adopters underline the need for clear and user-centred labelling of AT for people with dementia as discussed previously.

Another limitation was that the app could only be used on one series of tablets (iPads) during this study and this of course excluded potential participants who had access to other kinds of tablets. For practical and financial reasons one specific type of tablet had to be selected when designing the app for this study, and selection was based on various factors, e.g. that the iPad was the most common tablet in Denmark [35].

Data included in this study were generally rich and provided interesting results and observations, however there were also limitations in relation to data quality and quantity. Disease related information was only obtained from medical records and no pre-post measures were applied. This could be changed in future studies, however, as shown by previous studies [36, 37] it is difficult to capture the essence of such interventions by applying traditional outcome measures addressing e.g. cognition, daily activities or quality of life. In line with the broader field of psychosocial

interventions there is a great need to develop outcome measures which are more appropriate for the specific intervention [38]. In addition, applying a survey to this group of end-users causes limitations. Completing a survey can be challenging for a person with dementia and impossible for those more severely affected by their disease. Our results showed that months since diagnosis was close to significance (p=.06) when comparing participants who replied to the survey with those who did not reply, indicating a risk that data could be biased by being collected from participants who were less severely affected by their disease. In addition, the amount of survey data obtained from caregivers was limited. Even though data quantity was low, the survey did contribute valuable data. In future studies we suggest that feasibility of surveys must be considered, but not generally abandoned as a method for data collection among this group of participants.

The study was designed to provide separate log data from participants and caregivers, however this does not reveal all details on how the app is used in real life, e.g. caregiver support could be more intense than revealed by current data. In future studies richer data can be obtained by including more qualitative data, e.g. by interviewing participants and caregivers. The aim of the study was, however, to obtain detailed data from a large group of potential users of the app and this could be obtained by the mixed methods design applied in this study. Analysis of extensive log data from participants and caregivers brings an important new methodology to this field of research.

## Conclusions

Results of this study showed that the ReACT app was applicable and useful for a mixed population of people with dementia and that the methods used for deployment and self-applied implementation were applicable for this group of end-users.

The study clearly demonstrated the benefits of applying mixed methods when accessing applicability, usability and effectiveness of AT. The analysis of detailed log data contributed valuable insights into use-patterns and allowed a detailed analysis of factors influencing adoption. In addition, it provided detailed data used in the process evaluation and validation of the ReACT app. To the best of the authors' knowledge this study is the first to include such a large and rich dataset from the everyday use of AT among people with dementia and their family caregivers.

Results from the study revealed factors that could influence adoption of AT among people with dementia. Timely introduction of AT and support from caregivers had significant influence on whether participants adopted the ReACT app. However, data also revealed great variation among adoptors when it came to personal, disease-related and contextual factors and the predictive value of caregiver involvement was small. This underlies that adoption of AT among people with dementia is influenced by a complex set of personal and contextual factors, which is made even more complex by the changing needs imposed by living with a progressive dementia disease. This complexity and variability restrain the extent to which adoption and adherence to AT can be predicted and underlines the importance of incorporating this wide range of changeable factors when designing and implementing AT for people with dementia.

## Ethics approval and consent to participate

The protocol for the ReACT study was evaluated by the regional scientific ethical committees of The Capital Region of Denmark (protocol number H-15005558), who decided the study did not need approval, since it was not considered to be within the framework of biomedical research. All participants received oral and written information about the study objectives and methods and they all gave written informed consent.

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## Conflicts of Interest

None.

## Abbreviations

AT - Assistive technology

MMSE - Mini-Mental State Examination

ReACT - Rehabilitation in Alzheimer's disease using Cognitive support Technology

## References


1. Prince MJ. 2015. Alzheimer's Disease International. World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends. https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf. Archived at: http://www.webcitation.org/6n4mswcQg
2. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. 2016. World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future. https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf. Archived at: http://www.webcitation.org/6oh3f64VB
3. World Health Organisation. 2017. World Health Organisation (WHO). Global action plan on the public health response to dementia 2017–2025. http://apps.who.int/iris/bitstream/handle/10665/259615/?sequence=1. Archived at: http://www.webcitation.org/6FamFFyd8
4. Asghar I, Cang S, Yu H. Assistive technology for people with dementia: an overview and bibliometric study. Health Information & Libraries Journal. 2017;(34):5-19 doi:10.1111/hir.12173.
5. Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia. 2016;(15):681-701 doi:10.1177/1471301214532643.
6. Knapp M, Barlow J, Comas-Herrera A, Damant J, Freddolino PP, Hamblin K, et al. 2015. The case for investment in technology to manage the global costs of dementia. http://eprints.lse.ac.uk/66482/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_LSEE_The%20case%20for%20investment%20in%20technology.pdf. Archived at: http://www.webcitation.org/6lBdC3Jtp
7. Kenigsberg P-A, Aquino J-P, Bérard A, Brémond F, Charras K, Dening T, et al. Assistive technologies to address capabilities of people with dementia: from research to practice. Dementia. 2017:1471301217714093 doi:10.1177/1471301217714093.
8. Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR rehabilitation and assistive technologies. 2017;(4(1)) doi:10.2196/rehab.6376.
9. Fabricatore C, Radovic D, Lopez X, Grasso-Cladera A, Salas CE. When technology cares for people with dementia: A critical review using neuropsychological rehabilitation as a conceptual framework. Neuropsychological Rehabilitation. 2019:1-40 doi:10.1080/09602011.2019.1589532.
10. 2019. Assistive Technology Industry Association. What is AT? - Assistive Technology Industry Association. http://www.atia.org/at-resources/what-is-at/. Archived at: http://www.webcitation.org/6lHhBGu7u
11. Ienca M, Fabrice J, Elger B, Caon M, Pappagallo AS, Kressig RW, et al. Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. Journal of Alzheimer's Disease. 2017;(56):1301-40 doi:10.3233/JAD-179005.
12. King AC, Dwan C. Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. Dementia. 2017:1471301217735180 doi:10.1177/1471301217735180.

13. Eysenbach G. The law of attrition. Journal of Medical Internet Research. 2005;(7,1):e11 doi:10.2196/jmir.7.1.e11.

14. Krebs P, Duncan DT. Health app use among US mobile phone owners: a national survey. JMIR mHealth and uHealth. 2015;(3):e101 doi:10.2196/mhealth.4924.

15. van Gemert-Pijnen JE, Kelders SM, Bohlmeijer ET. Understanding the usage of content in a mental health intervention for depression: an analysis of log data. Journal of Medical Internet Research. 2014;(16) doi:10.2196/jmir.2991.

16. Øksnebjerg L, Woods B, Waldemar G. Designing the ReACT app to support self-management of people with dementia - an iterative user-involving process. Gerontology (in press). 2019.

17. Øksnebjerg L, Woods B, Vilsen CR, Ruth K, Gustafsson, Moa, Ringkøbing SP, et al. Self-management and cognitive rehabilitation in early stage dementia – merging methods to promote coping and adoption of assistive technology. A pilot study. 2019.

18. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975;(12):189-98.

19. Lund AM. Measuring usability with the use questionnaire. Usability interface. 2001;(8):3-6.

20. Leech NL, Onwuegbuzie AJ. An array of qualitative data analysis tools: a call for data analysis triangulation. School Psychology Quarterly. 2007;(22):557.

21. Fereshtehnejad S-M, Johannsen P, Waldemar G, Eriksdotter M. Dementia diagnosis, treatment, and care in specialist clinics in two Scandinavian countries: A data comparison between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry. Journal of Alzheimer's Disease. 2015;(48):229-39 doi:10.3233/JAD-150144.

22. Slots- og Kulturstyrelsen 2018. Mediernes udvikling i Danmark 2018. Internetbrug og enheder. https://mediernesudvikling.slks.dk/2018/internetbrug-og-enheder/.

23. Gibson G, Dickinson C, Brittain K, Robinson LA. Personalisation, customisation and bricolage: How people with dementia and their families make assistive technology work for them. Ageing & Society. 2018:1-18 doi:doi.org/10.1017/S0144686X18000661.

24. Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J. Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. Dementia. 2019;(18):725-41 doi:10.1177/1471301217691617.

25. Dawson A, Bowes A, Kelly F, Velzke K, Ward R. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. BMC Geriatrics. 2015;(15):59 doi:10.1186/s12877-015-0053-9.

26. Prince M, Bryce R, Ferri C. 2011. World Alzheimer Report 2011: The benefits of early diagnosis and intervention. https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf. Archived at: http://www.webcitation.org/6FamFFyd8

27. Vichitvanichphong S, Talaei-Khoei A, Kerr D, Ghapanchi AH. Adoption of assistive technologies for aged care: A realist review of recent studies. 2014 47th Hawaii International Conference on System Sciences (HICSS),. 2014:2706-15 doi:10.1109/HICSS.2014.341.

28. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up,

spread, and sustainability of health and care technologies. Journal of Medical Internet Research. 2017;(19) doi:10.2196/jmir.8775.

29. van Gemert-Pijnen JE, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, et al. A holistic framework to improve the uptake and impact of eHealth technologies. Journal of Medical Internet Research. 2011;(13) doi:10.2196/jmir.1672.
30. van Gemert-Pijnen L, Span M. CeHRes roadmap to improve dementia care. In: van Hoof J, Demiris G, Wouter EJM, editors. Handbook of Smart Homes, Health Care and Well-Being. Switzerland: Springer; 2017. p. 133-46.
31. Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. Ethical design of intelligent assistive technologies for dementia: a descriptive review. Science and engineering ethics. 2017:1-21 doi:10.1007/s11948-017-9976-1.
32. Chaurasia P, McClean SI, Nugent CD, Cleland I, Zhang S, Donnelly MP, et al. Modelling assistive technology adoption for people with dementia. Journal of Biomedical Informatics. 2016;(63):235-48 doi:10.1016/j.jbi.2016.08.021.
33. Joddrell P, Astell AJ. Studies involving people with dementia and touchscreen technology: a literature review. JMIR rehabilitation and assistive technologies. 2016;(3) doi:10.2196/rehab.5788.
34. Lim FS, Wallace T, Luszcz MA, Reynolds KJ. Usability of tablet computers by people with early-stage dementia. Gerontology. 2013;(59):174-82 doi:10.1159/000343986.
35. 2016. Computer World, Nye danske data afslører: Her er de mest populære smartphones i Danmark https://www.computerworld.dk/art/238637/nye-danske-data-afsloerer-her-er-de-mest-populaere-smartphones-i-danmark.
36. Hattink B, Meiland F, Overmars-Marx T, de Boer M, Ebben P, van Blanken M, et al. The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact. Disability and Rehabilitation: Assistive Technology. 2016;(11):61-71 doi:10.3109/17483107.2014.932022.
37. Meiland FJ, Bouman AI, Sävenstedt S, Bentvelzen S, Davies RJ, Mulvenna MD, et al. Usability of a new electronic assistive device for community-dwelling persons with mild dementia. Aging & Mental Health. 2012;(16):584-91 doi:10.1080/13607863.2011.651433.
38. Øksnebjerg L, Diaz-Ponce A, Gove D, Moniz-Cook E, Mountain G, Chattat R, et al. Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. Health Expectations. 2018;(21):1056-65 doi:10.1111/hex.12799.

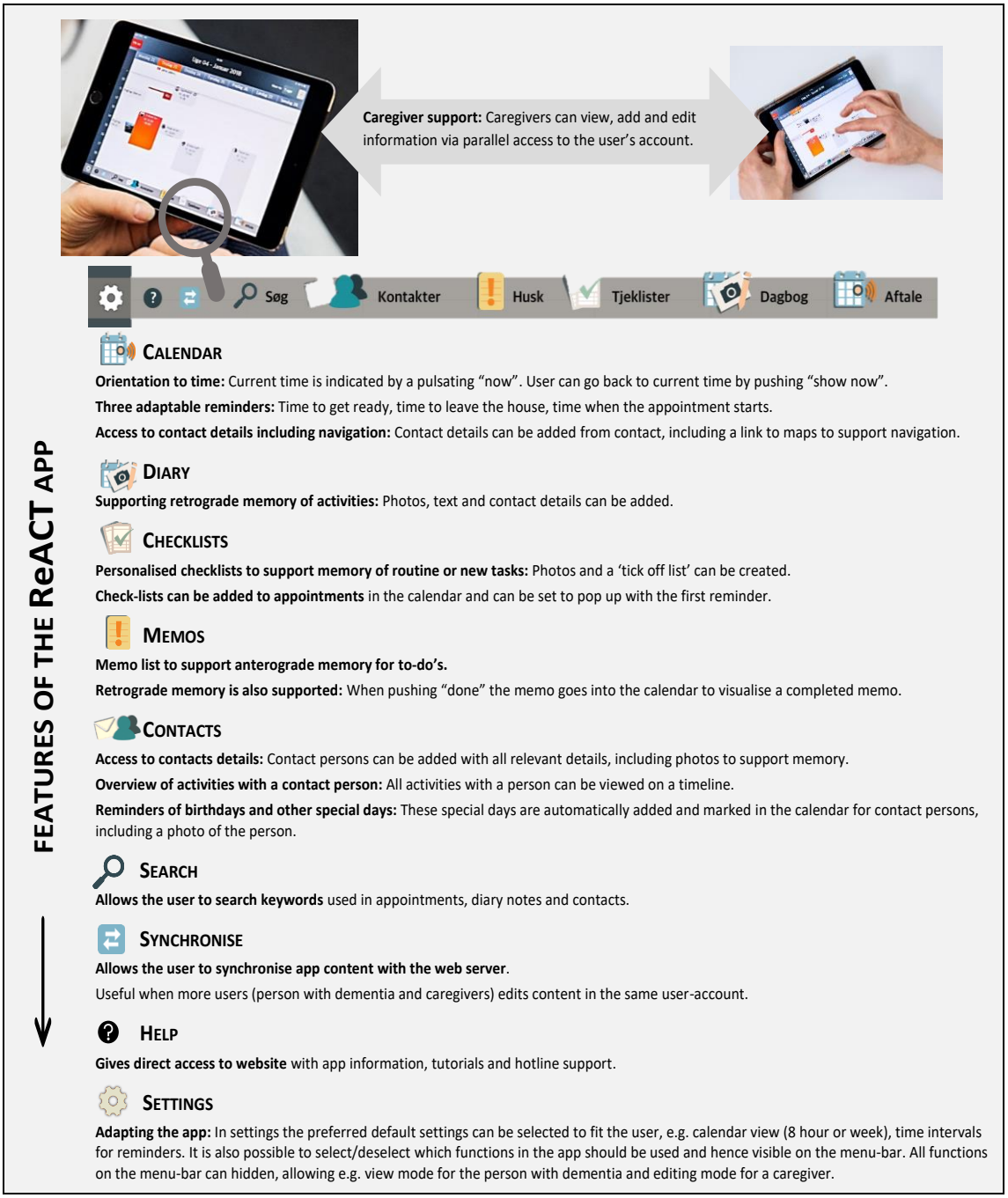


Figure 1. Features of the ReACT app

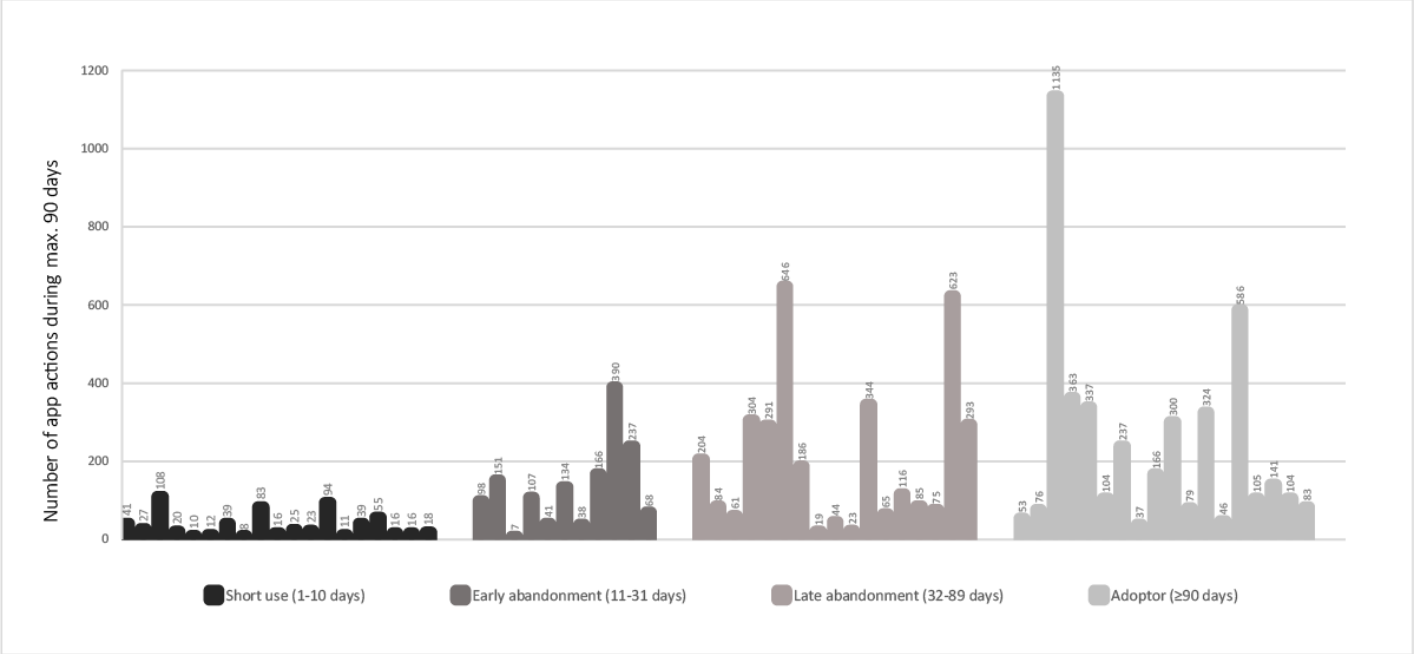


Figure 2. Number of activities in the app (max. 90 days) for all participants who activated the app

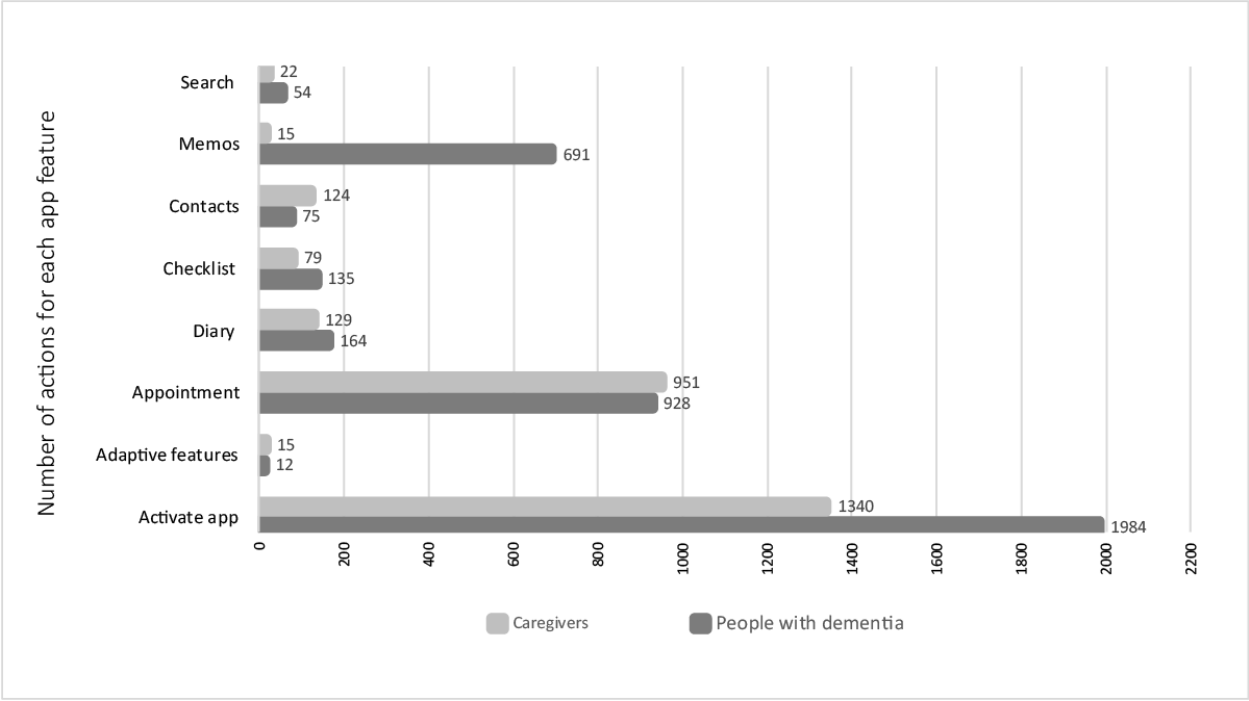


Figure 3. Log data from adoptors illustrating what app-functionalities were used.

## Identificering af 3 personlige mål

**Mål nr. 1**
**Beskriv, gerne med detaljer og eksempler:**

**Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :

**Hvor vigtigt er mål nr. 1 for dig:**

Ikke vigtigt ①②③④⑤⑥⑦⑧⑨⑩ Meget vigtigt

**Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :

**Hvor parat er du til ændringer for at nå mål nr. 1:**

Ikke parat til ændring ①②③④⑤⑥⑦⑧⑨⑩ Yderst parat til ændring

**Mål nr. 2**
**Beskriv, gerne med detaljer og eksempler:**

**Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :

**Hvor vigtigt er mål nr. 2 for dig:**

Ikke vigtigt ①②③④⑤⑥⑦⑧⑨⑩ Meget vigtigt

**Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :

**Hvor parat er du til ændringer for at nå mål nr. 2.**

Ikke parat til ændring ①②③④⑤⑥⑦⑧⑨⑩ Yderst parat til ændring

| |
|---|
| **<u>Mål nr. 3</u>**<br>**Beskriv, gerne med detaljer og eksempler:** |
| **Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :<br>**Hvor vigtigt er mål nr. 3 for dig:**<br>Ikke vigtigt ①②③④⑤⑥⑦⑧⑨⑩ Meget vigtigt |
| **Spørgsmål til deltageren** (vis skala til deltageren, appendix A) :<br>**Hvor parat er du til ændringer for at nå mål nr. 3?**<br>Ikke parat til ændring ①②③④⑤⑥⑦⑧⑨⑩ Yderst parat til ændring |

## Deltagerens 3 mål formueret som SMART mål (Specifik, Målbar, Aktiv, Realistisk, Tidsbegrænset)

**Mål nr. 1/2/3**

| | |
|---|---|
| **Nuværende funktionsniveau** Deltagers beskrivelse og vurdering på skala (appendix B) | Beskrivelse:<br><br>Vurdering:<br>Slet ikke i stand til ①②③④⑤⑥⑦⑧⑨⑩ Helt uden problemer<br>Deltagerens tilfredshed med det nuværende funktionsniveau<br>Slet ikke tilfreds ①②③④⑤⑥⑦⑧⑨⑩ Meget tilfreds |
| **Nuværende funktionsniveau** Pårørendes beskrivelse og vurdering på skala (appendix B) | Beskrivelse:<br><br>Vurdering:<br>Slet ikke i stand til ①②③④⑤⑥⑦⑧⑨⑩ Helt uden problemer |
| **100 % opnåelse af mål =** | *"Hvordan vil det være/opleves hvis målet er opnået 100%?".* Beskrivelse: |
| **75 % opnåelse af mål =** | Beskrivelse: |
| **50 % opnåelse af mål =** | Beskrivelse: |
| **25 % opnåelse af mål =** | Beskrivelse: |
| **Ressourcer og barrierer** | Hvad kan deltageren gøre for at opnå målet? |
| | Hvad kan andre gøre/hvordan kan andre bedst støtte, så målet opnås? (F.eks. pårørende, fagpersoner i ReACT) |
| | Hvilke ressourcer (ting, handlinger, aktiviteter) kan bidrage til, at målet opnås? |
| | Hvad kan forhindre, at målet opnås? |
| **Din faglige vurdering af nuværende funktion** | Slet ikke i stand til ①②③④⑤⑥⑦⑧⑨⑩ Helt uden problemer<br>Evt. kommentar: |

## <u>Evaluering af deltagerens mål</u> 1/2/3 (Midvejs/slut)

### <u>Beskrivelse og vurdering af færdigheder/funktionsniveau ift. mål</u>

1. Beskrivelse af aktuelt funktionsniveau (hhv. deltager, pårørende og fagperson).
2. Vurdering af aktuelt funktionsniveau (via skala, appendix B, som vises til deltager og pårørende).

   *Deltagerens nuværende funktionsniveau* ift. mål (vurderes af deltager, pårørende og fagperson):
   Slet ikke i stand til ①②③④⑤⑥⑦⑧⑨⑩ Helt uden problemer
3. Vurdering af deltagerens tilfredshed med funktionsniveau (via skala, appendix B, som vises til deltager).

   *Deltagerens tilfredshed med nuværende funktionsniveau ift. mål:*
   Slet ikke tilfreds ①②③④⑤⑥⑦⑧⑨⑩ Meget tilfreds

| **Beskrivelse og vurdering af hvert mål** | **Deltager** | **Pårørende** | **Dig (fagperson)** | **Fagpersons vurdering af % opnåelse af mål** (sæt ring) |
|---|---|---|---|---|
| 1: **<u>Mål nr. 1:</u>**<br>**Beskrivelse af aktuelt funktionsniveau** | | | | 25%<br>50%<br>75%<br>100% |
| 2: **Vurdering af funktionsniveau ift. mål nr. 1** | Angiv tal: | Angiv tal: | Angiv tal: | |
| 3: **Deltagerens tilfredshed med funktionsniveau ift. mål nr. 1** | Angiv tal: | | | |
| 1: **<u>Mål nr. 2:</u>**<br>**Beskrivelse af aktuelt funktionsniveau** | | | | 25%<br>50%<br>75%<br>100% |
| 2: **Vurdering af funktionsniveau ift. mål nr. 2** | Angiv tal: | Angiv tal: | Angiv tal: | |
| 3: **Deltagerens tilfredshed med funktionsniveau ift. mål nr. 2** | Angiv tal: | | | |
| 1: **<u>Mål nr. 3:</u>**<br>**Beskrivelse af aktuelt funktionsniveau** | | | | 25%<br>50%<br>75%<br>100% |
| 2: **Vurdering af funktionsniveau ift. mål nr. 3** | Angiv tal: | Angiv tal: | Angiv tal: | |
| 3: **Deltagerens tilfredshed med funktionsniveau ift. mål nr. 3** | Angiv tal: | | | |

## Appendix A:

**Besvares af deltageren**

## Hvor vigtigt er målet for dig?

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

Ikke vigtig — Meget vigtigt

## Hvor parat er du til ændringer for at nå målet?

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

Ikke parat til ændring — Yderst parat til ændring

**Appendix B:**

**Besvares af deltageren og pårørende (individuelle svar fra begge):**

## Nuværende færdigheder i forhold til målet

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

Slet ikke i stand til — Helt uden problemer

**Besvares af deltageren:**

## Tilfredshed med nuværende funktionsniveau i forhold til målet

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

Slet ikke tilfreds — Meget tilfreds

ICECAP-O

# Spørgsmål til din livskvalitet

*Sæt 1 kryds i hver sektion ud for den sætning der bedst beskriver din livskvalitet her og nu*

| **1. Kærlighed og venskab** | | |
|---|---|---|
| Jeg kan få al den kærlighed og venskab jeg ønsker | | 4 |
| Jeg kan få meget af den kærlighed og venskab jeg ønsker | | 3 |
| Jeg kan få lidt af den kærlighed og venskab jeg ønsker | | 2 |
| Jeg kan ikke få den kærlighed og venskab jeg ønsker | | 1 |

*Sæt 1 kryds*

| **2. Tanker om fremtiden** | | |
|---|---|---|
| Jeg tænker på fremtiden uden bekymringer. | | 4 |
| Jeg tænker på fremtiden med få bekymringer. | | 3 |
| Jeg tænker på fremtiden med nogen bekymring. | | 2 |
| Jeg tænker på fremtiden med mange bekymringer. | | 1 |

*Sæt 1 kryds*

| **3. Gøre ting som får dig til at føle dig værdifuld** | | |
|---|---|---|
| Jeg kan gøre alt det, som får mig til at føle mig værdifuld. | | 4 |
| Jeg kan gøre meget af det, som får mig til at føle mig værdifuld. | | 3 |
| Jeg kan gøre lidt af det, som får mig til at føle mig værdifuld. | | 2 |
| Jeg kan ikke gøre noget af det, som får mig til at føle mig værdifuld. | | 1 |

*Sæt 1 kryds*

| **4. Glæde og fornøjelse** | | |
|---|---|---|
| Jeg kan have al den glæde og fornøjelse jeg ønsker. | | 4 |
| Jeg kan have meget af den glæde og fornøjelse jeg ønsker. | | 3 |
| Jeg kan have lidt af den glæde og fornøjelse jeg ønsker. | | 2 |
| Jeg kan ikke have noget af den glæde og fornøjelse jeg ønsker. | | 1 |

*Sæt 1 kryds*

| **5. Selvstændighed** | | |
|---|---|---|
| Jeg kan klare mig helt selvstændig. | | 4 |
| Jeg kan klare mig selvstændigt i mange sammenhænge. | | 3 |
| Jeg kan klare mig selvstændigt i nogle få sammenhænge. | | 2 |
| Jeg kan slet ikke klare mig selvstændigt. | | 1 |

*Sæt 1 kryds*

Appendix E – Supplementary material:
Danish versions of B-ADL

# The Bayer Activities of Daily Living Scale (B-ADL)

## Spørgsmål omkring din pårørendes funktionsniveau ved aktiviteter i hverdagen

| | *Har personen vanskeligheder ved at….* | Din vurdering | Kan ikke besvares | Ved ikke | Point |
|---|---|---|---|---|---|
| 1. | …organisere sine aktiviteter i hverdagen | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 2. | …tage vare på sig selv | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 3. | …tage medicin uden hjælp fra andre | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 4. | …personlig hygiejne | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 5. | …være opmærksom på vigtige datoer eller begivenheder | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 6. | …koncentrere sig om at læse | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 7. | …beskrive hvad han/hun lige har set eller hørt | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 8. | …deltage i en samtale | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 9. | …bruge en telefon | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 10. | …modtage en besked, der skal videregives til en anden | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 11. | …gå en tur uden at fare vild | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 12. | …købe ind | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 13. | …lave mad | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 14. | …optælle penge korrekt | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 15. | …forstå sine egne økonomiske forhold | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 16. | …forklare en rute, hvis andre spørger om vej | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 17. | …bruge husholdningsmaskiner | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 18. | …finde rundt i ukendte omgivelser | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 19. | …benytte transport | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 20. | …deltage i fritidsaktiviteter | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 21. | …genoptage et gøremål efter en kort afbrydelse | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 22. | …gøre to ting på samme tid | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 23. | …klare sig i uvante situationer | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 24. | …gøre ting på en sikker måde | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| 25. | …klare en opgave under tidspres | aldrig ①②③④⑤⑥⑦⑧⑨⑩ altid | | | |
| | | | | Samlet point | |

# USE-dem spørgeskema: Tilfredshed - Brugervenlighed - Læring

Du har i en periode prøvet at bruge xxx (produktnavn).
Vi vil gerne høre din mening om den. Om du er tilfreds med den, om den er brugervenlig og hvordan det opleves at lære at bruge den.

***Sæt kryds over det tal, der bedst passer til din vurdering* f.eks.:** Uenig ① ② ③ ④ ⑤ Enig

| **Anvendelighed og tilfredshed** | | **Din vurdering** | **Ved ikke** |
|---|---|---|---|
| 1. | Den er nyttig | Uenig ① ② ③ ④ ⑤ Enig | |
| 2. | Den hjælper mig til at fungere bedre i hverdagen | Uenig ① ② ③ ④ ⑤ Enig | |
| 3. | Jeg er tilfreds med den | Uenig ① ② ③ ④ ⑤ Enig | |
| 4. | Den indeholder de funktioner jeg har brug for | Uenig ① ② ③ ④ ⑤ Enig | |
| **Brugervenlighed** | | | |
| 5. | Den er nem at anvende | Uenig ① ② ③ ④ ⑤ Enig | |
| 6. | Den fungerer på en logisk og overskuelig måde | Uenig ① ② ③ ④ ⑤ Enig | |
| 7. | Jeg kan bruge den uden at være i tvivl om hvad jeg skal gøre | Uenig ① ② ③ ④ ⑤ Enig | |
| 8. | Jeg kan bruge den uden at lave fejl | Uenig ① ② ③ ④ ⑤ Enig | |
| **Læring** | | | |
| 9. | Det er nemt at lære at bruge den | Uenig ① ② ③ ④ ⑤ Enig | |
| 10. | Jeg kan bruge den uden brugervejledning | Uenig ① ② ③ ④ ⑤ Enig | |
| 11. | Jeg kan bruge de funktioner som jeg har synes er vigtige for mig | Uenig ① ② ③ ④ ⑤ Enig | |
| 12. | Jeg kan bruge den uden hjælp fra andre | Uenig ① ② ③ ④ ⑤ Enig | |

**Dine kommentarer/feedback:**

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